

# Nursing Homes

The Family's Journey

Peter S. Silin



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# NURSING HOMES



NURSING  
HOMES

*The Family's  
Journey*

Peter S. Silin

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*To my parents, Ann and Melvin Silin. I love you.*

*To Bobby G. Thanks for being my friend.*



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# Preface

This book started out as a small project for a nursing home where I provided social work services from 1996 to 1999. I asked the family members in a support group I was facilitating to write their stories about what they went through during the time their relatives were admitted to the home, and how they had coped afterward. I thought those stories would be helpful to family members of people who were just being admitted. Reading those stories, I thought, would be like having a hand to hold or a friend to talk to as they went through a difficult process.

As I began to gather the stories, I was also giving tours of the home for prospective residents and their families, and I worked with the husbands, wives, sons, daughters, and friends of current residents. I saw that each of those people had to learn how this “is done.” So I decided to write a short introduction to the booklet of stories the families were writing which could give some practical information. The more carefully I listened to families, the more I realized how much information they needed. I also saw how complicated a task it is to be the family member of someone in care. The project grew from there.

This book was written by listening to family members like you. The stories are by caregivers who have been through what you are going through. For some, their relatives had been in care for only a short time when they wrote about their experiences; for others, it had been several years. Their voices (some disguised in part) are interspersed among the chapters.

In the sections I wrote, I alternated pronouns, rather than always writing, “your mother or father or wife or husband, your relative, etc.”

## PREFACE

However, all the information is meant for all of you, whether you are a spouse, partner, child, or sibling of someone going into care. It is also meant for the person going into the home, if he or she wishes to read it.

In several places I refer you to Web sites for further support or information. If you are not using the Internet, try to learn. Even if you feel intimidated by the technology, you can do it. I did, and I am one of those people who should never use anything more complicated than a toaster. At least try to find a short course—four hours, even—and try it.

Throughout the book, I speak about nursing homes, but the information is relevant to transitions to all types of care: group homes, assisted living, and senior centers. No matter where they are going, people still have to face leaving their homes, their future, and declining health or capabilities. The same issues of change, grief, and loss apply, no matter what kind of housing option they choose.

# Acknowledgments

This book is the story of the hundreds of nursing home residents and their families whom I have worked with over twenty years. Thank you.

Special thanks, too, to the family members who had the courage to share their stories with those who need them. You have given a wonderful and special gift.

I want to acknowledge the staff in the nursing homes I have worked in, especially all those compassionate nurses and nurse's aides who have shown me what good care and caring can really look like.

Thanks also to Professor Lillian Wells, at the University of Toronto, who has encouraged and supported me along the way.

I owe a debt and probably a dinner to Janet Murie, of Raincoast Books, in Vancouver, for letting me know that this material is valuable enough to be published and for giving me advice and guidance.

Thanks also to Wendy Harris, medical editor at the Johns Hopkins University Press, who encouraged me and took a chance on me.

Finally, thanks to Damaris Rowland, my agent, who has been a stabilizing guide for me as the process of going from manuscript to book progressed.



**PART I**

**CARING DECISIONS**



## CHAPTER 1

# When Someone You Love Goes into Care

### Becoming a Caregiver

If you are a caregiver reading this book, you may be preparing for a relative to enter a nursing home. If you are looking down that road, you may be imagining the day when the person you are caring for finally walks through the door of the home. You may be anticipating (or already having) some fear, anxiety, or guilt. You may be hoping the day will never come. Or you may be feeling so exhausted from caregiving that you think the day can't come fast enough. Perhaps you are feeling a combination of all of these emotions.

You are in the middle of a process. It may have started only a few weeks ago when your husband had a stroke. Or you might look back over several years and remember when your wife began to forget things and do things out of character. Now you know this is due to Alzheimer disease, but back then these incidents gave you only a vague sense of discomfort. You may look even further back and remember the time you were walking down the street with your mother and noticed that she couldn't walk as fast as she used to. That was the first time you thought to yourself, "My mother is getting old," and you felt a little sad and protective.

During this process, which we could call "becoming a caregiver," you learned the ins and outs of having to take care of someone who is disabled. Even if the caregiver role came overnight, learning how to do it took some time. The longer you did it, the better at it you became. You learned whom to talk to, where to go for help, who was available. You learned how "the system" functioned. You also learned



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what to watch out for, what to do if certain events occurred, and how to plan for potential problems so they didn't occur, or so they didn't occur a second time. You developed some expertise in being a caregiver.

### Becoming “the Family Member” of Someone in Care

A caregiver's process often leads to and entails another process—that of being and becoming “the family member” of someone in a nursing home. It begins when you first realize that you have become a caregiver and wonder what will happen over time. It continues when you start telling yourself, “No, not yet, it isn't time.” Then later, when it becomes more necessary, you visit several different care facilities. You talk with the doctor or your siblings or your friends about what to do. As the time draws closer and the name moves up a waiting list, you label clothes and read admission agreements. Finally, the telephone rings and a voice tells you that there is a room available—tomorrow.

If you are beginning this process, you need to know that learning your role as “the family member” will continue after you have turned around and gone home that first day. For some people it is easy, for some it is harder, but for all it is an adjustment. It doesn't happen in one day or one week or even one month. If you already have a relative in care, you know that this process can take months.

Your new role will bring about many changes in your life. Your relationship with your relative will change. You won't be doing the same things for him, nor will you be relating in the same way or having the same responsibilities. This means that how you live your day and plan your time will change.

You will also have a whole new set of relationships. You will come to know the nurses, nurse's aides, recreation therapists, housekeepers, and dietary people in the home. You will have a relationship with the laundry personnel, the social worker, and the administrator. You will come to know the other residents of the home and their families.

You will develop a relationship with “the system.” You will come to learn how the home functions. Or, as it will sometimes seem to you, how it does not. You will learn how to find lost laundry, how to

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solve a problem, whom to talk to about why your husband is not eating or how he is sleeping. You will learn to sign him out when you take him for a drive or appointment and to sign him back in when you return.

Along with these new relationships will come a set of expectations—what the staff in the home expect to be doing to carry out their jobs and what they expect from you as a family member. You will discover that you also have many expectations of them: how they carry out their jobs, how they relate to your relative, and how they relate to you.

You will also go through an emotional process in learning your new role. It will unfold for both you and your husband during the transition to care and in the months afterward. Although your experiences will be different—being the resident is obviously different from being the family member—you go through the adjustment simultaneously. It is a family journey.

So, when the day comes and you walk through the nursing home's door with your wife or father or sister, you will be in the middle of a process, not at the end. You are changing from one phase to another and, as in the earlier parts of the process, you will learn new skills and face new challenges. The hard part of the process is not doing the practical tasks, it is dealing with the emotions that arise while you do them. This book is written to help you as you go through that process and experience those emotions throughout the time your husband is in care, and after.

As you read and as you go through the process of becoming “the family member,” please keep this in mind: whatever else changes, and no matter where you or your relative go, you will always take with you the caring part of your relationship. It is the part you will always do best and the part that will matter most. Other people can give the medications, provide recreation, or dress, wash, and feed the person you love, but they can't give the same love and attention that you can. No matter where your mother, husband, father, sister, or brother is, you are still a son, wife, daughter, or brother.

## *Alastair*

His suitcase was packed and the car was at the front door. We went down the front steps together. Our son, Donald, looking sad and stressed, put the bag into the trunk. My husband got into the car without saying a word. We drove the kilometer to St. Mary's Home. He had no doubt visited parishioners there many times during his active ministry. He read the sign aloud, then said nothing more. Donald and I fought back the tears.

We were met by the receptionist, who called the head nurse. All dementia patients were housed on the secure second floor, which meant that a key was needed to activate the elevator. Upstairs we were shown to his room. Again he said nothing. We told him that he would be staying here until he was feeling better and that I would be coming to see him twice each day. When it came time to go home, we headed for the elevator. The image of his face as the elevator doors closed is burned into my brain. That day, July 18, 1996, was a major turning point in, and the saddest day of, my life.

Alastair had retired fourteen years earlier, and for the first ten of those years we had had a wonderful retirement, with several trips of great interest. In January 1992 we visited Trinidad, where we had met and been married. Several times during that visit, I was very uneasy about his behavior. He had always had a way with words and was never visibly upset when asked to speak extemporaneously, but when he was invited to speak at a school graduation ceremony in Trinidad, he lost his train of thought several times. As the months went by, he began to have frequent fainting spells, and after each episode his memory failed him more and more often. He was asked to perform a marriage ceremony, something that he

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had done hundreds of times, but this time he had the couple take the vows twice.

We consulted our doctor, who ran innumerable tests both in and out of the hospital. Finally, imaging of Alastair's brain showed that he had had many little strokes and each one had done damage. I learned that these little strokes were called TIAs and that they caused a dementia called multi-infarct dementia.

The doctor encouraged me to have Alastair attend adult day care. He enjoyed this for more than two years but his memory continued to deteriorate. He became more and more confused and we went from crisis to crisis.

I had visited homes for the aged many times during our marriage and, like most people, I felt sorry for the poor old souls who were ending their days there in what I thought must be endless misery. If I thought about it at all, I was sure that we would never be living as those people were. Now it was our turn and our day had arrived. Days and weeks of adjustment followed. The staff advised me not to take him for a walk outside for the first couple of weeks. They also said it wouldn't be a good idea to take him home until he had settled into his new quarters. There was a lot of pain and a lot I had to learn in those first few months.

Gradually the visits became less painful. Alastair and I began to develop a routine of a daily walk around the beautiful little park across from the home. He started coming for a trip home every Sunday for dinner. Even though speech was becoming more and more difficult, he always had a big smile for family members as they arrived.

Soon I began to make friends with the relatives of other residents, especially with two of the other wives. A very bright light at St. Mary's was the chaplain. He preached a great sermon, had a keen sense of humor, obviously loved the elderly residents—especially the dementia patients—and had a fine singing voice. When he walked into the room, the energy level rose immediately.

I also got to know the other residents. Some of them were unable to communicate, but others were very interesting. Ninety-one-year-old Gladys, a rotund English lady with a booming voice, was one of the most colorful. One day I visited St. Mary's wearing an outfit that she liked. While Alastair and I were waiting for the elevator, Gladys came up to us and told

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me in a voice that could be heard across the room, "You're a pretty lady." Two of the other old ladies were seated side by side in the nearby sitting area. One leaned over to the other and said, "She's all right, but she isn't that pretty!" The chaplain had enjoyed the whole episode and with a chuckle added, "That's what I like about these people: they're so honest." When he realized that his remark hadn't been particularly gallant, he tripped all over himself trying to make amends.

Every Thursday evening a student from Sri Lanka comes as a volunteer to entertain at the piano. The residents enjoy his music and have a great time when members of the staff get up and dance with them. One of the ladies is unable to say anything that makes sense, but her face is radiant when she dances. Hands, arms, and feet make joyous rhythm with the music.

By now we have settled into a routine. I know that Alastair is being well cared for and I have started to get on with remaking my life and developing new interests. I am again taking the art classes I began after our retirement. I am registered for exercise classes and life writing at the community center. All three activities are great tonics and most enjoyable. The support of our family and friends has also been with me throughout this time of separation from my husband.

Life is not the disaster I thought it was in July 1996. In fact, I can almost say what my mother said to me one day from her nursing home bed when she was almost ninety-five, "Well, it's not such a bad old life after all!"

## CHAPTER 2

# Deciding about Care

Ideally, the process of going into care will be one in which your husband participates. If it is your husband's choice, it is easier on him as well as on you. He will adjust better, because having a choice means he still has some control over his life. To make it his choice, he will need time to get used to the idea and emotionally prepare himself to accept it. It is best if he accepts the idea of care before you begin the process of looking at options.

## How to Talk about Care

Most people find they don't know how to start having this conversation. Once you have started, it will become easier. Think about it as a conversation you need to have in order to make a difficult decision together. If your husband participates, it is a shared decision. It will not be something you are doing alone or something you are doing to him. You share the burden and you share your sadness, too. As you talk, it can become a decision made in the context of your relationship that can bring you closer and lighten your emotional burden.

Even persons with dementia can participate in making decisions about care, depending on how the choices are presented and the extent of the dementia. They can still talk about what they want and feel even if they will not remember the conversation. The conversation can also be valuable for you: it can help you gauge how your husband will react to the transition and to care.

Talking with your husband about the need for care may be frightening for you: it makes you acknowledge what you are facing. You

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also may be anxious because you don't know how he will react to the subject of a nursing home. When I have asked people what their worst fear is, they say they are afraid their husband will become angry and lose his temper.

Your husband may react with anger because at some level he knows his memory is failing or he can no longer manage on his own. Acknowledging his need to be cared for can be a message about many things—his health, age, and mortality—that he wants to hide both from others and from himself. When you talk to him about care, that makes him face all these issues. The anger helps him cover up his fear. It also helps keep you away—if he gets angry, then you will stop talking about it. This kind of behavior is especially true if your family tends not to face and deal with anger directly.

When you bring up the subject of care, especially with a parent, your mother's first reaction may be a fear of being abandoned—that she won't see you any more and will be cut off from the family. She may also have a sense of rejection and a feeling of being old and useless. Watch for that reaction, and ask if it is something she is feeling. If she says no, address these issues anyway. She needs to hear about her value, both as a person and as a member of the family.

You may want to tell a friend or family member that you will be having these conversations, and then talk to him or her about them as they are occurring. You don't have to give the details. Just have someone who can support you while you face this task.

Whatever your husband's or parent's reaction is at first, you may have to return to the subject several times before there can be a discussion. The first time, he may be angry; the fifth time, he may be more willing to listen.

When you do finally talk about care, the first step is to ask your husband what he hears you saying—does he think that you will abandon him or that you don't love him anymore? Acknowledge his feelings and fears. When he sees that you understand his feelings, it will be easier for him to move to the next step of being able to discuss the issue. Be ready to discuss your own feelings. What will it be like for you if he goes into care? It may take a few conversations to talk about the feelings before you get to the issues. This is normal. Acceptance

## DECIDING ABOUT CARE

is the end of a process of emotions that unfold and are passed through. Give the process time. You don't have to resolve it in one sitting.

Once you start talking, you may find that your husband acknowledges his need for care. Many husbands know when they are ill, and know that their wives cannot care for them much longer. Many residents have told me that they chose a nursing home because they knew they needed help and did not want to burden their children with their care. They knew that their children need or want their own lives. They wanted to maintain their own independence. Some have told me that they were lonely or not eating, afraid of falling, etc., when they lived at home. Despite their fears about going into care, they were willing to acknowledge their needs and make the decision that followed.

Younger people also usually know at some level of their minds when they need some kind of care. They see how they are managing, and they see the strain on their caregivers and families. This may make it easier for them to "work through" the process. On the other hand, younger people may have more resistance, anger, and grief, because they see going into care as the loss of so much of their lives. They feel cheated, and in a sense they have been (and so have you). Acceptance may take longer. Anger at the caregiver can be greater as these persons deal with their loss and sense of abandonment. As the recipient of that anger, together with the strain of being a caregiver—perhaps working and being a parent of young children as well—you can become angry in return. If you can, instead of reacting, try to say something like, "I know you are angry; I am angry and sad about this too." Try to remember that although the anger is directed at you, it is not about you. If you are having trouble, bring in a professional who can help you both. Younger people especially should be given every opportunity to explore for themselves all possible alternatives. Going through this exploration process is part of the path of acceptance.

In starting a conversation with your husband about care, talk generally. Frame it as planning for the future for both of you. You can say, "I have been thinking about what we would do if something happened to either one of us." You can tell him what you would want and how you would want him to handle things. This can lead naturally to a discussion about his condition and what he wants.



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You can introduce the idea of a home as insurance—"in case." This is why it is a good idea to start planning as far in advance of when you will need a home as possible. You might say, "I know you don't need it now, but we should take a look." You can use the same approach to put his name on a waiting list. Talking about the issue of care as a possible future gives your husband time to become accustomed to the idea without being frightened by its immediacy. You can also say that you want to look at alternatives, maybe senior housing complexes, maybe room-and-board homes. However you broach the subject, try to do it in a way that allows him to have choice and a feeling of control.

If there is a possibility of rehabilitation, make sure you discuss this. Many people who enter nursing homes do go home, or do manage at a different level of care. Younger people sometimes move to group homes. In your discussion, talk about use of the nursing home as helping to increase the possibility that he can move or return home and function better.

Sometimes it is better to focus on the condition or disability rather than on the solution. Ask your husband how he sees his health. I often ask people about their memory. Many memory-impaired people do not know they are failing or will not acknowledge it, but some will. Often they tell me that they have "slipped somewhat" or use a similar expression. I ask them what will happen if they slip more. If they are physically impaired, I ask them what kind of help they need and who is giving them that help. We look together at their needs and what we think will happen. Then sometimes I can say to them, "It sounds like you are getting a lot of help from your wife. I wonder how she is handling it?" This can lead us to a discussion that will bring up the alternatives. When we talk about alternatives, we can talk about a nursing home as one of them.

It may be easier if a doctor, home health nurse, or social worker in the hospital tells your husband that he needs more care than he can get at home. He may listen to a professional in a position of authority more than to someone in his own family. He will not experience it as rejection or criticism from you because it is coming from a professional. If he is going to become angry, it will be with the doctor. When someone else has initiated the conversation, it also allows you

## DECIDING ABOUT CARE

to deal with his reaction as a sympathetic person and someone who is on his side. It allows you to say, "What are we going to do now?"

When people think about nursing homes and care, they often have in mind pictures of what facilities were like twenty, thirty, or forty years ago. They don't know how care alternatives have changed. For example, they are not aware of, or have not seen, assisted living facilities. So when your husband becomes angry or refuses to consider care, he may be refusing something different from the picture he has in mind. If he will agree to take a look at some of the options, his reaction may change.

If you are one of several adult children who are concerned about one or both parents, it may be that one of you would be better at bringing up the subject than another. Often, a mother will listen to a son, or father to a daughter. You all might want to sit down with one parent who is the caregiver and discuss your concerns (see Chapter 3, "Family Decision Making"). Or you may want to sit down with both of them at the same time. Talking with them both can take the burden off the parent who is the caregiver; you can be the one to speak to the parent who needs care. Sometimes a parent will listen to an adult child more than to a spouse.

When meeting with both parents, define the issue as a family problem as opposed to there being something wrong with your father. List some of the issues and describe how they affect everybody. When your father hears from you the situation of your mother as she tries to take care of him, he may be more willing to accept his condition and the need for some kind of care. The idea is not to have him feel guilty; it is to help him develop a realistic view of his condition and its repercussions in the family.

However you bring up the subject, in the end you may have to just do it. You may have to set a deadline for yourself and just start talking. The fear of doing so will probably be worse than the actual event; afterward you may have a sense of relief. You may also have a sense of sadness, knowing that this process has begun and it really will happen.

Contrary to what you may think, many people who have long resisted care end up being content once they are there. Although they would never have admitted it, life at home was a struggle. They were not eating well, small personal care tasks were painful and slow, they

## DECIDING ABOUT CARE

were lonely, afraid of falling, etc. They find that it is a relief to have someone helping them dress, that it is enjoyable to have well-cooked meals and to have people around them. They feel safe. Some of the shame is gone.

Despite themselves, some people in care in a good home have actually thrived. Their struggle was in the idea of giving up their independence and pride in being on their own. Once they got through those feelings, they would not go back to what they had. They realize they are the same people they were at home. What is important for people in a home is to maintain a sense of dignity about themselves despite the fact that they need care.

Unfortunately, no matter how you bring up the subject of care, your husband may not be able to accurately look at his condition and will not be able to participate in the decision. His memory may be so bad that he will not remember what you have talked about. He may be so scared or angry or “in denial” that he will refuse to talk about it and you will not make any progress. He may be so overwhelmed that he can’t hear or react to the stress you are having.

The process should not stop and you should not give up because your husband will not participate in the decision. The caregiving process will continue. Most likely his need for care will increase, as will the burden on you. If he is not participating in the decision, you may have to begin the process without him. That means you will look for the home, you will ask the questions, and you will put his name on a waiting list. Your job will then be to help him—and yourself—prepare as the time comes closer. I discuss this later in the book.

## Choosing the Right Time

The ideal answer to the question “When is the right time?” is, “When your wife recognizes the need and is ready to act on it.” As far as the caregiver and the caregiving process go, there is no “right” time to place your wife. When we are talking about the right time, we mean the right time for you—*when you can no longer do it for whatever reason*. Caregivers’ abilities to handle a burden vary enormously, depending on their own circumstances and their emotional makeup. However, for all caregivers there are both warning signs and alarm signs. When

## DECIDING ABOUT CARE

you don't pay attention to the warnings, they will become alarms. Those are the times when you get into a crisis.

One of the reasons people find themselves in a crisis is that they close their eyes to the fact that their situation is progressive. For whatever reason, they do not want to hear it. If you find yourself avoiding asking the doctor what is going to happen, or refusing to consider the word *Alzheimer*, or getting angry when people try to talk to you, this is a signal to you that you are shut down.

The problem with waiting for the alarm to sound is that when you finally hear it, your options may be limited. The waiting list for the home of your choice could mean it would take one, two, or three years. If you and your wife are in crisis, it can mean that there is greater physical and emotional risk to both of you than if she had been placed earlier. It can mean that your emotional and financial reserves are strained to a breaking point. Waiting for the alarm may not do anyone a favor, and you may end up causing some damage to yourself and your wife.

Please, have the courage to be good to yourself and your wife: "Plan, Don't Panic." Here are some of the warning signs that the caregiving burden is becoming overwhelming:

1. *Is your physical health beginning to suffer?* Don't wait until you are exhausted. Don't wait until you are never getting a night's sleep or you are not eating. By that time, you may not be able to provide care the way you should.
2. *Is your emotional balance beginning to be affected?* You find that you are crying or are feeling hopeless or even are feeling nothing. You find that your sex drive is gone, you are not eating, or your sleep is disturbed. These are signs of depression.
3. *Is your wife's health beginning to suffer?* There may come a time when, despite your best efforts, your wife's health will suffer and she is at risk. This may be because she is not eating, taking her pills, or allowing herself to have the physical care she needs. Is she getting bedsores or other rashes?
4. *Is your wife's safety becoming an issue?* She may be opening the door to strangers, wandering out of your home and getting lost, leaving the oven on, or leaving lit cigarettes around.

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5. *Are you physically unable to provide care?* You cannot lift or do the tasks required.
6. *Are you feeling resentful, short-tempered, or angry?* These are signs of stress and can lead to your becoming abusive.
7. *Are people, including your doctor, beginning to tell you that it is time?* Usually, people on the outside notice the changes in you and in her; because they don't carry the guilt or other feelings, they can be more objective.
8. *Is the community unable to meet your wife's needs or your needs through the services it can provide?*
9. *Are you hiding the extent of your wife's disability and your physical or mental state from your family or friends?* Hiding something from family or friends means that you are closing off your support network. It also means that you are trying to deny to yourself what you know to be true but don't wish to see—that your wife needs help. You may be holding back feelings of shame or guilt. All of these factors increase the risk to yourself and your wife.

If you answer Yes to one of these questions, it is a warning in itself. If you have answered Yes to three or more, it is getting to be alarming. If you have answered Yes to six or more, then I hope your wife is in care or on a waiting list. If not, my guess is that you are either unwilling or unable to make a decision. You need to talk to someone. You are at risk.

## Stress

If you are not already stressed out from being a caregiver, it is very possible that you will become so at some point during the process you are in. It is essential that you learn to recognize your stress and be alert to how you are dealing with it. Stress will affect your health. It will have an impact on your heart and your immune system. It will affect your ability to be an effective caregiver as you deal with nursing homes and other systems. Resultant behaviors from stress can include increase in the use of alcohol and drugs. Many people find that they are eating more, almost compulsively. These behaviors can spin out of control:

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they can increase your isolation, further affect your health or caregiving ability, and even kill you.

Throughout this book I will talk to you about taking care of yourself by using the people and supports that are available to you. Use them to deal with your stress too. Also do activities that deflect your attention or give you a break. Make sure you eat and sleep well. Exercise. Make a list of your options that will lower your stress, and build them into your schedule.

Put yourself first in the order of whom you take care of. If you don't, you will have a tendency to leave yourself out. By the time you figure out what is wrong, you will have some habits and behaviors that are destructive to you. Paradoxically, putting yourself first will make you better able to respond to your wife's needs.

### When a Parent Chooses to Live at Risk

Several times when I have been on staff in a nursing home I have offered a room to someone who declines it despite the fact that she or he has fairly serious memory loss and/or physical problems. On occasion, I will then hear from a stressed-out son (or daughter) who has been the primary involved caregiver. "She just won't go," he tells me. I hear the exhaustion in his voice and the resignation of knowing that he will be continuing in this stressful situation with no relief in sight. When I look at the relationship, I find that he has been at the beck and call of his mother for years. Anything that she needs, he will go out and get; anytime she calls, he will rush over there. The mother has been able to survive on her own because he has not been able to put any limits or boundaries on her. Of course, Mom is not going to move! She is all right living on her own! She has a personal, twenty-four hour attendant!

If Mom is alert enough to make a decision, then I suggest to the son that he start setting some limits on what he will do for his mother. Let her "sink or swim" on her own until she makes the decision. This can be very painful and frightening. He then has to step back until something happens to his mother. For instance, she will walk without a walker until she falls and breaks a hip, or she will prepare meals inadequately to the point where she becomes malnourished and has to

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be hospitalized. Then the mother has no options, but she knows it and acknowledges it for herself. The son has to have the courage to let things progress naturally and on his mother's time.

Your mother has the right to make her own decisions, even bad ones. You are not responsible for her bad decisions. She is an adult. If she wishes to live at risk, that is her right. It does not matter whether you like it or are worried. But then it is also not your fault when something happens. Along with her right to choose comes responsibility for her choices. You need to allow her the rights and responsibilities of being an adult. Just because she is elderly does not mean that she should have any fewer freedoms or responsibilities than anyone else.

There is a payoff for you in stepping back and allowing your mother to take the risks she wishes. It allows you to know that you have truly respected her as a person. It is knowing that you have given her a gift of love that says you will handle your anxiety in a way that does not interfere with her. Your responsibility is then to learn to deal with that anxiety effectively.

It may be that your mother has been dominating and controlling throughout your life. If that is so, your inability to set limits in being a caregiver is probably characteristic of your relationship with your mother in general. If this is your situation, then you may want to buy a book or take a course on assertiveness training. You may want to see a therapist to look at the relationship you have had with your mother. Even when you are fifty or sixty, you can still have a dysfunctional relationship with a parent.

How you handle this situation can ultimately have a very strong positive effect on your life in general. Learning to assert yourself and learning to hold back from asserting yourself inappropriately over your mother are examples of learning about personal boundaries. It will give you a sense of freedom and of relief when you come to understand that you are best off when you try to control only yourself or that the only one who can dictate your behavior is you. Personal boundaries give you the ability to interact with others effectively. When you learn to assert yourself or change the dynamics of a primary relationship, such as with a family member, other relationships can improve.

Please note that allowing your mother to live at risk is an option

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only if she is able to make a reasonably competent decision. She must be able to understand the consequences of her actions. If she is not, then you must find some other course of action. It may include having her deemed legally incapable by a physician or someone else. Usually, however, it does not come to this.

### Your Legal Right to Make Decisions for Your Relative: A Warning

If you have been your husband's caregiver, you may think that you are the one who should be able to make decisions about his care. In fact, you probably have been doing so.

There is a legal process for obtaining the right to make decisions for someone. This includes both financial decisions and decisions about personal matters. If you are totally exhausted from caregiving or if your husband is very impaired but refusing to go into care, you still may not have the legal right to have him admitted. Once he is admitted, you may want to sell your house and move to an apartment, but if his name is on the deed you may not have the legal right to sell it. Without the legal right to make decisions, someone in your family or elsewhere in the system may challenge you. This could make things very slow, hard, and expensive for you.

You don't always need the legal right to have your husband admitted to a care facility (see Chapter 10). Here I just need to emphasize that if he or someone else says no, you may be out of luck, and the nursing home or someone else in the official or medical system may back him up.

There are two ways you can obtain the legal right to make financial and personal decisions for your husband. First, if he is mentally competent, he can complete documents that give you that right. You may be able to do this through the bank or a notary public regarding financial decisions by obtaining what is usually called the "power of attorney." If your husband has given you power of attorney while he is competent, you will need to make sure that it is an *enduring* or *durable* power of attorney. This means that if he becomes incompetent, you still have the right to make decisions. If it is not enduring and he is incompetent, the power of attorney could become invalid.



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While he is competent, even if you have power of attorney, he still has the right to do his finances, and he can revoke it whenever he wishes.

To make personal care decisions for someone else, you need to become the “committee of person” or “medical power of attorney” (or other term). If your husband is competent, he can give you the right to act for him if he becomes unable to act on his own behalf.

If your husband is no longer competent to make personal or financial decisions, you will have to go to court. The court will want evidence that he is not competent to handle himself or his affairs. This can entail several lengthy and expensive interviews with a psychologist, physician, or other professional. In all states and provinces, there is legislation regarding financial and personal competency.

Personal and financial competency can be very gray areas. Even though you may believe that your husband is competent or even if a lawyer witnesses a document that your husband signs, these documents are sometimes challenged through the courts. I have seen families engaged in horrible battles both over funds and over what to do with a loved one because there was no agreement as to a relative’s competency or ability to have signed documents. If you think that this may become a problem, have a physician and psychiatrist or other professional do a competency exam and send you a report. It is more expensive in the beginning, but it can be worth it in the long run.

### Advance Directives and Medical Decisions

Advance directives are a series of different documents that relate to the question of caring for a person if she becomes disabled to the point that she is no longer able to make decisions for herself. These include the power of attorney documents as well as (although sometimes using different names) living wills, care agreements, degree of intervention, and DNR (do not resuscitate) orders. They all answer the question “What do you want done if . . . ?”

Advance directives documents vary throughout the United States and Canada. They may also vary from home to home. You need to ask the home what its policy and procedures are regarding end of life, terminal illness, or disability. In the resources section you can find *Aging with Dignity and Partnership for Caring: America’s Voices for the*

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Dying. Both organizations have documents that deal with these issues and that are legally recognized in most states.

A living will, which sometimes incorporates some of the same directions as the medical power of attorney, is an overall document that describes what you want to have happen in various situations, such as if there is a question of needing life support, if you have a heart attack, or if you need pain medication. Do you wish only comfort care if you become terminally ill or do you want all the intensive care that is available? Whom do you want to make decisions for you if you are no longer able? Whom do you want to decide whether you are competent to make your own decisions? If you are terminally ill, do you want to be given artificial feeding and hydration through tubes? A living will is sometimes limited to the time when the principal has a terminal illness.

DNR (or “no code”) orders are instructions on a person’s chart or in a will which guide the attending medical personnel not to perform CPR or otherwise try to revive you if you have had a heart attack or stroke. It says that you want them to let you die naturally.

The degree of intervention is a guide that describes what you want to happen if you become ill in the nursing home. It is often four levels (or degrees):

Level 1: Stay in the home and be kept comfortable, but not given antibiotics or other medications to cure you.

Level 2: Stay in the home and receive all medications and treatments possible within the home.

Level 3: Be transferred to a hospital but not given CPR or taken to intensive care.

Level 4: Be taken to a hospital and given all possible medical interventions.

The advantage to choosing level 1 or 2 is that it allows someone to die naturally in familiar surroundings.

The term varies, but the medical power of attorney or committee of person document asks you whom you wish to have make decisions for you when you are no longer able to and under what circumstances you want that person to take over. It also describes the limits on that person’s decision-making rights.

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Before or after admission, the home will present you with documents that ask you to decide some if not all of these advance directive type of questions. The home will use them as a guide in the provision of care. Any home receiving Medicaid or Medicare funding must inform you of your rights regarding advance directives.

You and your husband ideally will have talked about these questions previously. If not, do it now. You may want to have a family meeting in which anyone who has a stake is given some input. (See the next chapter, “Family Decision Making.”) If you don’t discuss these issues beforehand, you can end up in conflict later because different members of your family will have different feelings. It also saves you and your family from having to make painful decisions, because your husband has already told you what he wants. It gives you permission to do something that you might feel is too painful to do otherwise. For example, an advance directive can say that if your husband has dementia and comes down with pneumonia, he is to be kept in the home, given fluids, and kept comfortable only. That saves you from having to decide if he should be sent to the hospital and/or given intravenous antibiotics. He has told you that he doesn’t want that.

Discussing advance directives can be as difficult as the decision about care. People do not like to talk about death. That might be you, or your husband. Use the same approach I discussed earlier. Another approach is to say, “I’m afraid to make a decision you might not like,” or “I’m afraid we will all fight about . . . if you don’t give us instructions.”

Make sure you understand the implications of the documents you sign and the decisions you make. For instance, if you have questions about the conditions under which a DNR order will not be carried out, ask. If you have signed a form saying that you don’t want heroic measures, does that mean the home will never transport your husband to a hospital?

The *decisions* you make now are usually reversible—you can always change your mind. However, *documents* that your husband has signed and are legally recognized may be irreversible, despite your wishes. The problem is that if you have not given any instructions or signed any documents that give the home some guidance, the home will

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probably do what it needs to do to protect itself legally. This does not mean that a bad decision will be made; they may err on the side of caution, but the decisions they make may be quite different from what you or your husband would choose.

Some of the issues generally dealt with in advance directives include:

- Whom do you want to make decisions for you if you become disabled?
- Whom do you want for a second person?
- What kind of decisions do you want your representative to make? (legal? financial? medical?) Do you want different people to make different ones?
- What do you want done to decide if you are disabled? Physician's assessments? Psychologist's?
- If you become disabled and are in a coma, what do you want done? Artificial respiration? Feeding tubes? For how long?
- If you become disabled and your representative deems that you have a poor quality of life, and if you have a heart attack or stroke, do you want to be revived?
- How do you want someone to decide when to take you off life support?
- If you are disabled and are dying, what kind of care do you want? Comfort care and pain control only? Intensive care? Care at home? Do you want to be transferred to a hospital?
- If you are dying, do you want pain relief even if it reduces your alertness or makes you unaware?
- Do you want someone with you when you are dying? Whom?
- What kind of funeral and burial arrangements do you want?

Check with your ombudsperson, health department, office on aging, Alzheimer association, coalition for disabled group, Five Wishes, or Aging with Dignity for the legally recognized advance directives form where you live. Remember to have your form witnessed and notarized. Give copies to your physician, lawyer, and family members.

## *Lydia Jean*

It had been at least five years since I first suspected that my sister was losing her mental faculties. I live more than five hours' drive away, and we have no family members in the city where she lives. Lydia Jean was very good at hiding her declining abilities. I believe some of her friends were unaware for a long time that anything was wrong. She didn't think she was getting old and objected when any family member suggested she go into a home where she would be well taken care of. Her response was always, "I can take care of myself."

No one could talk to Lydia Jean about her memory. She got very angry and blamed others when she forgot things. She would claim that nobody had told her. She once complained that a niece had stolen her teacup. None of us was able to convince her otherwise. I found that cup, broken, carefully wrapped and hidden away. There were many of these instances. One time she told us that Tiny, her dog, came to visit her. But Tiny had died several years before. She was hallucinating, and I knew she was not on any medication. Call it dementia or Alzheimer's, the progressive stress made my life a torment as I tried to cope with the suspicions, anger, and obsessions that were obscuring the personality of my sister.

Finally she received a letter from the motor vehicle department saying that because she was diagnosed with dementia her license was revoked. She could not understand why, because she had never had an accident. She was unable to understand the meaning of dementia. She said she wouldn't drive but wanted the car to stay. We said okay, but she forgot and drove nearly every day. When the mental health worker phoned me and said the car had to be taken or they would take action themselves,

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I had no alternative. She was very bitter and I bore the brunt of her rage. This was a nightmare.

I had many sleepless nights wondering how I should handle the situation as her memory got worse and she got more frail. A very concerned neighbor kept an eye on her and one day found her in the bathtub unable to get out. She was very cold and very confused.

I knew she had to have someone with her twenty-four hours a day, but she would not allow this. Another sister came from out of town and stayed with her for months; at times she found Lydia Jean intolerable. She had to leave.

After that, Lydia Jean fell three times that I am aware of. The last time was outside in her empty carport. A friend was driving by and saw her lying on the cement and called an ambulance. She was taken to the hospital and diagnosed with a fractured hip. Under the circumstances, this was a blessing. After a lengthy stay in the hospital, she was transferred directly to a nursing home. They would not discharge her home. Finally, I knew she would be well taken care of.

Lydia Jean has been in the home over six months now. She is adjusting well, no more eating alone and no more lonely evenings. I am not familiar with her medication, but it is certainly calming her while not changing her personality. My nieces who live out of town went to see her. They took her back to her home for a visit, then out to lunch. They reported that they had never had a nicer visit with their Aunt Lydia Jean. She wanted to go back to her home after lunch, but they had no trouble returning her to the nursing home. When they told me that, it was the first time I had had a good feeling about her being in a nursing home. It helped convince me more than ever that the right decision had been made.

I love my sister very much, and it has been a painful process. I know she is too sick to be alone in her own home and good care will improve the quality of her everyday life. I truly believe she is in a good care facility.

## CHAPTER 3

# Family Decision Making

### Family Relationships and Care Decisions

It may be that more than one family member is involved in making the decision that your mother needs care. This can lead to a good deal of family stress or conflict. The conflict may be a continuation of ill will that has been overt or covert since long before Mother needed help. Often, however, conflict arises even in families in which relationships have been good.

Families in which one person lives out of town often experience conflict (see Chapter 15, “Out-of-Town Caregivers”). Your brother, living far away, may not realize Mother’s true condition. When he comes into town to visit her, she will be able to rise to the occasion, hiding the extent of her disability or masking from him how much care she needs. Sometimes the out-of-town child (particularly if it is a son) is Mom’s golden boy. She has idealized him and they have a relationship that pairs them together, leaving the in-town caregiver outside. Or he may come into town, get involved for a weekend, then leave you to pick up the pieces. As he is only involved for a weekend, and is involved with your help, he does not experience the full burden of the caregiving process or the full scope of what is needed over the course of a month or so. So he can go home and think, “Where’s the problem?” Despite his best intentions, this can leave you feeling angry with both him and your mother.

If you are the one in town, you may feel that you have more right to be making a decision than your brother who is out of town. After all, you are doing most of the work. You may be dismayed that he is calling you

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and making suggestions. It may even feel like he is criticizing what you are doing. Whereas you want his support, you may feel that he is making things more difficult for you. You can end up feeling resentful. If you don't say anything, you can end up boiling for a long time.

Even when all the children are in town, conflict can arise. This is because of your family dynamics and family roles. Even though you all are adults, as soon as you have to start dealing with your siblings in a decision-making process, especially one in which your parent is involved, you revert back to behaviors and roles you used when you were children. The older sister becomes the older sister again, the younger brother becomes the baby again. You also may still be carrying around the feelings toward each other that you had when you were children. Although you don't like to admit it, maybe there is jealousy, maybe there are feelings of inadequacy, maybe you felt that Mom loved your brother best. (I've seen families in which each child thought Mom loved another one best. It was amazing how she had managed to divide all her children, setting them against each other for life, until they realized what she had done.) This is a stressful and emotional situation for all of you. When we get into that kind of situation with people from our past, we tend to deal with them and the situation as we did in the past because we have no other model to use.

Even though you are all going through the process of having Mom go into a home, it does not mean that you are all emotionally resolving things at the same time. One of you may be ready; one of you may not be able to bear the fact that she is getting older. One of you may feel guilty; one of you may not. You have all had different relationships with your mother and you are all different people. You also all have different personal, work, and financial stresses on you. These differences will affect how you evaluate a situation and how you feel about it. They will have an impact on what you think should happen and when it should be done. It does not mean that any one of you is right or wrong. It means that you are different people with different lives.

### How to Make Family Decisions

If you are the primary caregiver, begin keeping a journal. Describe the process of decline and record the things that your mother has done



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which indicate her need for care. Also record the tasks you perform as the caregiver. Include the doctor's visits, phone calls, shopping, and so on. You are not doing this to score points with the others. You are doing it so that they have a clear understanding of what is happening with your mother, her needs, and what your role has been.

It may help if the out-of-town relative takes care of your mother for a couple weeks, or up to a month. This gives him an opportunity to go through her cycle of care needs. Once he has had that experience, there is a common framework for understanding and planning.

As early as possible in the caregiving process, everybody who is involved or who has some emotional or financial interest in your mother should define roles by deciding who will do what. This includes what out-of-town siblings will do. List the tasks and divide them up. Also, be very clear about what everybody expects from his or her contribution. If you expect to be given the family house in exchange for living with Mom and taking care of her, everybody else should know that. If your out-of-town sister is contributing money and expects to get it back from the inheritance, you should know this now.

It may help to get together to have a discussion about what your family was like as you were growing up. Discuss the roles you think you played. See if you can verbalize the family rules (see an explanation of this under "Guilt and Shame"). Look at communication patterns in the family. See how parental relationships affected you all. (A word of caution about this kind of discussion: you can describe only what happened to you. When talking about anyone else, you need to ask, "It always seemed to me that . . . ; how did it seem to you?" Don't tell anyone else what her experience was like or what she did.) This kind of discussion can help you understand each other better and move beyond what is keeping you all stuck. It might bring you all closer.

You may want to have a *formal* meeting to discuss the situation. If you do, these points may help:

1. Have it in a restaurant or some neutral place.
2. Make up an agenda. Set some goals, such as defining the problems, finding resources, or coming up with solutions. If there is a lot to discuss, schedule several meetings, rather than press yourselves to finish everything at once.

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3. Keep to the facts.
4. Start with some ground rules: nobody accuses anybody of anything, you will stay on topic, you will wait for one person to finish before someone else jumps in.
5. The focus is on your mother.
6. This discussion is not the place or time to work out your own relationships.

One of the goals in a family meeting may be to understand what everyone is thinking and feeling about the current situation. (This is different from working out your relationships.) The first thing that you may want to put on the agenda is a round robin in which everybody has a chance to say what it is like for him or her. What are they feeling as they watch Mom decline? How are the tasks that they are doing affecting them? How is it affecting their spouses and children? How does it feel to be an out-of-town relative while someone else is more involved? The task for everyone who is not talking is to listen. Wait for everybody to have a turn. At the end, there should be no comments, arguments, or crosstalk. There should be no attempt to talk someone out of what she is thinking or feeling. She is not right or wrong; it is what is true for her. This part of the discussion is also not about winning, it is about understanding. You are not contestants on the “Queen for a Day” show, where the best of the bad luck stories wins the new washing machine. If you are all trying to win, you all lose.

Make sure you put finances on the family conference agenda. Does everybody know what the financial situation is, where assets and finances are, and what is available to be spent on care? Does everyone agree on how finances should be handled? If finances are a “hot topic” in your family, you may want to have a separate meeting to make decisions about them.

If there is conflict around money, it is especially important for everyone to have an understanding of your mother’s diagnosis and where a disease or disability is leading. Everyone should also understand the costs of responding to the disease and of care. This knowledge can lead to a natural decision on finances.

In the end, if you can’t reach an agreement on finances, maybe the best answer will be a trustee from the bank who can oversee money

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issues as they relate to care. A trustee costs money, but this solution ensures that finances will be handled fairly by a neutral party for the benefit of Mother first.

There is nothing wrong with wanting an inheritance. I know we all say we shouldn't count our chickens before they are hatched. However, if you have been promised something or have known that there is a certain amount of money in the family and then find it is not going to be there for you, that really can be a disappointment. Feeling disappointed or resentful may not feel "right" to you, but many people experience those feelings even though they won't admit it. What is not acceptable is when the feelings translate into adverse actions. It is not all right to deny care or opt for a lower standard of care because you want an inheritance. That is financial abuse.

Make sure that you feel comfortable with the agreements you make and that the rules are fair. If you do not feel that way, try to identify why not and continue problem solving until you do feel it is fair. Remember to watch out for the family dynamics. If someone is acting as the older sister and not as an equal, bring that up and see if you can work around it. Even though she is the older sister, she may still be right. Give yourselves time to work things out. If you have to have several meetings, allow yourselves to do so.

If there continues to be conflict in your meetings, you may want to hire an outsider to help you resolve it. Hire a therapist or a geriatric care manager (see Chapter 15, "Out-of-Town Caregivers") who is experienced in dealing with these issues. The money you spend will be worth it if you end up saving your family relationships.

Finally, remember to keep your eye on the ball (or, in this case, your mother). She is the one who is important here. Remind yourself that what is best for her is the solution you are looking for. That is how everyone wins a washing machine.

At the end of your discussion, everybody should be able to write down what he or she is doing and why it is best for your mother. Everyone should also write down what he is giving, what he expects back, and in what form or amount he expects it. Compare what you have written. From this you can develop a single document that will be a clear contract. Make sure that you feel comfortable with the document and that it is fair. If you don't, don't sign it.

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Your written agreement may be an evolving document. As Mom becomes more disabled, there will be new tasks that need to be taken care of. Problems that you hadn't thought of can arise and the document may need to be revised. There may also be changes in the circumstances of those of you who are party to the agreement. Review it once a year or once every six months.

### Keep Your Relative Involved

To every extent possible, the care receiver (especially a younger person) should be actively involved in arranging or knowing about the arrangements that are being made around her. If she is not, anything that is decided can meet with additional resistance as she tries to maintain her sense of control, pride, and self-worth.

Keeping your mother involved means giving her the opportunity to understand what things are like for you and what the future can look like. It may mean telling her that you are calling your brother who is out of town to ask him to do some of the things you have been doing. It may mean explaining that you cannot do all the cooking you have been doing. Your mother will need to understand why the circumstances are changing.

You will need to stand firm, especially if she asks you if she is becoming too much of a burden or if you do not want to bother anymore. Keep track of your "guilt meter." It can go over the top and make you back down. This can result in more resentment, exhaustion, and, ultimately, earlier admission of your relative to care.

Your mother can be involved in a family meeting whether it is informal or formal. If she won't understand all the issues, have her sit in on the ones that she will. If it doesn't work out, then you can schedule a separate meeting. If she is in the meeting, make sure things are worded so that she understands that she is not the problem; the problem is the situation. This is another situation in which it can be very helpful to have a professional involved. He or she will help moderate the emotions and can act as an advocate for your mother so she does not feel ganged up on.

## *Mary*

The constant and intense nature of Mom's behavior finally made me aware that life was becoming difficult for her. My concerns had already been growing: for her safety, her inability to prepare meals, the danger of kitchen fires, her vulnerability to theft and mugging, her inability to handle medications. I was receiving repeated worried phone calls from her throughout the night.

Mom's obsession with bowel movements finally resulted in her referral to the university Alzheimer Clinic. My sister Faye came to the coast to be with us for the tests. After they were finished, the doctor, a kind and compassionate man, assured Mom that she was very healthy and had performed the puzzle tests very well. In private he told Faye and me that there was no evidence of stroke or accidental trauma to the brain, so in all likelihood Mom had Alzheimer disease.

We were to do the following immediately: get power of attorney, prevent Mom from driving her car, and put her in a safer living environment. We were not to tell her she had Alzheimer disease, correct her mistakes, or argue with her. We were to try to prevent as much confusion as possible.

Power of attorney was surprisingly easy to obtain. Faye and I calmly approached Mom on the premise of being able to look after her affairs if she ever needed our help. The first two attempts were met with a definite "No." The next day Mom was more agreeable, so off we went to see a lawyer. I'll always remember the guilt I felt when I signed my name on the power of attorney form.

Then came the letter from the Motor Vehicle Division requesting that she appear for a driving test. She failed but was given a learner's license.

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She drove anyway! We were finally able to get her to stop driving by taking her car in for servicing. We delayed returning it for as long as possible.

This time in our relationship can be described only as ugly. Mom was livid about the car. Her accusations of theft and her threats to commit suicide, to involve police, and to buy another car were relentless.

Her threat to buy another car opened up a new worry. We appealed to her bank to curtail her withdrawals. They were sympathetic but would agree only to red flag her account. I would be contacted if a large amount of money was being withdrawn—but they reminded me that it was her money. To take more drastic action, I needed to get a committee ship. Then I would have the legal right to control her finances. So we began our expensive visits to a lawyer to declare my mother mentally incompetent.

The Health Department became involved with us when Mom was diagnosed with Alzheimer disease. The caseworker assessed Mom in June. She advised us that Mom needed more structure to her days but was basically managing quite well on her own. We got her a companion and found her an adult day center to go to a couple days a week.

During that summer I took the caregivers course put on by the Alzheimer Society. This was invaluable. I now realized why Mom acted as she did. I was given strategies to ease Mom's agitation and, for the first time, I was given a clear picture of where we were heading with Mom. They said it was imperative that she be placed on a waiting list for nursing home care immediately.

We set out to find a room that would please Mom. We toured several homes, each one being met with great resistance from her. She repeatedly told us, "I have no intention of moving. I am perfectly safe and happy where I am." But I eventually got her name on a list.

This was the first time that Mom had let us see her account books. It was probably the clearest picture I had that her disease was progressing. It also showed me what a struggle Mom was having. I realized it was only a matter of time before I'd have to assume full control of her financial affairs.

Finally there came a time when I knew I was no longer going to be able to supervise Mom's daily routines. Every Sunday she came for a visit and dinner. Every time I would have a good ten-minute cry after Mom returned home in the evening.

The moment we'd been both waiting for and dreading finally arrived.

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Mom was to go to Bayview Manor Center. We chose a day when she would be at her day care. My husband and I went to her apartment in the morning to pack and label her necessities. We gathered a few treasures to help her like her new home, such as her comforter, a TV, and a cozy chair. We took these to Bayview and got her room ready.

Mom's companion picked her up at the day care and brought her to Bayview at 1:30 in the afternoon. The companion said her good-byes and the staff took over.

Mom was most anxious. She knew what we were up to and she knew she was powerless to stop us. We took her to her room and pointed out her clothes, her dresser, her chair, and her TV. We told her she would stay there only until I returned from summer holidays.

Mom was not to be dissuaded. She paced the floor. She ripped her name off the door. She shouted.

I will never forget Mom's phone calls and her constant attempts to escape in the beginning. She'd try every door and gate. Finally she turned to me and said, "This is a terrible thing you did to me."

I still dream about that first day. But then I only have to think about the next day when Faye and I packed up her apartment to realize it was the only thing—and the best thing—that we could do for Mom. I had had no idea about the kind of filth Mom had been living in. Envelopes of uncooked rolled oats were stashed all over the place. There were bugs everywhere. Mom had been the most fastidious person I knew. To see that she had been living in such filthy conditions was heart wrenching.

I view the first year that Mom was in Bayview as a time of adjustment for both of us. Her TV became a problem, so we took it home. She had lost the ability to concentrate, anyway. She insisted on wearing glasses that were the wrong prescription. They were weak and, as she no longer read, I realized it didn't matter that they were not the proper ones.

Bayview did its best to make families welcome, but it's hard to feel like a family when you have no living room setting in which to socialize. But a living room was our way of socializing, not Mom's. We slowly accepted it.

I've had to learn how to visit. I worry about Mom's jealousy and possessiveness with me and the other residents. She becomes very angry and vocal if I socialize with them. I am constantly trying to think of things I can do with her. She can no longer visit, so we must be where there are distractions to comment on. I realize that, to be successful, everything must

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be done in short intervals: half-hour car drives, short-order restaurants, picnic lunches, and outings for an ice cream.

Mom is quite content just to walk the halls at Bayview—up and down, around and around. I have tried crocheting, playing cards, crossword puzzles, photo albums (all things she used to love), but found these activities bothered her, so I try something else. The important thing is to keep trying.

The most difficult part of visiting is saying good-bye. Very rarely does Mom say good-bye without putting up a fuss. She wants to come home with me. I find it helps to reassure her that I'll be back in a couple of days. "Give me a kiss, Mom. I must go." Then I turn around and leave. It's difficult; I won't pretend that it isn't. I have no easy solutions.

I am losing my mom. Every month this loss becomes more apparent and I have to attempt to replace her in my own memories to make the pictures of my family fit.

My greatest comfort is knowing that Mom is safe. She is cared for by a knowledgeable and compassionate staff. Programs are numerous, especially music therapy, art therapy, and look good / feel good programs. I appreciate the coordinated effort of many: the social worker, administrator, program coordinators, nurses, and nurse's aides. I am made to feel that they care about her and that her needs are special.

Through all of this, my sister Faye, although living a great distance away, was an immense help with Mom. We were always in complete agreement as to Mom's diagnosis and care. Faye, too, joined the Alzheimer Society. We phoned each other at least once a week. She flew out to be with me on the tough days. Family support was so important because it helped me share my guilt.

Joining the Alzheimer Society and taking the caregivers course were essential. They matter-of-factly talk about the disease and let you know where you are now and show you where you are headed. They offer strategies to cope with your loved one's needs. They discuss your individual situation and advise you on not only what must be done but also how to go about doing it.

I found that my feelings of isolation diminished when I talked to others. I would advise other people in this situation to find someone who has been a caregiver or is going through similar experiences. Friends who do not share your experiences can be of only limited help. They don't un-



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derstand the depth of the disease, the constant worry, and the ever-changing and ever-present challenges. You think you've conquered one hurdle, only to come up against another.

I had to learn that my feelings of guilt are normal. I was making decisions for her that caused everyone much distress. I often worried, "How do I know this is the right decision?" I kept a diary and recorded unpleasant incidents and also the accompanying emotions. I had a desk calendar on which I recorded every contact that had been made with Mom that day. This record keeping allowed me to transfer my feelings to paper. It also showed me how increasingly dependent and frightened Mom was becoming. It helped ease my guilt because I could see how we had no choice.

Life goes on. I am coping no longer as a caregiver but once again as a daughter. Believe me, this is much easier.

## CHAPTER 4

# Guilt, Loss, and Grief

For many people, one of the hardest things they have ever done is walk out of the nursing home on admission day and leave behind their loved one. They will never forget saying good-bye at the door, turning their back, and walking away. It is the culmination of a turmoil of emotions they have been feeling for many months or even years. Chief among those are often shame and guilt.

### What Is Guilt?

Guilt is like a little voice in our heads. It tells us how we should act and behave and criticizes what we have done. It is the voice of standards that we have set for ourselves or, sometimes, that we think society has set. Sometimes it is the standard that our parents set. Sometimes it is our fears about how other people will think about us. Guilt is your inner voice (or that of people in your social group or family) telling you that you are not a good wife for putting him in a home. In a sense, guilt tells us that we are letting ourselves down.

Sometimes guilt serves a positive purpose: it can be a reminder to go back, look at and review something we have done or said. It gives us the opportunity to take responsibility for our actions and correct them. However, with caregivers I am going to assume that you do not need to review your actions. Most of you have hung on a long time and run the same racecourse too many times. I think if you need to review something, you could watch some reruns on television.

Shame, on the other hand, is the voice that talks to us about who we are; it follows the guilt. Shame can be incredibly destructive, more

so than guilt. It destroys the possibility of feeling good about yourself. It becomes an internalized belief about yourself by taking your actions and making them representative of the real you. For example, the message is that because you put your husband in a home, something is wrong with you, you are defective. The belief blocks your ability to listen to a reasoning voice, either your own or from someone else who tries to help you see yourself or your situation differently. It is as though you see the sky as red and everyone else sees it as blue. You “know” the truth because you can see it, and no one can convince you otherwise. If guilt is the judge, shame is the jail.

In a more humorous vein, think of guilt and shame as your conscience on steroids. Your conscience is that part of your personality which is useful and necessary to help you live a moral and ethical life. But when it becomes unresolvable guilt, it has ballooned out of proportion and gotten way out of control.

No matter where they come from, in the end the guilt and shame that we feel are something that we do to ourselves. No one can *make* us feel guilty. Someone can apply pressure, but ultimately, it is something we do to ourselves. It is our voice and our belief. The bad news about this is that we are often much harder on ourselves than anyone else is. The good news is that because we make ourselves feel guilty, we don’t have to depend on anyone else to forgive us. Because shame is our belief, we can change it.

### Conflicts that Give Rise to Guilt

No matter where you are in the process of placing your mother in a home, you may feel that you are abandoning, or have abandoned, her. You may see her as being at her most vulnerable, and yourself as the one who has protected and taken care of her when she became less and less able to do so for herself. You may begin to question yourself and who you are. “If I were stronger,” “If I were willing to . . .” Along with that may start to come the shoulds: “I should have waited longer,” “I should have been stronger.” When the guilt becomes very strong, you may start to blame other people: “If my brother/sister were around to help more often,” “If the doctor had ordered more home support for her, . . .” When you are having these feelings, look

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underneath to see what else is going on. Often there are feelings of helplessness or failure: "If only I were different, then this would not be happening." These are the messages that you use to convince yourself that something is wrong with you. Don't blame yourself; there is nothing wrong or defective about you. It is not your fault that she is sick or disabled.

You may have always thought of yourself as a strong person. To place your mother in a nursing home proves to you at some level that you are weak. This sets you up for a powerful conflict: if I am so strong, what does it mean if I do something that means I am weak? This makes you an awfully strong and harsh judge of yourself. Even strong people are allowed to say that they cannot do something or do not want to do it anymore. That doesn't take away your strength; it allows you to be realistic by acknowledging your limits. Sometimes it takes more strength to set limits for yourself than to give in to guilt. It is okay to say no.

After placement, you may feel a great sense of relief. Even the relief can lead to some guilt. It is almost as though you are thinking, "If I really cared, I wouldn't be feeling relief. This must mean I don't care enough." (Isn't it interesting what we go through to make ourselves miserable?) It is okay to feel relief from a burden. It does not mean that you love your mother any less. You can love her *and* not want to keep doing what you have been doing. People sometimes have conflicting feelings at the same time.

## Families and Guilt

Sometimes husbands and wives have an especially hard time. "I married him 'for better or for worse, in sickness and in health, till death do us part' and now I am doing this to him." It is helpful to remember that most of the time, this is not something you want to do. Think about what you would do if your spouse had a terminal disease. If he would be better off in a hospital, would you keep him at home? Probably not. Placing him in a nursing home when you are not able to provide the care he needs is no different.

Husbands and wives can also see themselves as having to choose between themselves and their partner. Placing your spouse may feel

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like you are choosing yourself over him, leading you to label yourself as selfish. What you need to remember is that by the time you are seeking placement, you probably have been putting him first for a long time. Nowhere does it say that you need to exhaust yourself or impair your health in your role as spouse or caregiver.

I recently had a man in my office who had been his wife's caregiver for many years. He was worn out from watching her and not sleeping or eating well himself, but he could not bring himself to bring her into care. He was wracked by the fear of abandoning her (and his fear of being alone). He was also wracked by guilt because he felt he should be bringing her into care. I finally had to suggest to him that if he chose to kill himself being his wife's caregiver, at least he should make some good plans for her for when he was gone.

For many women of the generation that is now seeking care, it was the husband who made the family decisions. For them to make the decision that their husband has to go into care can be frightening because they are not used to making big decisions. They may not have the confidence in themselves to make such a decision. They may feel that they are doing something wrong, and that they are taking over from their husbands. It is one more painful piece of evidence of the changes in him and their relationship that they are being forced to acknowledge.

Almost harder still is the placement decision for younger people. If you are in your thirties or forties, there is no role model, no support, and often no adequate facilities for your husband. It may also mean that you are placing the father of young children and are facing explaining to them why Daddy has to go live somewhere else. Underneath all of that, you, like your husband, may be struggling with anger and resentment at having "this" happen to you. The difference is that you also have the guilt about placement and then guilt about your anger and resentment, and no support for expressing it. I can tell you these feelings are very, very common.

If you are an adult child who is a caregiver, you are probably painfully aware of experiencing the difficult and anxiety-producing role reversal. You feel it when your father is no longer able or willing to make decisions for himself. You have to tell him to see the doctor, which bills to pay this month, when to change his clothes, and what

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to eat. Finally you may end up having to tell your father that he needs to go to a home. The person who was always strong and capable and there for you now needs to be taken care of. It is a little like a death. Making decisions for your father is a clear indication to you that the person you loved is, in some ways, gone.

Another reason role reversal is hard is because we grow up with what are called family rules. These are the guidelines that taught us how we behave with each other: who says what to whom, who makes decisions, how we talk to each other, what we talk about. In some families, for example, the rules can be “We don’t talk about sex,” or “Nobody criticizes Dad.” The rules are usually unspoken and learned since childhood. They feel natural and normal; we don’t even realize that they are there, governing our behavior. When you can no longer handle the caregiving and must tell your father what needs to happen, you are breaking the rule: “We do not tell our parents what to do, or set limits with our parents.” It feels wrong and uncomfortable.

Sometimes the rules must change because the circumstances change. Although telling your father what is best does not feel comfortable to you, that does not mean that it is wrong or you should not be doing it. It means that the behavior feels different. Like any new habit or behavior, it takes time to learn to do it, and it may never become comfortable.

For some children, guilt, shame, and the feeling that they are abandoning their father are worse because they promised that they would never put him in a nursing home. He may have remembered doing that to his mother or father. The terror of what those older homes were like was something he never got over. You think to yourself, “I promised him I would never do this. It was his worst fear and now I am making it come true.”

You may feel that your father took care of you when you needed him. You look at yourself and feel like an ogre of some sort because you are “refusing” to take care of him. This is especially true in the split between immigrant parents and first-generation children, for whom the cultural values of the old country still have a hold on both generations. What your father learned in his old country—children take care of their elderly parents—and therefore what he expects of you is somewhere in the back of his mind. It is unfair of you to com-

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pare yourself to your father, to your father's country, or to that culture. Yet he may be doing that and you may be feeling the pull.

If you are an only child or a spouse or partner with no children, the guilt can be especially hard because there is no one to share the decision-making process with you. Friends can help and they can listen, but you are the one with the emotional attachment. You are also the one with the responsibility. If something goes wrong, you see yourself as the one and only one responsible for what happened. Much of your decision-making process happens in your mind and in discussion with yourself. This makes it easier to be hard on yourself. There is no one around to help you put limits on your self-criticism or pull you out of it. Internal dialogue like this can make you feel crazy, and it is fertile soil for your conscience on steroids.

At a general level, you as a caregiver are dealing with the many cultural and social changes that have occurred in the last sixty years. For one thing, today there is less support available from extended families—brothers and sisters are separated, children move out of town. Second, more women are working outside of the home, so they do not have the time to assume the role of caregiver in the way that they may have done in the past. Third, society is more transient, so there is less support from informal sources such as neighbors and friends. Also, people are living longer with more frailties. They need more care, have more complicated needs, and need care longer. The result of these changes is that people can no longer look after elderly relatives the way families used to. Both the options available and the pressures on you are different from the ones that were present years ago. The needs have changed, but the cultural values change more slowly. This creates the gap between what you think should be possible and what is actually possible. This gap is a partial instigator of the guilt and shame.

Sometimes guilt and shame serve a psychological purpose. Although they are painful, they tell us and everybody else that we really do care. Without them, it may look to us or to others like we are cold and uncaring. Some people need the guilt and shame to counter the conflicting feelings they have inside, which makes them wonder if they do care. Other people at some level want the admiration that comes to them for all their hard work. You need to accept that you do

care or that placement was necessary. Nobody knows your situation better than you do. Others are not living with it in the present, and they did not live with it in the past.

### Not All Relationships Were Ideal

Not all marriages were happy and loving, and many children did not have supportive, loving parents. To end up being a caregiver for someone with whom you did not have a good relationship or who was abusive may divide you between doing what you feel is your duty and doing what you would like to do. That is, part of you tells yourself that you *should* be the caregiver, and part of you says that you shouldn't have to have anything to do with this person. A part of you is angry and resentful at what you have had to put up with in your life from your spouse or parent. A part of you wants to tell this person to go to hell, and a part of you may see a frail and pitiful old man. You may tilt back and forth, pulling yourself two ways. The anger and resentment are very normal and common feelings, but you may feel guilty about having them. They may make you question why you are placing your relative in a home. For those of you in this situation, placement becomes even harder.

Despite your anger and bitterness, you can still have legitimate reasons for seeking care for your parent or spouse. You have a right to set your own limits. You have a right to your life. You may be doing it earlier than someone who had a close relationship. The reason for this is that caregivers who have had a loving relationship with their spouse or parent generally have more emotional stamina for the caregiving role because of that loving relationship.

Emotional stamina is the ability you have to cope with stress. It is personal and individual. That is why you cannot compare yourself to others to prove to yourself that you should not be placing Dad in care. When the relationship previous to the caregiving situation was good, emotional stamina can be stronger. The love, caring, shared experiences, trust, and respect that you built created strong bonds and commitment. When those things did not happen, less of a bond was built.

Emotional stamina is complicated. It depends on internal strengths; some people handle stress better than others. It also de-



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depends on external situations, the pressures on you. Maybe you have growing children; maybe you have your own health problem. You may have a job that demands too much of your time. If your external situation is stressful or demanding, fewer emotional resources are available for the added burden of caregiving.

For many people, emotional stamina depends on the extent of their social or family support network. You may be a sole caregiver, or the only one of three children who is involved with your father, as opposed to a family in which all the children are sharing a burden equally. If you receive less support, you may be able to give less support.

Beyond the differences in emotional stamina, there are also differences in caregiving situations. Even though two people may have cared for their mothers for the same length of time, the needs of the two mothers may be very different. One may be wandering out of the house and the other may be afraid to walk out the door. One may be incontinent but sleeping and the other may be continent but not sleeping. Don't compare yourself to someone else; you cannot really know what he or she is going through.

Not everyone experiences guilt or shame when she has to place a relative. (Please don't feel guilty about not having guilt.) This may be because it was truly the relative's choice to enter a facility. She may have been lucky enough to have conversations with the relative before the need arose in which she got emotional permission for placement. Or she may just be able to realize and accept that she has done all she can do for her relative.

Some people do not experience caregiving as a burden. For whatever reason, they experience it as a special time and part of the relationship that they have had. Not that they would have chosen it, but they can take it as a gift that is both bitter and meaningful. That does not mean that they are somehow "better" or stronger people than you because you experience the caregiving as too great a burden. It is all right for you to decide for yourself when you cannot do it anymore. You do not have to apologize to anyone. It also does not mean that you are less of a caregiver; you aren't. It doesn't mean you love your wife less than someone else loves theirs. But, as I said in Chapter 1, you are allowing the role to change.

## Guilt and Dementia

Even though it is ultimately you who has to forgive yourself for your actions, people often tend to ask for forgiveness from someone else, usually from the person who has been “harmed.” When your father is angry with you for suggesting that he needs a home or when you visit him and he is angry with you for leaving him there, you may find yourself trying to explain over and over again why things are the way they are. Don’t try to reason with him or make him understand. Don’t try to seek his forgiveness. He is not able to reason things out and doesn’t have the capacity to forgive you. Agree with him, tell him it is not fair, then change the subject or drop it and don’t say anything. It will be hard for him to argue with someone who isn’t going to argue back. He is right: it is not fair, for either of you. If you continue to disagree, explain, or ask for forgiveness, you will be on a treadmill, unable to get off. If his reasoning and understanding are not intact, you need to turn somewhere else to ask for forgiveness.

The truth is that you may be a better caregiver after your father has gone into care than in some of the time preceding. You will not have the anger or resentment or frustration. You will be having a full night’s sleep. You will not have the fear of a telephone call that Dad has fallen and cannot get up. Assuming he is in a good home, you will know that he is clean, not wearing clothes soiled from urine, taking medication as it has been prescribed, and eating three meals a day. When you don’t have these worries or feelings, you can have a better relationship with your father and you can go back to being a son.

If Dad is not in such a good home, you need to remind yourself that he is there because that is what is available. Most likely you did not say to yourself, “Gee, this place smells terrible. Let’s put Dad in here.” You will do what you can to make it better.

## Dealing with Guilt

You do not have to be a prisoner to guilt. In this section are a number of actions that can help you. Read them and choose a few to try. You will have to work at them consistently over time. They do work if you allow them to.

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Many of these techniques fall under the description of what psychology calls cognitive or cognitive-behavioral restructuring. This assumes that feelings arise from thoughts that are developed from people's history and experience. The immediate thoughts, and therefore feelings, are based on patterns of thinking that have developed from that history and experience. The patterns are often not conscious; they are just felt as the "shoulds" that we experience. To change your feelings, you can work on changing your thoughts. The trick is that you have to work at it. It means you have to become committed to doing the work until the changes take place in your thinking. It does not happen overnight.

First, try to just give yourself permission to forgive yourself. You may have to have several conversations with yourself and practice saying, "I forgive myself for doing what I know needs to be done." Listen to your head, which knows that you have done what you had to, and not your heart, which is telling you to keep pushing for one more year or that you are being selfish and weak. Have the conversation in front of a mirror so that you can talk and listen to yourself.

You can also practice some affirmations. Affirmations are positive statements that are used to counter destructive thoughts and help you restructure your thinking. In this case, they would be something like, "I am a good and caring person" or "I am a worthwhile person and have a right to take care of myself." As with permission giving, say these in front of a mirror ten to fifteen times, twice a day. Post them on your refrigerator. Affirmations will help with the shame; they allow you to change your belief about yourself. Remember, that belief is only an emotional decision, which you have made about yourself. You can change that decision.

Most people have very good and valid reasons for placing their relative in a nursing home. In fact, most people hang on too long. You know why you are doing what you are. Make a list of what you have had to change in your life and how caregiving has affected you. What did you sacrifice? How much of your own life did you give up? How much sleep did you lose? How has worry changed you? How much did you neglect your own spouse and children? Or take a piece of paper and divide it in two, lengthwise. On one half, describe yourself

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and your life before you were a caregiver. On the other half describe the present. Compare the two.

Keep a daily journal to review and release your feelings as they occur. Reread it every now and then. If you are writing in it honestly, you will see what caregiving is doing to you and your family.

If you have not kept a journal (or sometimes even if you have), it helps to write out your caregiving story. Write down from the first minute up to right now what you have been going through and the reasons you are proceeding as you are. This helps you see what you have been through and acknowledges all you have done. You will find it is a lot more and a lot more difficult than what you give yourself credit for.

Take a look at the total picture of your life. Ask yourself what it would be like to keep doing this every day for another year, not just on the days when your father is having a good day. Do you find yourself getting short-tempered with him? Can you keep depriving the rest of your family or your wife of your attention? Are you ready to keep driving over there every day? Can you go that much longer with your sleep disrupted? You don't want to end up in a situation in which you become abusive, in which your family is suffering, or in which your emotional or physical health is impaired. If that happens, you will have ended up doing a disservice to everyone, including your mother, for whom you are trying to care.

Pretend that you are a friend of yours, and write a letter to yourself. Would you forgive someone else in your shoes? Sometimes the standards that we set for ourselves are much higher than those we would expect from others.

Another technique that comes from counseling may help you. It is best done with a guide such as a therapist, but you can try it on your own. Set out two chairs. You sit in one, and imagine your guilt (or use a doll you have labeled) sitting in the other. Talk to the guilt. Have the guilt talk back. (I know you feel foolish doing this. Do it anyway, okay?) Enter into a dialogue with your feelings. As you do this, listen to what both are saying. Notice how you feel and what you think about what you are hearing. At one point, you may want to switch chairs and sit in the guilt's chair. Be the guilt talking to you. Listen to

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how the guilt talks to you. If you can, record the conversations you have and listen to them.

One of the most effective actions you can take is to find a support group. See if there is a group in the nursing home. Call the Alzheimer's Association, the Heart and Stroke Foundation, or the Parkinson Foundation, for example. Many communities have caregivers' groups run through a hospital. A support group helps you to form a reference outside yourself that can help you to forgive yourself. It is like an external conscience. I have had people tell me that they do not wish to sit around and listen to a bunch of people talk about their problems. Most support groups also talk about solutions, both practical and emotional. They tell you what other people did and how they did it, so you don't have to reinvent the wheel. They also let you know that you are not alone and that your guilt is manageable. Sometimes they are fun. You can meet some wonderful people and make some close friends.

If there is no support group available, try to find an individual you can talk to. Sometimes just saying things aloud to someone else can help you to see them in a new light. Find a peer who has been through what you are going through. See if the home has a social worker or other counselor available.

If you are a religious person, ask God for strength, help to heal, and forgiveness. Frankly, God has a better grasp on life than you do, and has been doing it longer. Let God decide if you should be forgiven. Most likely, God will be easier on you than you are.

If God is temporarily unavailable, you can talk to your pastor, rabbi, priest, etc. Not only are they an excellent source of strength and comfort, but also they can stay by your side as you are making a decision about placement and for the whole journey afterward. They often are quite experienced with nursing homes and aging and understand what you are going through. As one woman said to me, "I couldn't have done it without [the pastor]. He was helpful in a way no one else could be because religion has always been such a part of our lives." Even if religion has not been a big part of your life, it is there when you need it. If you choose to believe in God, God is there for you when you need to turn to God.

John Bradshaw's book *Healing the Shame that Binds* is an excellent

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resource for examining the more deep-seated aspects of shame in our lives. He looks at how shame develops in our formative years, its meaning, and how it carries on into and affects us in our adult life.

If none of the above techniques works, write the word *GUILT* on a large piece of paper. Go to the broom closet and take out the largest broom you can find. Put the paper on the floor. Raise the broom high over your head. Then whack the heck out of the *GUILT* as hard as you can. Do it as often as you need to.

Some people absolutely refuse to let go of their guilt. If this is you, I have another approach for you. First, start rearranging your house. Empty out half the drawers in your dresser. Clear out half of the coat closet, set an extra place at the table, put another set of towels in the bathroom, and make up a fresh bed in the guest bedroom. If Guilt is going to live with you, you might as well make him as comfortable as possible.

In the end, you need to realize that you cannot save your father. Life is how life is, no matter how painful it can sometimes be. You are not a superpower, and you are not God. You did not make the situation he is in and you cannot make him better.

In summary, to heal from guilt and shame, you first must want to heal from it. You will not love your father any less without the guilt. You must allow yourself to heal by forgiving yourself for your actions, decisions, and feelings. You may have to work at it, but you can do it. Be kind and gentle with yourself. Allow yourself to say when you have had enough, and allow yourself to set limits and boundaries for yourself. Forgiveness does not come in a box that you unwrap. It is more like a piece of music that takes time to hear. Try to forgive yourself a little bit every day. At the end of some time, you will hear the melody.

## Letting Go

If your husband is going into care, you probably have already experienced to some extent the feeling of having to let go of him. You have let go of the image of who he used to be. You have let go of the hope that he will be able to do the things that he used to do—talk to you the way he used to, love you as he did. When he goes into a nursing home, the process of letting go may intensify or recur.

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As you let go of who he used to be, you let go of the relationship you had. You may even feel that your marriage is ending or has ended. Partly this happens because the things you used to do for and with each other change. Those actions made up the relationship that was your marriage. You replace them with actions that create a relationship of caregiver and care receiver.

When your husband enters the nursing home, you may feel like you are having to let go of the caregiver's role. Someone else will be taking care of your husband for the most part. You will be allowing someone else to help wash, feed, bathe, and dress him. You may find yourself wondering what that will leave you. You may feel bitter or resentful at someone else doing what you used to do, even if you were tired and worn out from doing it. Letting someone else take care of him is also like coming to terms with your own limitations and doubts, knowing that you cannot protect him any longer.

Changes of this magnitude in a relationship can be frightening. Partly this is because in some ways we define ourselves through our relationships. I am a wife, a father, a brother. When there is a change in your primary relationship, it can lead you to wonder, "Who am I?" and "How or to whom am I important?"

If you are an adult child, you may feel that you are losing your father when he goes into care. If you have already lost one parent, this can be especially hard. Even though you may be an adult, the feeling of having a parent is like having a psychological protector. Losing a second parent may in some way leave you feeling abandoned or all alone. This can be frightening at your very core. Even if you haven't felt for a long time that you "needed" your protector, just the knowledge in the back of your mind that he is there provides a kind of security. You don't know it is there until you don't have it anymore.

An only child has it harder still. Only children tend to have more intense relationships with their parents than do children from families of more than one child. So letting go can be harder. Also, as an only child, you are losing the primary family link you had with your past: what made you, for better or worse, who you are today. You are losing your only intimate history and the only person who accepted you unconditionally and nourished you since the day you were born.

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People have this feeling even if their relationship with a parent was troublesome.

Younger people have a difficult time in another way. For you, placing your husband means letting go of a future that you had planned and hoped for. It means rewriting the script that you have created for the rest of your life. So you are losing not only your husband but also your future.

When your husband enters the home, you will be letting go in the physical sense—he will no longer be in the family home. You will have to face what can be painful loneliness, and this can be a concrete reminder of the reality of your situation. It says this probably is not going to get any better; if anything, it is going to get worse. You are letting go of some hope. It is an emotional letting go.

As you go through the process of letting go, your husband is going through it too. He is letting go of his independence, his home, and his marriage. Often he is letting go of much of his decision-making rights. He is letting go of his responsibilities around the home. This is in addition to the other losses to which he may or may not have already adjusted: the ability to dress, walk, do his own banking or shopping, go out by himself in the larger community, or even think and remember clearly.

The most difficult periods in relationships are often when both parties are going through stressful situations at the same time. If it were just one of you, the other would be able to rally and be supportive. When it is both of you, you are both needy. This is the reason you may be experiencing increased friction with a parent or spouse as he goes into care. For you to support your husband can mean having to put aside your own needs for a time. Even though you may not mean it, you can end up feeling angry and resentful that your needs are not being met. That was not part of the agreement.

## Grief and Loss

Letting go is a process of grief and loss, the resolution of which often takes up to a year. To come to acceptance means ups and downs. It involves anger and rage and sadness and depression. You will have



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many different feelings and thoughts that come and go. You will have good days and bad days. If it is your mother in care, she may have bright days when it seems she could have still lived at home. Then you start to be hopeful that she will “come back” and you will wonder if you have done the right thing. If it is your husband in care, you may have days when your loneliness is overwhelming and your house feels huge and empty. Your resolution will waiver and you will want to take him back home just for a week.

Remind yourself firmly about your husband’s prognosis. Reread your journal or notebook about what you went through while he was at home. Often what he has is progressive: despite the ups and downs, he will get worse. Let your hopes guide you to enjoy what you can, not delude you into thinking that things will get better. It is so easy to allow yourself to hope, but your hopes can end up letting you down over and over again if you are not realistic.

The grief process can be more difficult in the circumstance of placing your husband in a nursing home than losing him to death or divorce, because there is not a sense of ending. This is a kind of ambiguous loss. Death or divorce has some finality. If your husband is in a home, you realize on one hand that you are still married, and on the other hand you may feel like you are less than married because the parts of what made up your marriage are missing. If it is your father who is in a home, you may feel when you visit that the person who stands in front of you is not really your father—he is not the person you knew, and yet he is. In a way he is gone, but in a way he is not. It is hard to resolve the grief over someone who is only partially gone. It is hard to let go when you can change your mind and take someone home or when her condition goes up and down.

Before the actual time of placement, you may be experiencing what is called anticipatory grief. That may be one of the reasons why you are holding back from placement. The grief—or fear and reluctance to feel it—can be so overwhelming that you try to avoid it by not allowing your husband to go into the home.

Around the time you are placing your husband and have to turn him over to the care staff, you may start feeling intense pain, because this is the actual time when you are letting go. It is also the actual event: what you feared or avoided is actually happening.

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You may be surprised at the feeling of anger when it comes. It may be directed at yourself, your husband, the care staff, God, or some or all of these. You may find yourself lashing out at your family or at the cashier in the grocery store. If you are not used to being an angry person, this can be confusing and frightening. Be assured that it is a normal part of grief. The anger is a way to help protect yourself from fear and emotional pain. If you are able to continue through the grief process, the anger will subside.

If your husband is in a home where the care is poor or suspect, you will have an even harder task. You will have to figure out how to let go, yet how to remain involved to the point that he is not at risk. Partly this will mean more closely overseeing care than providing it yourself. You will have to learn how the home functions or is deficient and see what you can do to meet those deficiencies, short of moving in yourself.

### Handling Grief

To let go, you need to be willing to let go. You need to understand that letting go is not abandoning and that hanging on will not change the situation; it will only prevent you from making the best of it. Letting go means being willing to face your feelings of grief and loss. You cannot hide from them, or try to be so strong all the time that you do not feel them. There will be times when you do not want to face your feelings, when the pain is too great. Be gentle with yourself. Distract yourself with an activity or something else, and come back to them when you are able.

If you are not willing to face your feelings, they can surface in other ways, such as depression and ill health. In the long run, the price you pay will be higher because you will be having the feelings longer. It is a little like the choice between short-term pain with relief and long-term pain.

Use supports and resources that are available to you. Find a support group or a competent therapist. Maybe it is someone from the health department who arranges nursing home placements. If the home that you are looking at has a social worker, helping with grief is often part of her job. Talk to another daughter or son or wife or husband who

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has been through the process. Use some of the resources and actions that I mentioned in the section under guilt.

Supports will help you meet those needs that you have put aside in responding to those of your husband. Now is the time to respond to yourself. If you don't, you will deplete yourself faster. Think of yourself as a watering can: if you keep watering the plants without filling up, the can is eventually empty.

Remember that even though someone else will be taking care of your husband, you are not replaceable. In some ways, your role is even more important than it was. You may not be doing the physical care that you used to, but you are still the primary caregiver in the emotional sense. Even the very best staff can never replace the loving relationship and feelings that exist between family members. Staff will never be able to validate a resident's importance and individuality the way you do. Staff will never be able to let a resident know that he counts the way his family can. When your husband goes into care, you can concentrate on the emotional aspects of your relationship. Ultimately that is what creates and maintains love.

## *Marjorie*

I would like to put into words how very difficult it is to watch a much-loved and capable parent floundering in the confusion of her mind from insecurity and frustration. You fight so hard to keep things going as they were. It is very difficult to accept the changes and the reversal of roles. It is also frightening from a personal point of view and makes one feel very vulnerable. Writing this down gives me some sense of release and is very therapeutic.

We had been the grateful recipients of varying degrees of assistance before Mum went into the home. She received home care from the province and an assessment at the hospital. The staff at the hospital treated us with empathy and appreciated the stress that caring for Mum was putting on my husband and me. They directed us to other channels of assistance and advice.

Mum started attending adult day care for two and then three days a week at the nursing home where she was going to go to live. She also got two hours of home support services on the other weekdays. It afforded her the opportunity to mingle and enjoy the company of her peers in a safe, pleasant, and friendly environment. It also gave her a chance to perform mental and physical activities such as crafts, quizzes, discussions, and exercise. After a few months of attendance, she changed from being nervous, shy, and clinging to more her former self. It also gave her something of her own to talk about with us.

The day care and home care enabled my husband and me to have some free time together, which we urgently required. There were many other benefits, most of all a terrific relief in not having to worry about

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Mum's happiness and welfare twenty-four hours a day. We could *not* have carried on as we were without this day care.

Before Mum moved into the nursing home, she had a week of respite care there. That week helped her to see what it would be like when she actually went to live there permanently. Even though she might not remember, we could remind her that she had already been there and enjoyed it.

The transition of moving into the retirement center went smoothly and pretty well stress free for my mother. It just seemed like a natural progression. She already knew a lot of the people, both residents and staff, and was familiar with the building and the routines, so she did not experience the natural trauma of someone coming from her own home environment into "care." Members of the day care helped her settle in by paying a visit to her room and welcoming her.

I was the one who felt stressed. When I left Mum at the home that first day, I felt a real sense of loss. It helped that I knew the day center staff would keep an eye on her. They and the staff of the home gave me positive feedback as to how she was doing. This was very reassuring to me. It helped me feel I had made the right choice.

I still am finding the letting go very difficult. Even though I know it is the best thing for us all, it is difficult. With the help of some counseling from the social worker at the home, I know I am getting to the point of acceptance. I am reconciled to redefining my role in Mum's future care. I can't do what I was doing. I have come to realize that I cannot and should not be totally responsible for my mother's happiness. With the help of the staff at the home, I can still be there to complement their good work and feel that I am helping my mother.

Just writing this has been very therapeutic to me. It helps me see what I have been through. I know I have a lot further to go, but knowing I have come this far makes me hope I can keep on going and my feelings will continue to get easier.

PART II

THE NURSING  
HOME



## CHAPTER 5

# About Nursing Homes

What makes a fulfilling life, do you think? It seems to me that it varies from person to person, but usually includes having a pleasant physical environment, interesting activities, and loving, fulfilling relationships. It usually includes having found some meaning and purpose to life. People who have fulfilling lives have found contentment through a healthy psychological adjustment. They have an acceptance of who they are, what they have done, are doing, or hope to do in the future. Ideally, you could find a nursing home for your father where he would be able to achieve this kind of life.

Unfortunately, your father may not have had a fulfilling life before going into a home. It is unlikely that any home would make up for that. They cannot change your father into someone he wasn't and they cannot change the things that have happened to him. Also, even the best homes rarely meet the ideal that can make a life fulfilling. Life will not be perfect in care, and it will never be like someone's own home. But there are ways that a home can try.

What you need to remember is that you also cannot "give" your father a fulfilling life. You cannot make up for what he has lost or is losing by giving up his home and going into care. You cannot bring back his eyesight, his health, or his wife. You also cannot be everything to him that he needs. If you think you can and you try to do so, you will be lost in an ongoing struggle that you cannot win. Or you will end up totally giving up your own life. He has to find fulfillment, meaning, and purpose on his own to whatever extent is possible for him, given his psychological and financial resources. What you can try to do is maximize the potential for fulfillment. Partly that is done



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through your ongoing relationship with him. Maintain your relationship, but be aware of your limitations and boundaries. Another way you can help to do this is by choosing the appropriate home.

### Where to Start Finding a Nursing Home

In the United States, both state and federal regulations govern nursing homes. All states have offices on aging that are responsible for seeing that nursing homes are meeting regulated standards. These agencies handle complaints and do yearly nursing home surveys. In addition, each state has smaller area offices on aging mandated under the Older Americans Act to provide information on services and funding. Some of them also provide services. Each state also has an ombudsperson, mandated under the Older Americans Act, whose office is responsible for protecting the rights of residents (see Appendix 1, "State Ombudsperson Offices"). Although the area agencies on aging may not be able to recommend one specific place to you, they are excellent resources for general information.

You can call the ombudsperson or the state agencies for lists of nursing homes and for copies of the survey results. You can find them in the phone book in the government sections or by calling directory assistance. The easiest way to find them is to call the Eldercare Locator (800-677-1116) or look on the Web at [www.aoa.dhhs.gov](http://www.aoa.dhhs.gov). Eldercare Online ([www.ec-online.net](http://www.ec-online.net)) has a section where you can look for nursing homes by ZIP code or by state. They also have government reports and additional information on each nursing home, as well as information on nursing homes and care facilities in general. It is an excellent site. Medicare's Web site, [www.medicare.gov](http://www.medicare.gov), also has extensive information on homes and surveys by state.

The Senior Housing Net ([www.seniorhousing.net](http://www.seniorhousing.net)) lists all kinds of housing options and has evaluation guides to help you decide what kind of housing is appropriate for your needs.

In Canada, nursing homes are regulated through provincial legislation. The regulations may be enforced at the provincial or the local level, often through the health department. Local health departments may also have specific guidelines and regulations. Look in the government pages of the phone book to find the numbers of the health

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department, or look at Appendix 2, “Accessing Care in Canada,” at the back of this book. You might be lucky to reach a worker who will give you the real information on which homes are better than others. Often they are not able to tell you this, as they work in the system. You may have to ask a question like, “Where would you want your father to be?” Generally, although not always, the better homes have longer waiting lists. If a home always has a vacancy, there is a reason for this. Different provinces, however, have differing amounts of resources, so waiting lists can vary enormously for the better homes.

The Resources section at the back of this book lists several other Web sites you can use. Often you can find names of homes through the Alzheimer’s Association or other caregivers’ organizations. Ministers, doctors, social workers, and hospital discharge planners usually have knowledge about facilities. In the United States and to a very limited extent in Canada, you can call a geriatric care manager (National Association of Professional Geriatric Care Managers, 520-881-8008; [www.caremanager.org](http://www.caremanager.org)), who will help you sort through the maze of options. The advantage to going these routes as opposed to government routes is that people will often recommend which places you can trust and which you should stay away from. Government agencies will not be able to do that, or not directly.

You should also do some networking among your friends, people you know at church or in your workplace, and so on. Try to talk to more than one person with experience of the same home, and compare what they say. Talking to other people helps you really understand what the nursing home is like. You can fine-tune the questions you need to ask at the particular home. It can also help you figure out what is realistically possible as opposed to what guides like this one tell you.

A word of caution: If someone you know has had a bad experience with a particular home, this does not necessarily mean that the home is not a good one. Assess the person you are talking to. If she is deep in grief, denial, or resentment, then no place may ever fit the bill. Also, even the best homes are not perfect, and there can be glitches.

When you are first considering a nursing home or other care option, you should also begin to formulate an understanding of the care system in your state or province. Each state or province and some-

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times each home has its own rules for eligibility, for waiting lists, for payments, for Medicaid, etc. When I have been on the staff of nursing homes, I have often spent a good deal of time with people explaining to them how the system works and how they can make it work for them. Often you can stumble on someone in the system who will do this for you. Hospital discharge planners are good people to explain things to you, as are the Alzheimer's Association and the various caregiver support networks (see Resources). In the United States one of the best places to start is the state ombudsperson. In Canada, try starting with your local health department.

One tactic to make sure you understand the system and how it really works is to call two or three different offices of the same agency and ask the same question. If you are given the same answer two or three times, then you can probably trust it. If different people give you different answers, keep digging and asking questions. Sometimes there is more flexibility in a system than it first appears. Rules are often not straightforward and can be open to interpretation by the staff person applying them.

## Keeping Your Relative at Home

You have probably used all the options available to maintain your father at home. In Canada all the provinces have subsidized systems that include home care, adult day care, and respite beds (in which a person goes into care for up to four weeks a year). Adult day care will often pick up your father at home, provide a full day program, maybe give a bath once a week, pack meals to take home, and monitor medications and health. The various parts of the system are integrated with the residential care systems. This means that once someone is in the system, he can progress as his needs become greater. In the United States, all of these options are available, but you must find means to pay for them privately and the care system is not integrated. In both countries, it is possible to put together a plan that will help someone stay at home for a long time. If you do not have the time or knowledge, this is another area where a geriatric care manager has expertise.

If you do take the route of caring for someone in the community, it is essential that you develop a plan to help you cope with the emo-

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tional and physical burdens that you will experience. Part of this plan includes social support and relief from caregiving duties for yourself. A couple of studies have indicated that people who take advantage of this kind of support are able to continue caregiving longer than those who do not.

A number of books and Web sites have information to help you keep someone at home. Books include *The Baby Boomer's Guide to Caring for Aging Parents*, by Bart Astor; *The Complete Eldercare Planner*, by Joy Loverde; *Keeping Them Healthy, Keeping Them Home: How to Care for Your Loved Ones at Home*, by Ellen M. Caruso; and *Therapeutic Caregiving*, by Barbara J. Bridges.

Web sites and books can help you decide if keeping your father at home is something that you are really able to do. In theory, you may want to; in reality, it may not be practical. They will also give you a picture of the difficulties you may encounter and guide you in planning so that these difficulties don't become problems. Plans and knowledge will help you minimize the stress and anxiety that can lead to exhaustion and burnout. Take a look at these; there is no reason for you to have to waste your time and risk your health by finding solutions on your own.

Use books and resources to help you until you have to take the next step. Do not use them and convince yourself you can avoid using a nursing home. If you do, you may be setting yourself up to fail and you will make your next steps harder. Do not use them to push yourself, to find "the answer," or somehow to increase your guilt because you eventually have to use outside care.

If you decide to care for your father by bringing him to your home, remember that you are deciding about something that is not static. It is likely that your father will deteriorate in some way. This means that the burden on you will become increasingly difficult. You may not be able to do it for very long. This will mean that your father has to move again, suffer another loss, and feel "not wanted" by you in your home.

If you want to give yourself an objective picture of your caregiving "career," make a list of all the tasks you or your family perform for your father. Next to it, put two other columns and list the tasks that you expect to be doing in one year and two years from now. This chart

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will show what your caregiving role is now and what it will become. It will enable you to match your father's needs with the options available. It will also reduce the chance that you will opt for one type of care, only to have to make another move in the near future.

### Types and Levels of Care

To make a rational decision about what type of care is appropriate, you should understand what your father needs now and what he will need in the future. Obtain from the doctor a clear picture of his diagnosis and what it means. What is the expected progression and time frame? If he has an illness, contact an organization that deals with that illness, such as the Alzheimer's Association or the Parkinson Foundation. They will give you a full picture of what to expect.

It is very possible that you will find that the care your father needs will come not from a nursing home but from another residential option. Many different types of care are available to meet a variety of needs. Different states and provinces have different names for options and have different regulations. It can be quite confusing. You may find names like "independent living for seniors," "congregate care," "assisted living," "retirement communities," "nursing homes," or "skilled nursing facilities." It will be necessary to figure out which places in your area provide which services, and which places provide the care your father needs.

The basic level of care is usually called congregate care or seniors independent living or residential care. (The "ors" can go on and on.) Anyway, there is a dining room, and one, two, or all meals are available. Usually they provide some housekeeping, some laundry services, some recreation, and a bus for outings. There tends not to be any personal care.

A next level is generally called assisted living. Assisted living is characterized by emphasis on non-nursing/medical services. Residents have their own apartments or rooms. They may have facilities to cook, but all meals are provided. There may be a call bell for emergencies. There are also housekeeping and laundry services. Usually recreational activities are provided on site. There may be a nurse on duty to dispense medications, but there is usually no twenty-four-hour nursing

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care or medical monitoring. Sometimes there are regulations on what the nurse can do, if there is one. Generally there is help for personal care needs such as dressing and bathing, although you may have to pay extra for it. The services provided at the assisted living level may be all that even a fragile older person needs for quite a long time.

Assisted living is subsidized in the same way as nursing homes by some Canadian provinces. In the United States it is not generally covered by Medicaid, although some states or counties have obtained waivers and are beginning to fund assisted living. I expect more and more states will begin to do this. For the moment, because of the limitations on funding, an assisted living facility may not be an option for you unless you have private means for payment.

The advantage to assisted living facilities is that they give residents a greater feeling of independence and they feel less like a nursing home. This is because they do not function on the "medical model." The staff and services are oriented toward supporting a person in managing tasks like cooking, dressing, taking medication, and recreation, and not toward offering nursing care.

The disadvantage to assisted living is that almost nowhere are the standards regulated, or, if they are, the regulations are less stringent than those of nursing homes. Standards vary enormously. So do not be fooled into thinking that you do not have to monitor your father or the facility. It is true that if he is going into assisted living he may be more capable and can tell you what is going on. It is true that you will not have to monitor nursing care. But you will still have to know if he is taking his medications, how he is eating, and if he is engaging in a supportive and healthy social life. You will still have to figure out if he is changing his clothes and washing, or if those services are being provided the way the facility says they will be (and for which you may be paying extra). In short, you will have to make sure that the needs for which he entered the facility are in fact being met. The longer he lives there, the more his mental faculties may decline. As he becomes frailer, he still may not need actual nursing care, but he will increasingly need some kind of monitoring. Remember, there is less staff here, so there are fewer people to monitor areas of potential problems. If there is a problem with the facility, there may be no regulatory agencies and standards with which you can register a com-

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plaint. (Of course, health department standards will be in effect, as will standards for building and safety concerns, but there are none for care or services.) The industry association is called Assisted Living Facilities Association of America (see Resources), and it has voluntary standards.

Skilled nursing care facilities are what we think of as nursing homes. These homes provide full-time nursing coverage. Nurses perform treatments, dispense medications, and so on. They are responsible for monitoring the health of the residents. Nurse's aides will help with bathing, dressing, walking, and eating. There are other supplementary professions, such as social work or physical therapy. Nursing homes are highly regulated by the provinces and, in the United States, by the states and the federal government.

In some areas there are separate, hospital-like settings for people who are bedridden or who need a great deal of medical and/or nursing care. They have a much higher staff-to-resident ratio and residents are much more disabled. Even in these facilities, however, acute services such as X ray or emergency services may not be available, nor a doctor present.

In some areas there are also adult group homes, residential apartments, or room-and-board options. They usually have to be licensed to provide care. The regulations governing them are often minimal. Some offer only limited assistance in a family setting. Some have full nursing care. They may be very "homey" or they may be depressingly Spartan. One of the trade-offs for the family-like atmosphere of a small facility can be limited recreation and activities because there are fewer staff members. Some are excellent, but some may be decidedly less so. Several provinces and states have been actively developing different forms of group homes and residential care which are supported and monitored by professionals and are publicly funded to some extent.

If a place is licensed and staffed to provide only a specific and limited range of care, a resident may have to move when his condition deteriorates. Increasingly there are complexes called continuing-care retirement centers that offer a range of options—your father could start off in an independent senior's apartment, then move to an assisted living area, and then move to a skilled nursing setting. Here your father will not have to make another big move. Your mother and

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he can move there together; if one needs more care later, at least they are in the same complex.

For more information on and explanations of the different types of care, look on the Web at [www.seniorhousing.net](http://www.seniorhousing.net), under the section “Know Your Options.”

### Applying for Care

In the United States, you generally must seek out each home and apply individually on your own. If you are in the hospital, the social worker or discharge planner may initially contact potential homes for you. In some states a standardized process or form must be completed before you can apply. In some states you must have a doctor’s referral. You will have to find out the requirements in your state.

In Canada, most provinces now have a single-point entry system of care for elderly persons. “Single-point entry” means that one public agency will follow your father from first contact, when all he may need is care in his own home, up to and after placement. This agency will assess your father and decide how much care he needs. They will help him and you decide if he can manage at home or if he needs a residential setting. If he needs a nursing home, they will assess what kind of home can best provide it. They manage waiting lists for public facilities that very often offer a high quality of care. (See Appendix 2, “Accessing Care in Canada.”)

Remember that when you are applying for and viewing a home, the home is also checking out you and your father. A home wants to know whether you will be able to pay or if payment such as Medicaid or long-term care insurance has been arranged. Homes that depend on Medicaid payments may be looking for more impaired residents because their funding may be based on the amount of care a resident needs—the more care, the higher the payment. Some homes limit the number of Medicaid residents they will accept because Medicaid payments are often less than what they charge privately paying clients.

The home will also want to know whether they can provide the care that your father needs. To figure this out, they may do their own assessment, which can include looking at his ability to feed, wash, and



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dress himself; his ability to walk or transfer; and his memory and other cognitive functions.

Most facilities realize that they are admitting a whole family, not just the individual resident who will live there. They know that they are not just working with your father, they are also dealing with you: your feelings about him and about his going into a home, and the other stresses that you and your family have. They will want to figure out if they can handle you. If they feel that you will be extremely litigious, argumentative, demanding, or verbally abusive to their staff, they will think twice before admitting your father. I am not trying to tell you to put on your best party dress and shoes and act like a lady, but remember that they are trying to figure out what their future will be like, too.

### About Good Care and Good Caring

There is a difference between good care and good caring. You can have one without the other.

In the United States, according to the statistics, it is hard to obtain either good care or good caring. Studies have documented that adequate care is provided in less than 50 percent of the nursing homes in some areas. Some studies put the numbers closer to 3 percent. I don't want to scare you—good care, and good caring people are out there. But you need to have your eyes open. Good care means up-to-date and competent professional practice from all the staff members in a home. It can come only from people who have training and knowledge in the field of geriatrics. Registered nurses should have training in gerontology. Nurse's aides should have been through a training program that teaches them about how to provide direct care to fragile, impaired elderly persons. The recreation staff should at the least be headed by someone who has a degree in recreation therapy and experience in geriatrics. The director of nursing should have multiple years of experience and training in geriatrics. The home should have educational programs for its staff.

Good care also comes from the consulting and backup that is provided to the home. This means that they have access to geriatric

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physicians and geriatric mental health providers. Their pharmacist should be knowledgeable about medications for elderly persons.

Good caring, on the other hand, means that the staff understands the emotional needs of the residents and behaves in a manner that meets those needs. It comes from people who are warm and loving. Good caring comes about when staff members treat residents like people, with respect and dignity. It occurs when the housekeeper is talking to the resident as he or she makes the bed or cleans the bathroom. It occurs when the care aide talks to your father as he or she bathes, feeds, and dresses him. Good caring comes about through the building of good relationships between the staff and the residents and among the staff members themselves. Good caring also comes when there is a good administrative structure. The staff can have the best training in the world, but still not be providing good caring. They can also provide good caring without being able to provide good care. You want both.

At the system level, good caring comes from a nursing home that is client centered as opposed to system centered. This means that to the greatest extent possible the system is arranged so that it meets the needs of the residents and their families; it does not try to make the residents and families fit the needs of the system. That said, this does not mean that when you say, "Jump," they should say, "How high?" It means that the men and women who work in the system can understand your point of view and make an effort to accommodate it. Remember that when they cannot, it does not necessarily mean that they don't want to.

To be client centered, the home has to involve families and residents in care planning and decision making as well as in policy development and, to an extent, the running of the home. This is especially true when they are accommodating a younger and more able client. Client-centered care asks, "What does the client want?" as opposed to "What is best for the client?"

Asking what the client (or customer) wants is a key question. It indicates respect for the person as an individual. It puts the client in control of planning her environment. Asking what is best for the client puts the system in control and assumes dependency of the

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client and an inability to make decisions. This assumption entails an assumption about you, the family member, as well as about your father, who may or may not be able to make decisions.

Many homes have developed and implemented a client-centered system on their own. Many have hired consultants to help them (an excellent example of this can be found in William Thomas's *Life Worth Living: How Someone You Love Can Still Enjoy Life in a Nursing Home—The Eden Alternative in Action*).

Client-centered care entails a philosophy under which the home operates. They may talk to you about making the facility a real home, or maximizing every resident's dignity and self-worth. They may talk about the client being the team leader and about partnerships with residents and families. Unfortunately, many homes do not operate under either the philosophy that they think or say they use (which may or may not be spelled out in a mission statement). It is hard to figure this out when you are looking at a home before placement. The only thing you can do is watch and listen while you visit. When you are taking a tour, ask if they have a mission statement or philosophy of care and ask how they put it into action.

When you have found a home that provides good care and good caring, ideally what you have found is a home that also creates a satisfying life for your father. Your father may be going into care because of problems, but he is going there to live.

## On Abuse

One of the greatest fears that you may have for Dad is "What happens when I am not here?" Your worst fear may be abuse. If your father goes into a home that is not very good and where you can see evidence of neglect, not only will this fear be worse, but you can be overwhelmed by anger and by a sense of helplessness as you try to figure out what to do or how to encourage the staff to pay attention to him. It is beyond the scope of this book to do an in-depth examination of senior abuse, but we can take a look at why it occurs, when, what it is, and maybe how to prevent it.

There are several forms and varying severity of abuse. Abuse can be hitting someone, holding the person roughly, or the inappropriate use

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of restraints. It can be coercing the person into making decisions against her will. Abuse can be emotional, in that residents may feel frightened of or threatened by the staff, insecure in their environment, and become sad, lonely, and withdrawn.

I think it is abuse when a resident is overmedicated or on the wrong medication. I think it is abuse when a resident's condition declines because the home has not adequately investigated a problem or made adequate attempts to correct it. I think it is abuse when a resident becomes incontinent because it is easier to keep her in diapers than to help her to the bathroom; or when she loses the ability to walk because it is easier for the staff to push her around in a wheelchair or let her stay in bed than to walk with her to the dining room or to recreation programs.

Financial abuse is spending the money of a dependent person when it is needed for her care, not providing enough money for her to receive adequate care, or even not buying her whatever extras she could afford. Financial abuse is using someone's money for any purpose for which she would not approve.

Neglect and physical and sexual abuse do occur in nursing homes, though the incidence is difficult to measure. Much abuse is unseen and unreported. Residents and families can be frightened to report what has happened. Staff members sometimes can be intimidated by threats that they will lose their jobs if they complain or report abuse. Or they can be fearful that, if they do report it, the home will close. Some residents are disabled to the point that they are incapable of reporting. The result is that accurate statistics are hard to come by. However, there have been estimates that abuse and neglect occur systematically in 30 to 97 percent of U.S. nursing homes.

No matter how much legislation, education, and monitoring we have, there are always going to be people who abuse, so there is always going to be abuse; we cannot monitor the whole world closely, just as we cannot monitor child abuse out of existence. You should be able to expect that the system and homes themselves would not be set up to foster abuse, but unfortunately this is an unintentional result of the present U.S. system. Abuse can happen in the best of homes, but is less likely in a good home if you have done your homework, and if you pay attention and stay involved.

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Often, abuse is about power or control on the part of the perpetrator. This person has the psychological propensity to abuse. He puts himself in a situation in which he has power over someone. The other person is already vulnerable and unable for whatever reason to stand up for herself. Usually the abused person is dependent either physically or emotionally on the abuser. A nursing home is a prime situation for this kind of perpetrator because the clients are frail, vulnerable, and dependent on the staff. The situation can be rectified only when a home discovers the perpetrator.

When abuse is not about power, it is often about feelings of inadequacy or helplessness on the part of the caregiver. Anyone can be an abuser. Even the best caregivers, whether in the home or in a care facility, can become overwhelmed. It happens when a caregiver feels that nothing she is doing is working or she is so tired that she can't go on. She is isolated and has minimal support. She sees no way out and no way to relieve the emotional pressure. Anger, irritation, and depression occur, creating the potential for an abusive situation. Whereas being overwhelmed by a *feeling* is acceptable, the *action* of abuse is not.

Think of what it is like for you in your work when the staff is being cut and you are supposed to do the same work or more with less help. You may try to cut corners, or you may stop doing the extras. If you can never finish the work, are exhausted, and feel you have no choices, you can become lethargic and uncaring. Certainly you may feel overwhelmed, stressed, and inadequate. You may have a feeling of resentment toward the boss, but on whom or on what do you take it out? This is what happens to nurses and nurse's aides. Sometimes they are victims of the system also. One advocate for the elderly told me that she receives as many calls from nurse's aides who are upset about conditions in a home as from family members.

Whereas abuse is an action perpetrated on another person, neglect can be seen as a lack of action—when something is not done. This can be when someone is left on the toilet too long, or when he hasn't had his toenails attended to by a podiatrist, when he hasn't been changed from soiled clothing, or when bed rails are not locked when they are raised for the night.

Often the staff members do not intend to neglect a resident; it hap-

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pens when they are too busy. Sometimes they have to make a choice, a kind of on-the-spot triage. Are they going to change Mr. Smith's dressing, take Mrs. Carino's blood pressure, turn Ms. Martin in bed, or make sure Mrs. Eckel is drinking her vitamin supplement? In some homes, staffing is so poor that only the first few priorities will receive attention. The nurse's aides are not to blame; it is the home, the company that owns it, and the system which allows for poor staffing.

Neglect should not happen and you should not excuse it when it does occur. You need to be aware that it has happened and address it with the staff immediately. However, the time to become alarmed with the home is when you see that it is happening regularly, throughout the system, and when several staff members are involved. This is an indication of problems with the home and the care as a whole.

In some ways nursing homes in a for-profit system are set up to have abuse and neglect occur. If there is a squeeze for profit, they will have to find more money from somewhere. More revenue can come from cutting the food budget or the cleaning budget. It sometimes comes from charging for services that have not been performed or for equipment that has not been used or ordered. But the prime place to save money is on personnel, because staffing is the largest share of the budget. Homes may either reduce staffing or hire minimally qualified people. Economizing on staff is possible because the minimal standards of care in the United States are woefully inadequate. Standards for staff qualifications as nurse's aides are often minimal, which allows homes to keep wages low. In the for-profit sector, profit and care can be competing forces. It is easy to see how management and ownership systems can give rise to the conditions under which abuse occurs.

The U.S. system of funding and the very size and organization of the bureaucratic systems of monitoring are factors that allow abuse and neglect to occur and continue. When a complaint is lodged with the authorities, it is supposed to be investigated within seven days. In fact, it can take months. Because standards are so low, a complaint about care may not make an impact. When fraud and abuse occur, the homes and the companies that run them are given minimal slaps on the wrist. Fines are low, and can be appealed. They are told to clean up or improve their practice. Unscrupulous owners are permitted to keep running homes. Rarely are they closed down. A *Time* magazine

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article in October 1997 noted that in one year more than 95 percent of the homes that inspectors recommended not receive funds got them anyway, more than 97 percent of the homes recommended to require special staff training did not have to follow through, and more than 90 percent that were recommended to be fined for violations paid none. When inspections do not lead to effective action on problems, there is no incentive to make the provision of good-quality care more important than profits.

In Canada, the vast majority of facilities are nonprofit and/or charitable organizations. Wages are much better than in the United States. The system is smaller, which makes monitoring easier. Many of the homes are unionized, so management treats the staff better. This is not to say that abuse and neglect do not occur in Canada; they do. If you find problems, it will often be neglect rather than abuse. Lately there have been more for-profit homes and chains setting up. Some of these do provide very good and competent care. This is especially true of the ones that are attached to assisted living and seniors' apartments, or that charge premium rates. But when I look back at the homes and systems that I have known in Canada, many of the best ones were the nonprofits.

To look at the other side, handling complaints about staff abuse can be difficult for an administrator. All complaints need to be taken seriously. But sometimes residents can misconstrue things, forget things, or be simply seeking attention. I have seen many residents who accused staff members of stealing, only to find the "stolen" item somewhere that the resident had hidden it and forgotten. On his Web site, "The Truth about Nursing Homes" ([www.jeffdanger.com](http://www.jeffdanger.com)), Jeff Danglo relates a story about a nurse who was holding an agitated resident's hands at her side until she regained control rather than administer a medication. This action could look like abuse, until you understand the situation and have some trust in the staff. I have also known residents who said a staff member was rude or hit them when clearly it did not occur.

Complaint handling can also be difficult in a unionized facility. I have seen unions that protected their members from termination even though it was clear that neglect or abuse had occurred. I have seen homes that did fire staff members for neglect and abuse, but the

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only way they could do it was to buy out the person, which cost several thousand dollars.

The difficulty for families in monitoring care is that sometimes what looks like abuse can be the result of a fall or the natural bruising that happens to older people's fragile skin. Sometimes people do stop eating or it is very difficult to get them to take liquids. Conversely, even if you rightly suspect abuse, the home can tell you that, for example, your father had a fall, fell out of bed, or is not eating.

What prevents abuse? Clearly, adequate staff will help nurse's aides and others have a feeling that they are able to do their job—that it is not a losing battle. This is why it is important to look at the ratio of nurses and nurse's aides to residents.

The potential for abuse is also reduced when the staff, especially nurse's aides, are well supported by the management of the home. That means they are treated with respect and are well compensated financially. It means that the management pays attention to them so that they are not overwhelmed or under undue stress. One way for a home to support its staff is an Employee and Family Assistance Program (EFAP) through which employees can access counseling.

The staff also need to know that the home will back them up and support them where and how they need it. (This does *not* mean protecting them when there are legitimate concerns or inadequacies.) They need to know that the management will not let them be unfairly harassed by families or residents and that they will not be placed in dangerous situations because a home is more interested in revenue and resident numbers than in staff safety. If you think physical and verbal abuse of staff do not happen to nurse's aides, dietary personnel, and other staff, let me tell you they do. Yes, sometimes staff has to be called on the carpet because of neglect, but sometimes they are unfairly harassed by people who are unable to handle their emotions in any other way or by residents who treat them like servants. Sometimes they are attacked by residents who should not be there in the first place because the home is not equipped to handle them, but who are there because they can pay the fee.

The staff should be adequately trained to do the jobs for which they were hired. If they are not, the home should either provide the training or let them go (or not hire them in the first place, but frankly,



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getting good staff who are well trained is not easy). Training should include information about not only physical care but also the aging process and decline. They need to know how diseases such as Alzheimer's and stroke affect people. Staff members need to understand the meaning of violent behavior. They need to know that some behavior is not aimed at them personally but is part of a resident's illness or emotional condition. They need to know skills to avoid aggressive behavior or to defuse it if it does occur. This information and these skills can be taught. It is not fair for staff to be placed in situations for which they are unprepared, and it is not fair to residents.

A nursing home with open communication that confronts issues such as abuse directly is less likely to create conditions under which abuse would occur and is less likely to shield people who are potentially abusers. Does the home talk to the residents about it? Do they encourage open communication and input from the residents and the family? Do they take complaints about the staff seriously? Is education about abuse part of their ongoing education guidelines? A strong family council (see Chapter 16, "Making a Home Better") can be instrumental in mitigating the causes of abuse because it provides support to the staff. This can decrease their sense of isolation and feeling overwhelmed by a difficult job. In a home that is not so well run, it also lets them know that many pairs of eyes are watching.

My general experience has been that most staff members in nursing homes are incredibly good and caring people. This is true whether they are laundry, dining room, or nursing staff. They go out of their way, beyond their job descriptions, and spend out of their own pockets because they care about the residents. They are troubled by the inadequacies they see and frustrated by their helplessness to fix them. There is often a genuine closeness between some staff and residents. I can tell you that the relationships I have had with many, many residents (and their families) have touched my heart and my life in ways for which I will always be grateful.

Once you have done your homework, all you can do is monitor your father, the care, the staff, and the home.

- Are there bedsores (decubitus ulcers) on his body? Are there unexplained bruises?

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- Is he clean? Are his clothes clean?
- Has his physical state or ability declined for no apparent reason or for unacceptable reasons?
- Is he having falls?
- Has he become incontinent all of a sudden?
- Has he become depressed or agitated for no apparent reason?
- Is he suddenly being restrained or having medications added?
- Does he seem afraid of the staff or of a particular staff member?
- Is he saying that someone has hit or pushed him?
- Do you feel the staff or administration is taking your inquiries seriously?
- Do you have the feeling that the staff or administration are trying to hide something?

Visit at different times during the day and evening. Get to know the staff and try to treat them with respect and understanding. Get to know other families and the verbal residents and be aware of what their experiences have been. You can follow some of the suggestions I list in Chapter 16, “Making a Home Better.”

You need to be aware and take precautions (which *may* include setting up a video monitor). Once you know the home and have some trust in it, start to relax, bit by bit, and see if it is justifiable to allow your trust to grow. If abuse does occur, you will need to begin either to remove your relative or to start another process. (See Chapter 13, the section on complaints.)

## Specialized Dementia Care Units

The 1980s saw the creation of special care units, or dementia units. These are usually sections of a home dedicated to residents who for some reason would be at risk in a general population. This may be because they would wander away or because their behavior would put them or the other residents at risk. The units are usually secured so that residents cannot leave without knowing a code or having a passkey. Ideally, there is particularly low stimulation (not low activity) so that agitation or upset is minimized. These residents should have a separate dining area. There should be some room to wander

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about in and access to the outdoors. There should be consistency in staff who know the residents well. Consistency of caregivers is very important to elderly persons; it makes them feel safe. It is even more important with confused people.

There is a wide variation in how dementia units have been designed and actually function. In some homes, it is an area that has been specifically built for people with dementia. The hallways are shorter, and the physical space encourages interaction and orientation to the environment. In other homes, it is nothing more than a locked unit that has been sectioned off from the rest of the home. In some, the care is warm and loving and meets the needs of the impaired residents; in others, the staffing and care is no different from that in the rest of the building.

Just because your father has dementia, however, it does not mean that he belongs in a special care unit. Does he need a low level of stimulation? Would he get lost or frightened in the larger facility? Would he try to leave and then get lost? Would he be socially or physically invasive to other residents or their space? If he does need a special care unit, make sure you view it specifically before admission.

You may have a strong reaction to dementia units—even stronger than to a home in general. It can be quite upsetting to think that your father is at “such a bad stage” that he needs this type of unit. Some people, however, function very well in these units, much better than they would in the general population. Often the staff is better trained and more focused on providing care for people with dementia. There is less pressure on the residents to perform to a social standard that they can no longer meet. It is acceptable for them to wander into another resident’s room, wear someone else’s clothes, or be dressed somewhat bizarrely. Residents do not get lost and they tend to feel more secure because the spaces are smaller. They can make friends among people who are similar. I have seen some very touching companionships take place here between residents.

## Costs

The costs of care can vary enormously, depending on where you live. In the Canadian public system, for example, someone can have a pri-

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vate room with sink and toilet for less than \$30.00 a day. In private facilities in Canada and the United States, costs can go up to several thousand dollars a month. Costs of care often go up as care needs rise or as a person moves from one section of a complex to another.

In the United States, the Department of Health and Human Services' Health Care Financing Administration (HCFA) is responsible for the Medicare and Medicaid programs. Benefits through these programs are often available to help defray costs in skilled nursing care facilities. Medicare is a federal insurance program that is basically the same throughout the country. Under certain conditions, Medicare (Part A) pays for twenty days in a skilled nursing facility and eighty additional days minus a co-payment (that is, the portion of the costs that you would normally have to pay in receiving the benefits). Medicare (Part B) may pay for doctors, therapists, and other services not covered by Part A. However, the amount paid for a particular item, such as physical therapy, may be limited. Once someone has had a certain number of treatments, he may be ineligible for the rest of the year. Benefits under Part B must be applied for separately. The premiums are relatively inexpensive and valuable because of the range of items covered. Apply for Medicare within seven months of eligibility, normally at age 65. If you wait a longer time, premiums go up.

Medicaid is the assistance program jointly funded by the federal and state governments which will pay for nursing home care when Medicare is not applicable or when Medicare benefits have expired. To be eligible for Medicaid, you may have had to "spend down," that is, dispose of the majority of your assets first. This means that you will have had to pay initial costs of a nursing home until your assets are below the required level. A spouse still living at home may keep a home, a car, and a certain (limited) amount of cash.

The rules and regulations of Medicaid vary from state to state. Make sure you understand what you have to do in your state and how you handle assets. Do not assume that you *cannot* keep them until you learn the rules. You will have to do some research in your area. Find out what kinds of documentation you will need to enable you to benefit from subsidies. This can include several years of income tax statements, bank statements, and receipts for medical expenses, for example. As I mentioned above, some states have received a waiver from

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Medicaid so that they are able to fund people in assisted living facilities that do not qualify as skilled nursing facilities.

Some homes want you to have your approval for Medicaid in place before admission. Others will help you apply for Medicare and Medicaid benefits. If you are turned down for either, you can and should appeal the ruling.

You can also buy Medigap or Medicare Select insurance policies. These are ten policies (A through J) that are bought through a private insurance company but are government regulated. All except Plan A cover the Medicare hospital deductible (what you must pay before Medicare starts paying). They also pay for most co-payments. Some pay for other Medicare deductibles. Some of the Medigap policies will pay the co-payment fees for days 21 through 100 in a skilled nursing facility. They, like Medicare, will not pay more. There are varying restrictions and benefits in the policies and eligibility times.

Figuring out the appropriate Medicare option is complicated. The Health Care Financing Administration (HCFA) puts out an excellent guide to help you understand Medicare called "Guide to Health Insurance for People with Medicare." It is available by contacting 1-800-MEDICARE or at [www.medicare.gov](http://www.medicare.gov). The Web site has many other features, including a guide to nursing homes and addresses of the ombudsperson in your state. Both the guide and the Web site will direct you to information sources and counseling regarding Medicare and Medicaid in your state. The AARP (formerly, American Association of Retired Persons; see Resources) also puts out excellent guides that explain Medicare, Medigap, and the various other Medicare options. They explain how to make some rational choices for what is right for you. Get all these guides before acting.

In Canada, provincial costs and subsidies vary. All provinces fund homes, and all provincial health care programs cover basic health care costs. A home's daily fee always totals less than someone's pension income. In some provinces there is a ceiling on fees to residents, regardless of assets and income. A couple of provinces require you to deplete your own resources before they will provide for you. Your provincial medical plan will not cover all the expenses incurred if you end up in a U.S. nursing home, so be sure to buy additional insurance

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if you are traveling to the United States. Canadian residents should look at Appendix 2, "Accessing Care in Canada."

Two other options for nursing home payment exist. One is the reverse mortgage. This is a plan in which a bank lends you money based on a percentage of the value of your home. They pay you either a lump sum or a specified amount over a specified period of time. There may be initial costs, interest charges, or processing costs. The money is paid back on sale of the property or death of the recipient plus accrued interest. If you are going to consider this option for nursing homes, you might also want to consider using it to help keep your father at home with in-home help. For more information on reverse mortgages, contact the National Center for Home Equity Conversion (see Resources). Their Web site is a great source for you.

The second option is long-term care insurance. These policies vary enormously in coverage, policy costs, elimination periods, and benefit periods. Options to inquire about include:

- What kind of care does the policy cover (home care, nursing home, assisted living)?
- Does it pay sufficient benefits over a length of time (up to three years minimum)?
- Does it pay all the actual expenses, wherever you receive care?
- What conditions does it cover (Alzheimer disease, other dementias, etc.)?
- What are the conditions under which the benefits will start to be paid?
- Is there inflation protection so that it is valuable when you need it?
- How many days are you responsible for (the elimination period) before the policy comes into effect?
- Are the premiums a set price, and are they waived when you receive care?

You may want to look at *The Complete Guide to Long-Term Care Insurance*, by Robert Davis (order at 800-587-3279). Most of the elder-care books and Web sites listed in the Resources have sections on long-term care insurance.

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Long-term care insurance can end up costing you more than your savings, and the monthly premiums can be very expensive. Buy it if you are trying to protect your assets and if your circumstances are such that Medicaid coverage will not be available for a couple of years.

Canadian residents will want to look very carefully to assess the benefits of long-term care insurance because provincially funded nursing homes are often adequate in the care that they provide. There is no need to go to a private home except if you are waiting for a space in the home of your choice. If you consider purchasing long-term insurance, do so because it covers assisted living and/or home support and home health care. Try to assess whether the payments will end up costing you more than the benefits. If you are spending time in the United States, you may want long-term care insurance that covers you in the case you need nursing home care on an emergency basis until you are well enough to return home.

Spouses need to find out how having a relative go into a nursing home will affect their pensions. In Canada this situation is called an involuntary separation, and when it happens, both members of a couple are allowed to apply for full Old Age Security and Guaranteed Income Supplement benefits. In the United States what a spouse is allowed to keep varies from state to state.

In the United States the costs of "qualified" long-term care and home care services are deductible as medical expenses in your taxes if they exceed a specified portion of gross income. In some cases you may also claim a relative as a dependent. Premiums for long-term care insurance may in some instances be tax deductible. Some costs are tax deductible in Canada as well. Consult an accountant for the specifics of your situation. Alzheimer's Association chapters are usually knowledgeable in this area also.

When you are considering a home and again when your father has been admitted, find out *all* the costs of care. In the United States, nursing homes that receive Medicaid funds are required to tell you all costs. They should tell you what is covered under Medicaid and Medicare and what you will be responsible for. If something is covered under Medicaid, make sure you are not charged extra for it. You should find out about charges for extras such as toiletries, bus outings, and extra care.

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The various styles of assisted living facilities have different costs and payment structures. These can include an initial large payment that would pay for an apartment and then monthly maintenance living charges. Or they may have a monthly rent but charge an additional fee for each extra service, say for help with dressing, monitoring someone taking medication, and help with a bath. If you are considering assisted living, be especially diligent about finding out all costs and limitations before you buy. Unlike for nursing homes, there are no regulations concerning the disclosure of costs and services for assisted living facilities.

### Nursing Homes and Legal Responsibility

Nursing homes are very concerned with legal issues in general, although with all the lawsuits for neglect, abuse, and fraud, it appears that many need to be a lot *more* concerned. Abuse and neglect are legitimate reasons for lawsuits. Sometimes lawsuits are frivolous and malicious and are the result of people inappropriately dealing with unresolved grief or other feelings. I can't tell you how many times over the past few years people have threatened to sue homes I worked in despite the fact that their relative had received very good care. The potential for lawsuits affects many areas of life in a nursing home. This includes how care is provided, whether and how restraints are used, what furniture is allowed in people's rooms, and what activities are provided. It affects who will be admitted or allowed to remain as a resident in the home. It means the staff spends a lot of time in meetings and keeping documentation.

The result of the threat of lawsuits is sometimes better care, but unfortunately it can mean more restrictions, less flexibility, and less hands-on care from the staff. This means that when you ask for something to be done or for a variation in some rules, a home may say no. It may seem like a simple request to you, but behind the negative response may be legal concerns by the home.



## *Mildred*

The first thing you notice is the smell. It's a soapy, antiseptic smell that lets you know you are someplace where soapy, antiseptic smells are necessary.

I had the unfortunate duty of having to tour nursing homes recently, trying to choose one for my mother. At age seventy-three, after three strokes and with advancing kidney disease, she needed round-the-clock professional care, much more than could be provided at home.

My brother and I were given a printout of Medicare guidelines, a listing of seventy-six Detroit-area nursing homes, and a week's time to make a decision. We made a few choices that looked promising and began touring the different facilities.

Medicare has a new Web site called Nursing Home Compare ([www.medicare.gov/nursing/home.asp](http://www.medicare.gov/nursing/home.asp)). It has a searchable database that shows comparative information about individual nursing homes, including annual inspection results and health status reports. For anyone anxious about finding a suitable facility for a loved one, such information is indispensable. I checked it daily as we began our tours of nursing homes.

We were led on these tours by nervous, talkative admissions counselors who rapidly walked us through their facilities, doing their best to put a positive spin on a dreadful circumstance. It was astounding what some counselors considered the selling points of their facilities. We were told the solitary 2' x 2' window in all the patient rooms allowed residents to "keep in touch with the outside world." Confused patients in wheelchairs sat alone in hallways outside their rooms, some crying, some mumbling to themselves, creating a time that, according to the admissions counselor, allowed them a "sense of freedom and independence." While some areas such as a pristine dining room and a vacant exercise room were

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proudly displayed, we were not allowed to tour the kitchen, and we were given a discourse on how the “importance of the nurse-to-patient ratio is really a myth.”

Most residents’ rooms looked like potential nightmares. Two patients were assigned to each room, which threw any pretext of privacy out the two-foot window. The rooms were exceedingly cramped, with every square inch of wall space taken up with beds, bureaus, wheelchairs, oxygen tanks, large lights, and clothes baskets. Each patient was allowed to bring a television from home, and the accompanying din caused by two TVs loudly tuned to different stations in such a small room was nerve wracking.

Subsequent visits to other nursing homes revealed that two people to a room was a luxury. Many times there were four and sometimes six people to a room. One coordinator commented that six to a room was actually a positive environment, as “one patient usually acts as a ‘mother hen’ for the rest.” This seemed odd as I looked around the room and saw all the patients lying in their beds, most wearing oxygen masks. It looked like a barracks in purgatory.

Most nursing home facilities had buzzer systems which were activated anytime an outside door to the building was opened. These were used as a kind of reverse burglar alarm, not so much to keep people out as to keep people in. The buzzer was going off with the regularity of a junior high school changing classes. Those few residents who were able to walk definitely wanted out.

Anyone who has an aging parent and thinks Medicare will cover any nursing home stay that might be needed is in for a terrible shock. Medicare covers only the first twenty days in a nursing home, or “skilled care facility.” For days 21 through 100, the patient must pay the first \$95.00 per day. After day 100, the patient is responsible for 100 percent of the nursing home charges. For any long-term admission, this can quickly become financially suffocating for any family.

As America’s Baby Boomer generation struggles through its fifth decade, their parents are struggling through old age. As of 1997, there were 1.5 million Americans in nursing homes, with three-quarters of them women aged 65 to 84. With medical advancements, new prescription drugs, and emphasis on personal fitness, Americans are living longer than ever before. The question for Americans seems to be, Now what do we do with them?

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Good nursing homes do exist, but they must be sought out using all the resources that one can muster. One great and immediate source of information is the Internet, where numerous protective agencies, watchdog groups, and family members can instantly voice an opinion or throw up a red flag. The Medicare Nursing Home Compare site promises to be an invaluable resource. The Michigan Consumer's Guide to Nursing Homes ([www.hcam.org](http://www.hcam.org)) has the latest scores from state inspections and what violations were cited.

Many times after visiting the different nursing facilities, I would come home physically ill. Nausea and dizziness would overcome me, brought on by the stress of making such a choice. By the time we had finished making all the tours, I had not slept or eaten a complete meal for days and was filled with dread at the problems and complications I knew life had in store for my mother and me.

We toured eleven homes in all and found only one that was marginally acceptable. That particular home had an admissions coordinator who seemed to care about individuals, not just patient files; she was more concerned with people than paper. And the home had a head nurse who actually sat down and talked to us about Mom's condition. The rooms still had a miserable quality to them, but trade-offs had to be made. The week's time we were given was almost up and we had to decide.

A few days before the transfer from the hospital to the nursing home, Mom died. While death is always a sad occasion, I believed that it was God's blessing that she did not have to make that last terrible move. I would never have gotten a night's sleep, constantly wondering about the care she was receiving.

Sometimes I remember all the other elderly moms and dads I saw on my tours, and I wonder if they are getting the care they need. And I wonder if their families get any sleep at all.

It is good to be young and strong in America. But the images I saw on my nursing home quest would have even the most robust American pondering: What will my room look like as my journey winds down?

## CHAPTER 6

# Viewing the Home

If you are not careful, searching out the right nursing home can be almost a full-time job. If you were to ask all the questions that you find in some lists (and what I have listed below) and do all the things that are suggested, visiting each home could be a marathon. (If you want to do the marathon, or at least have a guide to it, see *The Nursing Home Choice: How to Choose the Ideal Nursing Home*, by Marian R. Kranz, or *A Spy in the Nursing Home: Inside Tips and Tactics for Choosing the Right One in Five Days*, by Eileen Kraatz.) It might make more sense to develop a sense of a few of the homes you visit; then choose a couple for more in-depth visits and interviews.

Be aware of who is giving you a tour. Often it is a marketing director. This does not mean that he will give you a false image of what the home is about, but, as the job title implies, his job is to sell. Also, a marketing director may not be someone who really knows about how care is provided or about geriatrics and the needs of elderly persons.

Also be aware of who or what company owns the home. Is it a large chain, a small chain, or a single owner? Find out what their record of care has been, including their compliance with regulations and whether they have had fines, convictions, or other actions taken against them.

When you take a tour, pay attention to more than just the physical plant. Of course, it should be in a good state of repair, but an old building does not mean that the care and caring is not good. Also pay more attention to what goes on in the home than to how close it is to where you live. Even if you will be there to visit for a couple of hours a day, the home has to be adequate for your husband for twenty-four hours every day.

## VIEWING THE HOME

If you have friends who already have a relative in care, go with them to visit the home. They can point out details that you might miss, and it will give you an opportunity to go beyond the person who officially gives tours.

*The most important thing in visiting a nursing home is how the place feels to you.* Does there seem to be kindness in the atmosphere? Is there a pulse in the air? Is there kindness in the staff's voices or smiles on their faces? Watch for how the staff interacts with each other and with the residents. Watch how the residents act with each other during programs. Listen to how much noise there is. Notice the colors and the furniture.

Take a look at the residents you see. Do they appear well dressed, groomed, and washed? Do the women have on any nail polish or makeup? Is their hair done nicely? If any residents are using equipment such as a walker or a wheelchair, does it seem to be in good repair? If they have on bandages or dressings, are they clean and well put on? These things tell you that the staff members are doing their jobs, indicating good care and good caring. You may see a few residents who do not present a good picture; people are sometimes incontinent despite the best staff effort, and sometimes people do not want to wash or groom themselves. But the majority should *appear* well cared for physically.

A gauge of the quality of care is the incidence of bedsores (see Chapter 12). You can ask about this during the tour. (Whether they will give you an honest answer is something different.) You can also review the official inspection report, which will mention whether bedsores were discovered. However, it is a random inspection, so just because they are not mentioned in the report does not mean there have not been any. A good home will have had no (or a very low) incidence of bedsores.

When you are touring homes, develop a comparative chart for yourself such as the one in Questionnaire 1, "Guide to Viewing Nursing Homes," shown in Appendix 4. For each home, rate each item 1, 2, or 3, or write yes/no or good/fair/poor, or put in a check mark. Write a few notes after the visit to each home. This comparative chart will be very helpful to you after you have seen several homes and you can't quite remember how one compared to another.

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When you are asking your questions and looking around, be aware that you may not find your ideal. That is the reality of the game. If your husband is being discharged from a hospital, there will be pressure on you to make a quick choice, which may not be what you would otherwise consider. You may have to accept less than the optimal in all areas of good care and good caring. You will have to pick out what is really important and what is less important. This can vary according to your husband's needs—he may benefit most from a home that has good access to physical therapy. If he is blind, he may want a small home. If he has very reduced mobility, he may want short hallways. He may not want to use elevators (which tend to get backed up during meal times). If he is able to assist in the viewing process, consult with him about what is most important and maybe highlight those points on your list of questions to ask.

### Staffing

Ask about staffing. Compare ratios of nurses and nurse's aides to residents. What kind of turnover in staff has there been? A high turnover can indicate problems (or it can indicate that the home is cleaning up problems). Do they use a lot of casual or agency staff? Agency nurse's aides and nurses generally do not know the residents as well as those who are on the regular staff. That means that they are at a disadvantage in recognizing whether anything is different in your husband's condition and that may be a warning that something is wrong.

When you look at staffing levels, make sure you also understand the degree of disability of the people for whom the staff is giving care. If their clientele contains a number of people who have very high care needs, then they need a better caregiver-to-client ratio. If the clientele has only lighter care needs, then there can be fewer nurse's aides and nurses for more clients. Make sure they tell you the number of nurses and nurse's aides to clients, not the number of staff to clients. The latter can include the housekeepers, laundry personnel, and so on.

Find out who is on the staff beyond nurses, nurse's aides, and recreation staff. Is there music or art therapy? Is there a dentist or dental services? Is there a social worker? Is there a podiatrist who comes in regularly? In the United States nursing homes that receive Medicaid

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funding must provide access to physical therapy, occupational therapy, and speech therapy if it is not provided on site.

### Programming

Look at the programming in the home. Diverse programming should be available to meet the different needs and abilities of the residents. Is there programming that fits your husband's needs? If you like a small facility, remember that one of the trade-offs for the intimacy that a small home provides is that usually the recreation schedule is smaller. Ask for a copy of the monthly recreation schedule. How much weekend programming is there? Are there any programs to which families are invited? Are families welcome at all programs? How involved is the community and, more important, how involved can your husband be *in* the community?

You can also sit in on some of the activities to see how they are run. This could include the residents council, which most homes have. See if you can talk to some of the residents and/or some of the family members to see what their experience has been. If there is a family council, call someone on it or go to a meeting.

Find out what the home's attitude is about physical activity. Will they encourage independence and rehabilitation? For instance, will they encourage your husband to walk to the dining room, or will they put him in a wheelchair because they don't have time to help him walk? Will they help him to dress or will they dress him? Help him to shave or shave him? All of these small activities are important for maintaining independence and emotional health.

When you are looking at activities and recreation, try to find out about resident life and how it is encouraged. If you think about it, we all have activities that we do every day that make up our life. We water the plants, read the paper, make the bed, have tea, walk over to visit with the neighbor, go shopping, and so on. These are activities that we do aside from "recreational activities," such as going to a show, having a party, etc. Find out how the home encourages residents to have an everyday kind of life.

### Policies

All homes have policies and procedures. Here are several you should try to find out about.

What are visiting hours and policies? Can you have a meal with your husband in the dining room? Can you celebrate special occasions? Is there a resident kitchen where you can cook a meal together? In your own home you come and go as you wish, have visitors, serve coffee. You should be able to do all this in a nursing home as well. What is the policy on roommates and room changes? If your husband has to have a roommate, how does the staff handle conflicts with roommates if they arise? Do they encourage residents to stay up at night for activities, or do they try to get everybody in bed by 8:00 P.M.? If you are able to, you might want to do an evening visit before admission.

What are the policies and procedures concerning abuse? Find out if they have had incidences of alleged abuse and how they have dealt with them. Do they do criminal background checks on staff? What kind of screening do they do? Later, call the licensing system in your area to find out about charges of abuse or neglect.

What are the safety policies and practices? Do they have an evacuation plan, and have they ever practiced it? Do they have fire drills?

One of the most important questions to ask is whether there are limitations on the care that the home can provide. If your husband's condition deteriorates, will he have to move? What situation would that be? What are the requirements surrounding a move? Can you hire more help privately so he doesn't have to move? Does he have to take the first place available?

It is not legal in the United States to discharge someone because of Medicaid limitations. There are also regulations concerning discharge. A home must tell you the reasons for transfer, where your husband will be moved to, and the date of transfer or discharge. Residents have the right to appeal to the state and must be given the information necessary to access the ombudsperson.

You may want to obtain a copy of the preadmission agreements. In some areas they are standardized; in some areas homes have their own. This gives you a very good idea of what the home expects and what



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you can expect. Remember, you are going to have to sign this document. Make sure you understand it, if it is written in legalese. Make sure you are willing and able to live up to the terms of what it says.

### Dining

Look at the meals and dining service. How does the food look, and how is it presented and served? What happens in the dining room? Watch the service: Are the food service workers interacting with the residents and listening to them, or are they talking to each other above the residents' heads? Request a copy of the menus for the month. If your husband doesn't like what is being served, what happens? Will anyone notice? Will someone help him eat if he is unable to feed himself? Can you return another day with your husband and purchase a meal to try it?

### Physical Plant

When you look at the physical plant, look at lighting, equipment, and private space. Are fire exits well marked? Are fire exits accessible, or are they blocked by furniture or equipment? Is the bathroom equipped for a wheelchair? Are there grab bars around the toilet? How far are the dining room and activity rooms from residents' rooms? Are there single, double, or ward rooms? Go over in your head how your husband lives during the day. Will the physical plant be able to accommodate him in the way he lives his life? Is there a garden or other appropriate outdoor space? Are there stores or a coffee shop nearby?

### Surveys and Accreditation

Call your state or provincial office on aging or state ombudsperson to find out if there have been any complaints. If there were, make sure you find out how they were resolved. In the United States, read the inspection report. Legally, it is available to you. The inspection reports do not always reflect what is truly going on in a home. It is easy for an inspector to miss problems and for problems to be misreported. Problem areas can be window dressed so they are not seen. I wouldn't

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say don't read them, but don't let them reassure you of something if your heart tells you that you are seeing or suspecting something different. Be aware, however, that there can be malicious and destructive complaints that are found to have no validity, as well as valid complaints. For comparative information on rankings and surveys, see Robert Bua's *The Inside Guide to America's Nursing Homes: Rankings and Ratings for Every Nursing Home in the United States*.

Many homes, especially in Canada, go through an accreditation process similar to the ones that hospitals go through. The national accreditation process is expensive and quite complete. Some homes are required to be accredited through this process; others do it voluntarily. In the latter case, this is something of a commitment to care. However, homes know far in advance when the inspectors are coming and to whom they are going to talk. If the home has been accredited, find out what the assessor found that was positive and what needed to be worked on.

## *John and Joyce*

My father had been in St. Catherine's for four years before my mother had an aneurysm. They had no room for her at St. Catherine's, so for the nine months that remained of her life she lived in Sable Hill Home. We knew Dad was well looked after at St. Catherine's, but Sable Hill was a different story. The two facilities and our experiences couldn't have been more different.

Mom and Dad had both been Christian missionaries and priests. During their sixty years together, they were always a team. So when the signs of my father's Alzheimer disease were getting worse and worse, Mom was determined to take care of him. She was a woman of her time. It was her role to be responsible for everyone and everything in her family. She would have done it until she was dead. I watched her as she began breaking under the strain.

It started with the typical symptoms of Alzheimer's. Dad was having trouble with word retrieval. Then he couldn't remember people. Then he was taking off in the middle of the night. Mom was always on edge, wondering when he was going to walk out the door. He would just say, "I am leaving," and she couldn't stop him. He was arguing. He was even getting violent, which he had never been in his life. We had to lock him in the house.

Finally we took him for a geriatric assessment. The assessment team members were able to give my mother some objective information and directions. She was still reluctant to let Dad go into a home. Finally I said to her that I was already losing one parent and I didn't want to lose two. That's what made her finally decide.

Even though Mom made the decision, the first six months were hard. She would go to see Dad every day. When we told her to take a rest of at

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least a day or two, she refused. She was afraid that if she missed a couple of days he would forget who she was. She was extremely critical of the care. She didn't like the way the staff did things; it wasn't the way she did them. I think underneath, she couldn't get used to having people do for Dad what she felt was her role. She felt pushed aside, like they were trying to take him away from her.

My brother and I tried to give her as much support as we could. We would come to the home, sometimes while she was visiting and sometimes when she wasn't there. It helped her to know that other people were coming in and she wasn't alone. We would call her every day to make sure she was doing all right.

The staff was extremely helpful. Just by doing small things for Dad, they returned some humanity to him. For example, they would say hello to him as they passed him in the hallway. Especially the chaplain. He had a way of letting you know that your family member was still a person, that he still mattered. I had been used to thinking that these old people were off in their own little world somewhere. But when it was my own family member, I felt differently.

After about six months, my mother came to see that St. Catherine's was a good place. She came to appreciate the care that Dad was getting and the staff. She could see how they served him tea, called him by his name, and held his hand. They also talked to us, let us know that they were interested in us too.

The staff, other residents, and family members became like an extended family for my mother. It was like she had a new life there. She would tell us which resident did what and which family member did what. She would go to birthday parties. She would tell us what was happening with the staff members, who got married, who had a baby.

A few years after he went into the home, Dad had a stroke. That was another crisis for my mother. Now there was even less that she could do for him. She couldn't help him to walk anymore. He couldn't speak. The words he used were unintelligible. It was heartbreaking for all of us, but especially for my mother. It was like she was losing another piece of him.

I tried to help my mother by looking for the hope and the positive that was still there. Music was very helpful for us. When we gathered as a family or with residents to sing songs and hymns that were familiar to Dad, he would do his best to sing along. He would wave his arm as if he was

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the conductor of a great symphony. When he did this, we knew we had made a connection with him, and he with us. Dad still had a warm smile that engaged us and cheered our hearts. Sometimes when people asked him if he knew who I was, I would say, "of course." I knew he might not know my name, but he knew that I was someone who loved him. We read to him and we prayed with him beside us. Sometimes when we had a joke about something, we looked over at Dad and saw him chuckling to himself as if he were in on it too. All of these seemed to be ways to keep communicating with him.

Gradually, my mother adjusted to this phase of Dad's condition too. She continued to be a part of the St. Catherine's family. We could see she was adjusting.

Then she had her stroke. All of a sudden, everything changed. Mom had been driving, using e-mail; she was up and about and always doing things. In the back of our minds, we had always been preparing ourselves for losing Dad first. He was the one with the disease. It didn't seem right or fair.

Mom was first taken to the general hospital, and then later to the geriatric hospital. She became what they called a "bed blocker." They wanted us to find her a place right away. They said that she didn't need acute care, she needed a skilled nursing facility. At one point we had a meeting with the hospital staff. They proceeded to tell us that they wanted us to take her home that weekend. We told them that we couldn't. I was going away for a few days, the first vacation I had had in several years because I was always concerned about my parents. My brother had a flight out that afternoon. The social worker told us that the hospital was not a hotel. It was like they were just putting more and more on the family, and they weren't ready to listen to us. A couple of weeks later they took her to a facility. She was so sick that the facility sent her right back.

Finally, the hospital discharged her to Sable Hill because there was a bed available. The place was so big. The dining room held over one hundred people. When you went in the front door, the first thing you saw was all of these sick people being fed in this huge dining room. Nobody wants to see that as the first welcome into his or her home.

I hated going to Sable Hill. That was a horrible feeling to have. I felt so bad for Mom. I was just angry all the time. I was depressed and I felt hopeless because the care was so dodgy and so many things happened.

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I know how to be an advocate; I work in a large system. But there I always felt helpless. There were different staff every day who never seemed to know or care about my mother. Once when I went to the nursing station, there were five staff members standing around talking. They ignored me until I finally said something to get their attention. One time they lost her wedding ring. When I reported it, no one seemed to care and no one tried to help us find it.

As all of this was happening, my brother and I had to become the primary people for Dad. It meant that we had to step in and begin to pay the bills, be aware of his care issues, etc. We were always in touch, but it had been my mother who was “command central” and the connection with the home. However, we had to kind of put Dad aside. We had confidence in the care at St. Catherine’s. If something was on my mind, all I had to do was call the director of nursing and she would look after it. Sable Hill was totally the opposite.

I felt I had to go to Sable Hill every day. It felt like I was alone in having to watch out for my mother because it was so big and every day there was different staff. Even when I left for the day, I didn’t know what would happen later. I was upset by what I knew was going on. The staff would take their breaks during mealtimes. The food would be served in huge portions and it looked so unappetizing. If my mother got to the dining room, they would help her eat, but if she stayed in her room, she could be forgotten there. When you would ask for some assistance with helping her eat, the people who delivered the food would say that they were sorry, but it was not their job.

When I would come in to see my mother, I felt I had to check up on what had been happening. I was always upset because things wouldn’t get done. It was like I had to be on guard. I would ask my mother things like, “Have you been to chapel?” I learned that I could not make assumptions the way I could at St. Catherine’s. In the end, it seemed like the problem came from the fact that the staff had so little connection with the residents or the families. When you feel like the staff is connected to you or your family member, you feel that they will care. That is how they become your extended family in a way.

A lot of them did not mean to be mean or nasty. I knew how overworked they were. It was not their fault, it was the system. The system seemed to exist for the system. I don’t know why.

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I tried to talk to the staff all the time, to see what could be done. I was as nice as I could be. I brought them chocolates. I let them know when I thought they had done some good things for my mother. You can't go in there and attack people. I knew if I lost it with them, then we would end up being labeled a "problem family."

I finally ended up having to talk to the people in charge. I discovered that the recreation people were good people to talk to. They would listen to what I had to say. They were willing to learn about who my mother was. I wanted them to know what a high-powered person she had been and how many friends she had had. Not that it made a difference maybe, but it made a difference to me. When Dad went to St. Catherine's, they asked us to write up a description of who he had been. They wanted to know.

I also learned that I would have to build a better support network for my mother. I called the staff chaplain and asked him to come visit. I called other people and asked them to do the same. I also kept on talking to the staff. I made sure that she would get to the activities. If I hadn't intervened, they might not have taken her.

My mother had been at Sable Hill for only nine months when she died. The day she died, I went in to see her body. I was all by myself. There wasn't a single person who came into the room, not one staff person. I felt so abandoned. Finally, out in the hallway I found a staff person. I asked her to ask if the chaplain could come. He did and we said a prayer.

I guess we could have done better for Mom. If she had lived longer, we could have gotten her to a better place. Maybe I should have advocated more or talked to the ombudsperson. Even if I had, it might not have done any good—how would they change the system at the home? You don't know at the time. I just tell myself that we did the best we could. If you know it will be for only two months, you can go all out, but if you don't know if it will be two months or two years, then you have to pace yourself, otherwise you won't survive. You have to save something for yourself and for your family.

Dad is still living at St. Catherine's. I play the piano for the teas at the home. He will sometimes call my name when I am playing a song that he truly likes. Other times he will grab my hand and hold on for dear life as if to say, "Be with me."

I still have many unanswered questions about the consciousness of people with dementia. What is it like if you have no memory and no

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awareness of most things? How can I make peace with my dad when the relationship is complicated by the changes he has had? What are the most comforting things I can do for him? Perhaps in time we will know more about these things, about where the soul resides, about what people with Alzheimer disease really comprehend.

In the meantime, I guess I am more fortunate than most. As lost to me as Dad seems, he responds with a radiant smile that, to me, affirms his continuing love.



## CHAPTER 7

# Staff Roles: Who Does What?

It may help you to understand the roles and responsibilities of the different personnel and departments in a care facility. That way, you know who will be doing what for your father and, more specifically, who will be doing the things that you are used to doing. It will also give you an idea of whom to talk to if you need some information about care.

### Administrator

The administrator is the person who has ultimate responsibility for the home. If the home is not part of a large chain or company, she is also the one who sets the tone for how the home runs. If she is an open, relaxed person, the home will reflect this; if she is rigid, the home will reflect her rigidity. The background of nursing home administrators varies tremendously. She can be a nurse, have an M.B.A., have a social work degree, etc. She will not necessarily have a background in gerontology. A good administrator will spend some time among the residents every day, maybe not visiting all areas and all residents, but she will be visible to staff, residents, and families during the day. She will also be accessible within a reasonable amount of time. The administrator is the one you should contact when all else fails and before you go to a board of directors or an outside licensing agency. Try to get to know the administrator. This may entail having lunch or coffee with her once or twice a year or just stopping by for an appointment. It will help you feel connected to the home.

If a home is part of a chain or larger company, the administrator can be caught in the chain's system. The responsibility for profits and

## STAFF ROLES

the policies of a company that has priorities other than good care can mean that an administrator is not able or willing to put the residents' care and well-being first. This is why it is important to know about a home's parent company.

### Personal Care

Most of the personal care in a nursing home is done by nurse's aides or certified nursing assistants (CNAs) (the title will vary from place to place). These are the essential caregivers in the home. Unfortunately, they often have the least discretionary power or input into how the home is run. Nurse's aides are usually, but not always, part of the nursing staff. Ideally they have gone through a course that teaches them the basics of providing personal care for frail and fragile elderly persons.

It is the nurse's aide's responsibility to help get a resident up and ready for the day and to help her get ready for bed at night. They will also help with toileting and feeding. Usually they will help bring a resident to the dining room if the resident is unable to manage by herself. They also answer call bells. Nurse's aides do not give medication and they often do not chart in casebooks.

Nurse's aides are often the ones who know the residents best because they perform the most intimate personal care. They know what the resident is able to do or is not able to do. For the same reason, they may be the ones who have the closest personal relationship with the resident. They are also, therefore, the ones who most directly influence the resident's experience of the home.

A nurse's aide can be responsible for many people—fifteen to twenty is not unusual in a medium care facility. This means remembering who has a hearing aid, who wears glasses, who wants prunes in the morning, which family wants which resident dressed how, and so on. It means they must be aware of all sorts of changes in a resident's needs. Most important, depending on the acuity level of the residents, it can easily mean that they do not have the time to do their work properly even if they want to. If you remember this, it will help you be more understanding of them and how difficult their work is. Many people, residents and families alike, somehow expect nurse's aides to be like servants and they treat them as such. Please don't.

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As someone pointed out to me, an assistant in a zoo sometimes earns more money than a nurse's aide. Although there are some wonderful people who work as nurse's aides, the pay means that it will often attract relatively less educated people and lead to a high turnover. If the home is in an affluent area, it can mean a long commute for these people at times when transit is not optimal.

### Nursing

Nurses and licensed practical nurses have training that lasts between eighteen months and four years of college. They oversee the physical care that is provided on the floor or the unit. They are generally responsible for treatments and medications. They are the liaison between the resident and the physician. They are also responsible for doing initial assessments upon admission. They do follow-up assessments when it appears that a resident is not doing well. They have primary responsibility for the physical health of your father, so they need to have good training in geriatrics (but often do not). The nurse on the floor is a good person to talk to when you have an initial question about some aspect of your father's medical condition or how he is functioning on a day-to-day basis.

Many nursing homes use what is called a primary nurse model. This means that there is one nurse and one care aide who is your father's "primary" nurse and nurse's aide. They are responsible for your father's care plan and for routinely reviewing on a regular basis what is happening with your father. When the system is functioning well, it is kind of like an extra check to make sure that nothing is missed in your father's condition.

Most homes have a director of care who is responsible for nursing and nurse's aides. She is also responsible for many of the policies and procedures regarding care. She should be well trained in gerontology. She is often the person who will resolve a problem that the floor nurse is unable to. She has a good idea of which nurse is capable of doing what and how the nursing system is functioning in the home. The director of care is often responsible for other areas and professionals, such as recreation and therapies.

## STAFF ROLES

Similar to the administrator, the director of care may have to keep one eye (or more) on the parent company's policies and priorities, and try to balance those demands with the care needs of residents.

### Dietitian and Food Services

Most nursing homes have the services of a registered dietitian, who may or may not be head of the kitchen and food services. Even if she is not head of the kitchen, when there is a food- or eating-related issue, she is the one you can talk to. The dietitian does an assessment of each resident's nutritional needs. She will develop a diet and nutritional program that is appropriate for your father. This includes diabetic diets, gluten-free diets, low-fat diets, etc. Dietitians are also expert in the interaction of food, illness, and medications. Usually they are also knowledgeable about swallowing and eating difficulties. They will ensure that the food your father is served is the appropriate texture, such as pureed, minced, cut up, or whatever. The dietitian will monitor weights and intake.

Food Services does the actual cooking and serving of meals. They carry out the instructions from the dietitian and/or the nursing department. They are also the ones who set up the dining room. If your father has disabilities such as arthritis which make it hard for him to open small packages or use certain utensils, for example, it is the Food Services people who have to have this information. They will then make sure that it is done for him. If he has certain likes or dislikes, allergies, etc., they are the ones who need to know (more about this under communication) because they are the ones who will actually serve him his food. They may also be the ones who can give you a picture of how your father manages in the dining room. Because dining is a main focus of many residents both as an activity and as a social time, the food service workers are very important to the residents' lives. Ideally, they interact with the residents while they serve them.

Food Services is often the target of resident complaints. While this may be valid, the complaints may really be about other issues, such as depression, anger, or loneliness. Because it is hard to express those feelings, residents will focus on food or service, which is more concrete.

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### Social Worker

In the United States it is mandated that all homes have someone in a social service position, but she does not have to be a social worker by training. Usually this person is responsible for helping you with Medicare and Medicaid applications as well as other financial arrangements. In Canada, not all homes have a social worker. The social worker is a liaison with families and should be available to help people talk about the emotional or practical issues that arise. She is also sometimes like a detective. If there is a problem, she will help you figure out whom to approach and how, and will help you see it through. The social worker will help you set up conferences and meetings to talk about your father's care. She will also help you to access outside resources and agencies that might be useful to you and your father. Often she runs support groups, family councils, and residents councils. She should be able to provide information on community resources.

### Recreation

Recreation (or therapeutic recreation, activities, etc.) is in some ways the lifeblood of a nursing home. The recreation worker's job is to provide stimulating activities that not only entertain but also enhance your father's capabilities and potential. Of course, not every activity or program is therapeutic; some are just plain fun. Generally a good recreation department will want to help your father maintain his skills, interests, personality, and social ability. However, the idea is not to change him into something he never was. For example, if he was never a drinker, he probably isn't going to start having a nip during pub night. The recreation department can help your father find companionship and a sense of individuality (but they cannot do it for him).

The recreation staff will bring your father to programs that are appropriate for him if he cannot get there himself or forgets. The limit on this is their time. It takes a lot of time to set up a program and bring residents to it. Often a recreation worker will go to a resident's room and invite the resident, who will say no. Or he will say yes but then forget to go. After a while, the worker will know how best to ap-

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proach your father to encourage him to take advantage of the activities.

Most recreation departments produce a monthly calendar. It is a very good idea to have a separate meeting with the director of recreation to go over the schedule and help the staff know what might interest your father. At the same time, you can let them know what you think is the best way to encourage his participation. Most homes have bus outings. Make sure you find out who gets to go on those, how often, and where they go. Find out how you can be involved in recreation programs. What programs are there for families? Most activity departments will also keep statistics on program attendance. If you want to know after three months whether Dad is attending, they should be able to tell you.

## Rehabilitation

The rehabilitation staff usually consists of a physical therapist and physical therapy aides. There may also be an occupational therapist and/or speech therapist. Physical therapy is responsible for helping residents improve or maintain their physical ability. That includes improving the ability to stand up, sit down, get on or off the bed, etc. They help residents with walking ability, balance, maintaining muscle mass or flexibility, and simply exercise. Occupational therapists assist people in learning or relearning to do their ADL (activities of daily living), such as shaving, dressing, and washing. They (or the physical therapist) are also expert in assessing the equipment needs of a resident and recommending which kind of walker and wheelchair is best suited to the individual.

There is a wide variation between nursing homes as to the kind of rehabilitation programs that are available. In some areas, rehabilitation staff is required by law for every certain number of residents. Other areas require no rehabilitation staff. In the United States, Medicare pays for some physical therapy services. All U.S. residents have the right to access physical therapy, occupational therapy, and speech therapy. If the home does not provide it, it must contract with an outside agency. The problem with this "one size fits all" approach is that, as one occupational therapist told me, "it means that lots of

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people who cannot benefit from these services receive them, so it becomes a factory approach. The people who really could use the services the most don't benefit to their maximum potential."

In Canada the provincial health programs subsidize physical therapy services. If there is no physical therapy in the nursing home, you may have to arrange for it or have your father brought to a clinic. (Often the physical therapists do not want to come to the home because they are not allowed to bill the government for transportation costs.) In both countries the amount of service is limited. Even without rehabilitation staff, many homes have a program that is designed to keep residents physically active, often through recreation.

### Housekeeping/Building Maintenance

Support services personnel, such as maintenance, grounds, and especially housekeepers may have many similarities with nurse's aides: poor pay, little education, harassment by families, and bigotry and racism on the part of residents. Housekeepers, who are in the residents' rooms frequently, often know the residents very well and have developed close relationships with them. Housekeeping is done on a rotation, so rooms may not be thoroughly cleaned every day; but toilets, sinks, and sweeping should be done every day. It is not the job of the housekeepers and maintenance people to dust a resident's personal items, fix their TV or walker, etc. They may do so, but it is generally not their job. You may want to ask what the home considers their responsibilities to be and how often they are to carry them out.

### Pharmacy

The average person at age eighty-five is taking about five to seven medications. A pharmacist is thus a very important part of the care team. Different homes have different pharmacy arrangements. Sometimes pharmacists are at care conferences, sometimes not. Sometimes one pharmacy provides medications; sometimes several.

Remember, the medications, potions, and treatments your father takes in his own home are his business. The nursing home has legal obligations, and this can have an impact on its approach to medica-

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tions. For one thing, the home will be much more cautious about interactions between naturopathic remedies and prescription drugs. If Dad is on herbal or naturopathic medications, find out how the home will deal with these. It may be that they have to be obtained on prescription from a pharmacy.

### Physicians

Some homes have “house” physicians; in others, people use their own doctors. In the United States, residents have the legal right to choose their physician. The advantage of a house physician is that she may be there more often and may know the staff and system better than a doctor who only has one or a few patients in the home. Conversely, she may be responsible for many patients and several homes and not be really able to provide the care that your father needs.

Any doctor treating a resident must be willing to come see the resident in the home. The doctor's office should be close enough so that it is not a major inconvenience to do so. Usually if there is a problem, the nurse will contact the physician, but if you have questions, both you and your father have the right to contact the physician directly. Any physician working in the home should have an interest in geriatric medicine. She should also be available to you within a reasonable time if you would like to talk to her.

Almost all homes also have a medical director. She is there for a limited number of hours or sessions per week. She is responsible for overseeing the medical care, medical standards and policies, and procedures. However, unless there is a problem, she may not know the individual residents. She will not become involved with the physicians unless there is a problem—it is not a preventative position in most cases. The medical director may not be a gerontologist or even a physician who has an in-depth knowledge of geriatric medicine.

### Other Staff Members

A number of other disciplines are regularly involved in nursing homes. These include pastoral care workers (such as a priest or rabbi), music therapists, art therapists, and massage therapists. They are all



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very valuable in helping residents have a fulfilling life. These people will often have very insightful knowledge about how your father is doing and what his potential is. They can be valuable allies for you when you are setting goals and expectations.

Some homes are developing models that give the staff fewer residents to work with but broader responsibilities. This means that instead of separate nurse's aides, housekeepers, or recreation staff, one person will perform all of these roles. The same person who helps the resident get up in the morning and to the bathroom will help her in the dining room, make her bed with her, and then organize a card game with her and a couple of her neighbors.

## *Mabel*

A year ago we decided to seek a nursing home for my mother. She was on medication several times a day and on oxygen full time. She was unable to manage the medications and oxygen. I looked after her shopping, some cooking, paying her bills, and taking her to appointments. At this time, I was working four days a week. I went to her apartment every day around dinnertime to set out her medications for the following day and to make sure she was eating. Mom was requiring so much time that I had none left for my husband or children and grandchildren. We didn't go on any trips or even go out to dinner because we would have to rush home for the next medication time. The situation became a nightmare.

I requested a list of care facilities in our area from a local agency. Mom was assessed. I compiled a list of questions and made appointments with some of the places on my list. I toured a few and asked my questions. I then chose the one that seemed to address our needs the best, and Mom's name was entered on a waiting list. We were told that the wait could be as much as one year for her first choice.

As soon as there was an opening at one of the facilities, Mom and I went for a tour of the facility. She was not very pleased with what she saw. She felt that it looked like a hospital. I reminded her that she required twenty-four-hour nursing and that it was set up to meet that need. She seemed to agree. She also noted that there were several people who seemed to just wander about, and this made her uncomfortable. The lady conducting the tour told her that "some people's bodies go and some people's minds go." She said that they did not feel these people should be locked up. Mom agreed. She also saw that there were several old people who needed wheelchairs. She was able to walk; she wasn't as in-

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firm as they were. I reminded her that sometimes she was in a wheelchair to make it easier for her and that maybe many of them could walk too.

At the end of the tour we went into the office to do the admission papers. Mom seemed detached, as if it was not really going to happen. She said she didn't like it there and did not want to move. Then she started to cry.

When we moved her into the home, we tried to make things as familiar and comfortable as possible. We asked her opinion on where she would like things to go. We made sure she knew that if she needed anything, she would get it. We visited frequently so she knew we hadn't just left her there and forgotten about her.

Mom was used to the way she had been taking her medications and was insecure about the way the nurses were doing it. She complained that she had not received all her medications. The first few times, I checked with the nursing staff and they checked her chart and assured me she had. I assured Mom that she had received all her medications.

We had a problem with her oxygen equipment. I was told the staff knew how to operate the equipment. One day when I went in, Mom was upset because she had not been able to leave her room. She told me that the staff did not know how to fill her portable oxygen tank. I checked with the nursing station and found that to be true. I showed them how to fill it and that seemed to take care of the problem.

Mom complained about the food. I said that it was probably not what she was used to, but it was a balanced diet and that they were trying to please many different people. We made sure she always had goodies to eat in her room. There was a problem with some of the confused residents wandering into her room. I told her that maybe she should just ask them nicely to leave and if they didn't, then ring for the staff. If it got worse, then maybe she could close her door for a while or put a gate across it. She was afraid her laundry might go missing. When she had a concern, I checked her clothes and, if needed, checked with the staff.

For the first six months or so, she stayed in her room. She did not attend any activities. If she was urged to do so, she told the staff she did not feel up to it. She left her room only for meals and baths. She spent her time crocheting and watching TV. She did not make any friends. She said no one wanted to talk to her and the ones who did talk didn't know what they were talking about. She was not interested in joining in any family

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gatherings. She said it was too much trouble. No amount of convincing on our part seemed to help. Seeing her alone and unhappy and not doing anything to change it made me feel defeated and punished.

Mom became ill several times in the first few months. This did not help, as she felt the reason she was ill was because she was there. It helped that she was able to have her own doctor looking after her.

She often told me she would like to come live with me. When she said this, my heart felt like it was melting. I reminded her that I worked all day and no one would be there to help her for hours at a time.

After about six months, she began to feel more comfortable. She started to enjoy being with the staff and began to talk to them herself if she had any concerns. She became more interested in what was going on around her. She started making some friends and going out into the hall to be with people. She began having her hair done more frequently. She started to feel like part of the group. I started to feel I could visit a little less, as she now felt better about her surroundings.

After eight or ten months, she was more like herself. She was friendly and made a couple of close friends. She felt comfortable with the residents in the hallways. She was happy but was still anxious to move to the facility closer to her home.

One year after moving in, she was able to move to the care home of her choice. She regretted that she was going to leave the friends she had made but was excited and positive about the move. The second move was less traumatic than the first. She was able to keep all of her things and was now closer to family and old friends. She knew what to expect and was comfortable in her new surroundings. She has been reacquainted with some of her old friends, who also live in the new place. She has already joined the cribbage league again. In less than two weeks, she feels at home. She is interested in her surroundings and is willing to venture out to acquaint herself with her new home. She is happy knowing that family and friends are close.

I feel that it is all right to visit when I can, but if I can't, it won't be such a disaster. She is comfortable and well cared for. I feel I can go on a trip and thoroughly enjoy it because I don't have to worry about her. I can again have time to enjoy the rest of my family as well as my mother, and have time for myself.

## CHAPTER 8

# The Nursing Home System

No matter how “homey” nursing homes try to be, usually they still function to some extent as an institution. They are a group living situation; they work on a schedule; people have to wait for things. There is a lack of personal space and an increase in the amount of time one spends in public places. Individuality, so valued in our society, is not fostered in nursing homes, so residents easily feel devalued and “not special.”

Nursing homes tend to take away many of the individual choices that we have in our lives. The result is that residents can have a feeling of loss of control over themselves. Often, it is in little things. For instance, in some areas residents are not allowed to self-medicate, or even to take an aspirin on their own without a doctor’s order. They may not be allowed a refrigerator or kettle in their rooms, so they must ask for a cold drink or snack or coffee. Even though they’ve had a glass of wine every night before dinner, they may have to wait for the nurse to serve them that glass or wait for the doctor to order it. At dinner there may be a choice of entrees, but still they are not deciding when to eat, what to eat, where to eat, or with whom to eat.

The focus in nursing homes (when it isn’t on profits) is often more on *nursing* and less on *home*. For instance, monitoring bowel function is common in a home; every day a nurse’s aide may ask your husband if he has had a bowel movement even if he has not had problems with bowel function in the past. It can be embarrassing. The nursing focus is partly because nursing is the largest department. This is true even though many functions performed through the nursing department

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do not require any kind of medical training. Being the constant recipient of care can symbolize dependence for someone.

You can easily get caught up in the way a home takes away your husband's individuality and independence. For instance, instead of asking your husband what he wants or talking to him first about his condition or behavior, the staff may phone you to ask what you think. If there is a problem, rather than talk to him, they may ask you to handle it. Whereas this may be appropriate if your husband has dementia, a lot of times it is not. Reminding the staff to ask him what he thinks or what he sees as the problem will help train them to treat him like a person, not like a patient. In turn, this will lower the burden on you and help *you* to keep treating him like a person.

You can also try to help your husband maintain as much independence and responsibility as he can. Let him continue to handle his checking account, organize his taxes, buy birthday presents for the grandchildren, etc. If you feel he cannot do it, you may want to "consult" with him. Encourage him to take as much control as he can by making decisions for himself. Sometimes these are very small decisions. If he is coming home to visit, what does he want for dinner? If he needs new clothes, take him shopping with you or ask what colors he wants. Life is made up of lots of small decisions, not just the large ones.

The younger or the more mentally able someone is, the more important it is that he maintain input into not only what happens in the care facility but also what happens at home. If there are young children or a financial portfolio, for example, your husband should be involved. These decisions and input keep him anchored to the family so that he doesn't feel isolated, rejected, or useless.

### How the System Works

It is important that you understand how a nursing home system works (or sometimes doesn't). There are two aspects of which to be aware. First, a nursing home has several departments: nursing, maintenance, housekeeping, laundry, dietary, etc. One director may head several departments, but those departments tend to have separate

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staffs with separate job descriptions. Even though the staffs may co-operate, they function on their own. This departmental separation is one of the causes of gaps in communication and policy. Second, a nursing home runs on three shifts a day for seven days a week. That is twenty-one shifts per week. Over those twenty-one shifts, you can easily have six or seven different nurses and twice as many nurse's aides. You can have fourteen shifts of dietary personnel. When you include laundry, maintenance, recreation, casual or agency staff, and so on, there can easily be thirty people who will deal with one resident over the course of one week and more over the course of a month. If you think of the nursing home as a machine, think of all the shifts, all the departments, and all the staff members having to work together like the cogs in the gears.

If this were a perfect world, all the cogs would mesh together smoothly. Unfortunately, it's not and they don't. Information is one of the first victims of the gap. If you think of information as going into a machine at one point and having to flow along a path to others, you can see that the more complicated the machine, the more possibilities there are for the information to get lost or changed along the way. Remember what used to happen when we played telephone when we were little? A sentence that started out as "Johnny has new shoes" ended up as "Mary got locked in the bathroom." The communication gaps, losses, and mistakes often lead to the lack of continuity in care and glitches that you will experience.

### A Typical Day

It may help you to understand how a typical day in a nursing home runs. Starting off around 6:00 A.M., the night nurse will begin to give out morning medications and perform treatments. At the same time, the kitchen staff has arrived to start making breakfast. Somewhere around 7:00 or 8:00, the day shift will arrive. The nursing and care staff will learn what happened in the previous shift. The day nurse continues medications. The nurse's aides will begin to help residents get ready for the day. They will help them wash and dress. They will help them to the bathroom, or change them if they are incontinent. They may help with some treatments. They will begin to bring people

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to the dining room. Meanwhile, other support staff such as kitchen, laundry, and housekeepers arrive and begin to do their jobs. At breakfast, more medications are given out and the care staff help to feed people. Some people eat and are ready to go back to their rooms in ten minutes; others need an hour. After breakfast, people are brought back to their rooms. Nurse's aides and nurses will help them use the bathroom, be bathed, etc. Nursing will perform treatments, call physicians, do assessments, return phone calls from family members, and so on. During the rest of the morning, nurse's aides will give baths and help people to the bathroom. They will change people who have soiled themselves. They will answer call bells. During the morning, recreation staff arrive and start programming, which continues until the evening.

At lunch time, nurses and nurse's aides help bring people to the dining room, medications are given out, people are helped to eat. A routine similar to the morning happens after lunch until shift change. Also in the afternoon, caregivers help people to bed for a nap and then get them up again. Sometimes they have to get them up and down two or three times in the afternoon to use the toilet, or because they want to get in bed, then decide that they want to get out of bed, and then change their mind and want to go to bed again. The afternoon shift repeats the meal, medication, toileting tasks, and so on. Nighttime is the reverse, when people are toileted, changed, given medication, undressed, and helped to bed.

Besides making for a busy routine, many of the tasks take a lot of time, especially when they are done with the resident's dignity and comfort in mind. For instance, helping a resident to dress entails choosing clothes and helping her feel right about how she looks. If she has arthritis, putting on the clothes means taking care not to hurt her. If a nurse's aide has many people to help dress, you can see just with this one task what the work load entails. Another example is recreation. Recreation staff can take almost as much time trying to bring residents to a program as they spend on the program itself. Sometimes by the time they have brought the last resident, the first ones have forgotten why they were there and have left.

In the middle of the daily routine are medical emergencies, phone calls to and from physicians, and care conferences. Everybody is an-



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swering questions from residents and families. Sometimes there is a new admission or a room change. A tremendous amount of time is taken up in meetings and documentation related to governmental standards and requirements such as developing treatment plans. For example, in some areas if a resident has had an accident, such as a fall, the staff has to fill out a form that describes what happened and how it was handled. In all three shifts care staff have to record in resident charts if there is a change in health status, or some other issue. (For another, excellent description of a nursing home shift, see "The Truth about Nursing Homes," a Web site at [www.jeffdanger.com](http://www.jeffdanger.com).)

In between all of the above, staff have breaks, go for lunch, etc. When one person is on a break, this can mean that there will be only one staff member on the floor or unit. If one or two people are helping to get someone out of bed or washed, it can easily mean that if you go looking for a staff member, she is not going to be easy to find. If you can't find a staff person, it doesn't mean that she is not busy or that there is no one on the floor.

You may have some anxiety related to staff not being around and wonder, "What if he had a fall? How long would it take someone to find him?" You can see from the schedule I described that there can be someone in a resident's room several times during the day. Also, if a resident does not come down for a meal, this is a signal for the staff to check up on him. However, it is true that there is not going to be someone around your husband as much as you have been. There will be many times when he will be alone for several hours. This is not one-to-one care and, as I said earlier, staffing is often minimal. You have to accept that and work with it somehow. If you cannot, then you should not put yourself or your husband in a situation like this. It is not fair to him, to yourself, or to the staff at the home.

## *Cyrus*

When the lapses in my husband's memory first became apparent, I dismissed it as "getting older." However, when Cy's orientation and directions started to become a problem, I began to doubt my assessment of the situation. I took him to the university medical center for an examination, and there a diagnosis of Alzheimer disease was confirmed.

I was stricken by the blunt prognosis—that he would continually decline over a period of time and that eventually I would have to put him in a nursing home. At first I rejected that idea. I wasn't willing to accept that I would eventually be unable to meet the challenges that would arise.

Over the course of time, I saw that I was wrong and he would go downhill. I had to resign myself to the inevitable deterioration of a once razor-sharp brain. I became more and more of a caregiver. I sought out activities that could spark the interest of an individual with very low vision (legally blind) and almost no hearing (even with the most up-to-date hearing aids). With two of the five senses badly damaged, stimulation was almost totally lacking. There could be no reading, writing, tapes of music or voice, puzzles, newspapers, lectures, discussion, TV, or radio. With life so limited, he slept much of the time. Activities ceased. Weariness, boredom, and depression followed for us both.

Before his condition had deteriorated to the point that he could neither reason nor understand, we discussed our problems of health and of living arrangements in the future. In the meantime, we continued to live as fully as possible, seeing close friends, visiting family groups, celebrating special occasions, taking short outings, attending church, and enjoying our precious, intimate moments together.

We made a move to an apartment, all on one level, close to trans-

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portation, shopping, and service facilities such as banks, entertainment, and future care facilities. Best of all, it was close to loving family help.

Eventually, I investigated the nursing home nearby. I knew it was necessary for his future care. It was only a five-minute walk. I was delighted to discover a bright, inviting residence with pleasant lounges and activity areas and a friendly dining room. The residents' rooms were cheerful. They had their own private toilets and sinks and were adequately furnished, with room to spare for personal pieces.

Pictures and memorabilia from home were encouraged. The dining room served nutritious food that was well accepted by the residents and could be individually adjusted. Juices, fresh fruits, and grain snacks distributed daily were a welcome diversion. The busy, caring staff were cheerful and efficient. Residents were kept active in varying small groups of their own choice singing, exercising, working with their hands, even watching TV. Bus outings could include family. Special activities were planned monthly by the creative, energetic staff. Visitors were always welcome, including children and pets.

When the call came that there was a room available, my head responded with a rational "Yes" but even with all that I knew about the home and Cy's condition, my heart screamed "No!" It felt so unfair. I didn't know how I could do this to him.

In the few minutes I was on the phone with the social worker, an emotional battle raged within me. I went through doubt, fear, frustration, anguish, disappointment, sadness, and guilt. The rising inner turmoil left me unable to reason. I finally requested permission to temporarily escape. I hung up the phone and escaped in the comfort of home, where I thought I could put things into perspective.

I turned down the room. Later I changed my mind. They let me put his name back on the waiting list close to the top. When they called me the next time, finally, with the support and help of my children, I decided to go through with it.

The emotional struggle raged on. I was afraid. I didn't know how he would react to the news of his change of lifestyle and residence. How would I manage the whole situation and my own emotions? I tried to concentrate on the benefits to my husband that the new and stimulating surroundings provided.

After Cy went in, I continued to feel anguish, disappointment in my-

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self, and sadness at being without him. I tried to educate and involve myself in the goals and routines of the home. But at times I continued to feel frustrated and inadequate in that I couldn't take care of him myself. I tried to be flexible and find alternative solutions to problems when they came up. I didn't know if I could acquire the adaptiveness I needed to deal with the changes.

Eventually I realized that dealing with all my feelings would involve self-inspection and my acceptance of the inevitable. I also realized that I could solve the anguish, disappointment, and sadness only by fashioning a new and interesting life for myself.

It wasn't easy and it didn't happen overnight. It took tremendous personal effort and determination. I sought out new interests and activities, both mental and physical. I found that they proved stimulating and enjoyable.

Every step of the way I had with me, always, the caring support of family and friends. They reminded me that I had been getting exhausted from caregiving. They told me that I had made the right decision when I was doubting myself. I kept on telling myself that I had to maintain my own faith in an improving future. I kept walking this road, and after many months, things did get better.



PART III

MOVING IN AND  
SETTLING IN



## CHAPTER 9

# Preparations for Moving Day

As I said earlier, the transition to a nursing home is often a process of grief and loss. If your wife is being discharged directly from a hospital to a nursing home, you will not have much time to do any preparation. If she is coming from home and you have the time, adequate preparation before the move will help you and your wife through the process. There is both emotional and practical preparation.

### How to Prepare Your Relative

If your wife was not able to participate in the actual decision that she needs to move or to place her name on a waiting list, then a good preadmission process can help her participate in the decision. It will also help minimize the stress and anxiety that will arise. This, in turn, will make postadmission adjustment easier.

Try to bring your wife to the home for several visits before admission. See if there is a resident who can act as a buddy to her before she comes in. Obtain a schedule of activities and slowly let her start to participate in them, maybe even on a weekly basis. Maybe you can arrange for her to have a meal at the home one day a week. At first you may want to stay with her during the activity or meal, but gradually you may want to pull back and let her be there on her own so that she is used to it without your being there. For this to work, you may have to work out questions of responsibility for medications, toileting, and emergencies with the staff.

In the time before admission, talk to your wife in general about what is coming up. She may focus a lot of anger toward you. Partly this



## PREPARATIONS FOR MOVING DAY

is because you are a convenient target, but you are also a safe and visible one. Sometimes it is easier to be angry about our condition or fate with someone real and present than with God or even with oneself.

Have several discussions over time with your wife about what things she wants to take with her. Even if she has a dementia, she can often still make decisions about this. What pictures does she want to take, what pieces of furniture? Talking about concrete things helps people prepare psychologically for the future.

It can be heartbreaking to have to choose only one or two possessions out of the many you have collected over a lifetime. When I moved from Toronto to Vancouver, I sold my house and all my things. I had a garage sale and even sold extra lightbulbs. I shipped out ten boxes containing the only remaining things I had, including my clothes. The last day, when my telephone was shut off, I burst into tears. With everything I owned gone, I felt as if I had no identity, as if there was nothing left of the me that I had built up over years. If someone is breaking up her home in the last years of her life, that feeling of losing the self is overwhelming.

I sometimes suggest that children not break up a home or apartment for a little while after admission if they can afford it. If they cannot, maybe they can put their father's things in storage. It may be comforting for him to know that his home is still there or his things are still available. Later he may tell you when it is all right to sell. Doing this may be expensive, but the advantage is that your father will "only" have to deal with the move, and not the permanent loss of so much of what he has built over his lifetime. It also gives him more control over the pace of his loss and grief.

One way to approach the breakup of a parent's home is to ask your father to whom he would like to give specific pieces. As you go around the house or apartment, talk about the different things in it. Reminisce about where they came from and what they meant to both of you. Let your father know how you will treasure his things; it is a way of saying that you treasure him. This can be a sad thing to do, but it can be part of the healing and letting go. It may also help you when you have to clean out the apartment: your dad has given you permission to have his things.

When you are deciding what to bring, make sure you pay attention

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to the guidelines of the nursing home. Your wife may have a tendency to try to take “just one more little thing.” It may be hard for you to say no. If this occurs, call the home and have them talk to your wife, so you don’t have to be the one to say no. Remember that the staff needs to provide care; they must be able to maneuver around furniture. In an emergency, they must be able to get a stretcher or resuscitation equipment into the room and to a bedside.

If you truly think that your wife will not remember her visits or is so resistant to the idea that preadmission visits would make things worse, then you may have to let that go. It does not necessarily mean that she will not adjust well. I have known many people who were very memory impaired and absolutely refused to come for a visit or even consider the idea that they needed care. Their families were beside themselves with worry about how to bring them in and what would happen once they were admitted. It turned out that they were fine. Two days later they had forgotten they had just come in. They thought they had been living in the home for years.

If the nursing home admission is the result of an emergency or will be an admission directly from the hospital, you will not be able to do this kind of preadmission planning. Unfortunately, this can make your wife’s admission and adjustment more difficult. (On the other hand, it can make some practical tasks easier for you because you don’t have to worry about how you are going to move her out of the house, or what you are going to say to her.) You can still do an abbreviated version of the process; just do what you can. Talk about care. Bring in the brochure or information book from the home. Take pictures and bring them in. You can discuss what to bring and what will have to be left at home: which pictures, which dresses, and which purse?

### Get to Know the Home in Advance

Try to get to know some of the staff before admission. If your wife is able to be present at these meetings, make sure you bring her. You may not know the floor or room your wife is going to, but you can meet the recreation staff, the director of care (director of nursing), the social worker, and the administrator. If you can, have a meeting with them before admission to talk about the kinds of things you have

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been doing for your wife and how you have been doing them. Are there any tricks you have learned that make it easier for your wife to eat, to get to the bathroom? Is there one kind of incontinent pad that has worked and others that didn't? Is she prone to some skin breakdown or infections? How does she sleep; does she get up at night? Has she had any falls, and when do they occur? All of the things that you do in terms of providing care are important for the staff to know; write them down and discuss them beforehand if you can. Even if they don't remember the particulars, this will help them remember you—and that will help in obtaining good care.

Clarify for yourself and the staff your expectations for care. Do you want to be called every time your wife has a fall? Do you want to know every time there is a change of medication or there has been a routine doctor's visit? Do you want to know when there has been some weight loss? Do you want to know when she has had or is having a particularly good day? See if the home can meet these expectations. Find out what they think is reasonable and what their policy is on family communication. Try to let the staff know what kind of person you are. If you are very anxious and tend to worry, tell them. If you are having real guilt, let them know. They will most likely figure that out for themselves, but telling them will help them learn how to help you.

Often a home will ask for some written information about a person. It is helpful to write down not only the physical care information but also your wife's daily schedule and activities (see Questionnaire 2 in Appendix 4). Include in this when she snacks and sleeps, when meals are, what time is bedtime. What are the little things that make her feel secure and comfortable? Is she used to looking out the window at the park or talking to her grandchildren at 5:00 every afternoon? Try to find out which of these habits can be replicated by the home. The more of her routine your wife brings with her, the less anxiety, fear, and adjustment difficulty she will have. If the home where your wife is going is not so good, preadmission meetings can help to ensure that the staff knows you are involved and will be monitoring care.

It is helpful to write up a social history of your wife. A social history is a document that describes a person and her life (see Questionnaire 3 in Appendix 4). It can be very important for the staff. It helps

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them to see your wife as a person: who she was before she became disabled and what her strengths and weaknesses were. It also helps them to assess her adjustment. If after three months she is never coming out of her room, that would have a different meaning for someone who was always a loner and shy than for someone who was always the life of the party.

If she is able to, your wife should write the social history herself or help you write it. This is another way to reminisce and to prepare for the changes that are coming. It puts life in perspective as a path or series of events and changes. The transition to a nursing home is a continuation of that path and another change, albeit a huge one.

### Equipment

In the last few years, there have been some spectacular advances in equipment for disabled and elderly persons. You should have a good understanding of what is currently available and also what you need to bring. If your wife is using a walker or wheelchair, will she have to bring her own or do they have them at the home? Even if they do, it is a good idea for your wife to have one that is specifically measured to suit her. A proper walker will help her balance and gait and can prevent falls. If she uses a wheelchair, the wheelchair needs to be comfortable and one that she can maneuver. Poorly fitting wheelchairs can cause back problems and can reduce someone's ability to be mobile. If she spends most of her time in a wheelchair, it is like her home—it must be comfortable. Will your wife need a commode? Can she put in a pole next to her bed to help her get up and down? What about specialized utensils and plates to help with eating? If she has trouble putting on her own stockings, what about an aid to help her do that, or to reach things that she has dropped? A telephone with large numbers? A clock that speaks the time? Many cities have stores that specialize in equipment for elderly and/or disabled persons. Visit them or look on the Internet for equipment that your wife might benefit from. Even if there is nothing that you think she needs, look anyway. You can find things that help in ways you might never have considered.

## Valuables

I have worked in homes where almost nothing goes missing and in others where valuables went missing all the time. There is no correlation between this and the quality of care. If you bring in valuables, have them insured or find out if the home's insurance will cover them. Residents should not keep large sums of money on them, but make sure that there is at least a locking drawer where money can be kept. See if you can glue or screw small mementos down, perhaps on a board you bring in. Maybe you can bring in a small, locking glass case or shelving unit.

The basic rule is, "If you really don't want to lose something, you shouldn't bring it in." Accidents can happen, things break, and so on. No matter how much you are financially compensated, it might not replace the sentimental value of a ring or other item. On the other hand, if your wife really wants a cherished item with her, maybe the risk is worth it. What is the good of her possessions if she cannot have them? As I said earlier, they are part of who she is. If she understands the risk even only partially, let her make that decision. Even if something has been promised to a grandchild, its value to your wife should be considered first, even with the risk of losing it.

Residents can usually keep money in a comfort account or personal needs account. If their care is being funded by Medicaid, there has to be a certain amount available from their funding for their own use. These accounts function as a small bank account and are usually accessible during business hours. You can authorize a home to charge certain items such as outings or hairdressing to the personal needs account. You will have to monitor the account through monthly or quarterly statements. It is easy for a home to make a mistake with charges to a resident's account. Larger homes sometimes have a bank come in on a regular basis; it is done as a community service by the bank.

Even if your wife has dementia, she may want to have her purse with her and she may want to have some money in it. She may lose her purse continually, but to many women a purse is a part of them. I have seen women with advanced dementia still holding on to their purses and feeling lost and upset without them. Having two or five dollars makes a real difference to some people, even if there is

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nowhere to spend it or they don't know what to do with it. It is a good idea to put some other things in the purse, maybe some lipstick or a plastic holder for pictures of the children when they were small. *Always* make sure her name is on the purse somewhere.

### Clothing and Laundry

Take a look at the clothes your wife will be bringing. They should be fairly easy to care for. This means washable. A lot of elderly people do well with jogging suits because they are easily put on and taken off, and are loose and comfortable. There are many companies that specialize in clothing for elderly and disabled persons. They have beautiful and stylish pieces and may make your wife's life easier. They will have Velcro instead of zippers, fasten in the front instead of the back, sometimes be of material that is stain resistant, etc. Make sure they are well labeled. Also, make sure you bring enough in case the laundry isn't done often or they get soiled or lost.

Keep a list of all the clothes that your wife is bringing. After she is admitted, give a copy to the home, and if they wish to check it off with you, have them do so. Update it regularly when you bring new items.

If the care in a home is good, laundry is often the most frustrating problem. Clothing can go missing (how many socks have *you* lost in the dryer at home?) or people find themselves wondering why ten pieces of underwear are not enough and how come your wife is always running out.

Sometimes a home may use more laundry than you do. A resident is changed more often because she is helped to the toilet less often. The result is that she goes through more clothes.

Also, sometimes they do not do laundry on weekends. Sometimes labels fall off in the commercial-strength machines or fade so that they can't be read. It is possible that the person in the laundry can't read. Usually a home does all the residents' laundry together in batches. It is easy to mix up laundry when you are doing many people's together.

Find out how the laundry works, how often it is done and delivered, and what the procedure is for lost laundry and dry cleaning. In

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some homes, there is a resident laundry for residents to do their own small things. If all the residents' clothes are done together, get a mesh laundry bag so that all of your wife's laundry can be done together. You may want to do the laundry yourself. If you do, bring in a hamper and mark on the top "Family Does Laundry."

### Plan Ahead for Moving Day

Remember, moving is kind of a crisis for anyone. In a crisis it can be harder to make decisions. So your goal is to make as many decisions and plans in advance as you can.

Find out ahead of time what happens at the home on the first day. What are some of the forms to be filled out (and can you fill out any in advance)? Obtain a copy of the admission agreement and read it before admission. Will you have to pay rent right away? How much, and to whom?

Try to *do* as much beforehand as you can. This means practical tasks such as filling out government forms and change-of-address cards. It may mean talking to the bank, the lawyer, the accountant. Anything that you bring should be marked with your wife's name. This includes dentures and glasses. Make a list of everyone who is involved in your wife's life and figure out who needs to be contacted. Do you have to call the cable company and the power company? Do you need to hire a moving company?

Of utmost importance is contacting the insurance company to preauthorize payment if private insurance will be used. Find out from the insurance company what they need to know and when they need to know it. *If you do not do this, you can risk losing thousands of dollars in benefits.*

It will be especially helpful to make a written plan for what you will do when you are informed that a room is available and what you will do on moving day itself. Once you have a list, go back and number it from the first task you will do to the last one before you get into the car to leave. This will mean that when the call comes and on moving day you will not have to make decisions. Your list tells you what to do and bring; all you have to do is pack.

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If you are bringing many things, plan to have one suitcase with essentials and comforts. This would be the most important items that your wife will want in the first day or two as well as the things that will make her most comfortable and secure. For instance, she may be attached to a doll; she may like certain candies or wear a certain perfume. There may be one piece of jewelry or one dress that is a favorite. It may be a picture of you both on your wedding day or of your first grandchild—anything that would help to offset the strangeness and bring memories of home and family.

Have a plan as to how your wife is actually going to be told that there is a room available for her and that she will be moving soon. If she is alert and oriented, arrange for the home to call her and speak to her. If your wife is resistant or has some memory loss, it might be best if the doctor tells her. Maybe one of your children should tell her.

Decide how the actual move will take place. How will your wife get there? Who will go with her? Will someone meet her there? Will the rest of the family be involved? Are you going to be able to bring some of her things in first?

## Plan to Take Care of Yourself

As you are preparing your wife, you are also preparing yourself. When she is saying good-bye to her home and to your relationship as it was, you are saying good-bye to her and the relationship as it has been. If she can handle it and respond, talk to your wife about what you are feeling. If not, talk to other family members or friends. Remember, however, just because she is going into a home does not mean that she will not come back for a visit, that you cannot go on vacations together, or that you will never make love again. Your life, her life, and your relationship aren't ending; they are changing.

Once you have made all the plans for moving, make some plans for yourself. The actual time for placement will be a crisis for you too. Those first few days after she has actually moved may be hard. You can feel lost, lonely, and confused in this time. Be aware that the feelings of guilt and shame may intensify. During times of crisis, emotions are often magnified. The brain functions in a way that makes it harder



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to be rational in a heightened emotional state. This is a physiological fact. This means that you have fewer psychological resources to handle the intensified emotions.

Try to figure out what you will be feeling, and make some plans to help you cope with that. Maybe you want to make sure you are having dinner with your children or some friends. Maybe you want to have someone come and stay with you. Maybe you will want someone to meet you at your house when you have come back by yourself that first day. Whatever you think you may need, make sure you will have it. It is easier to cancel plans you have made than to make them at the last minute.

Don't be afraid to ask for support. This is not a time for heroism or stoicism. People want to help and support you. Let them. You will not fall apart because you have let someone help you. You may break down and cry, but your tears will stop, and you will be stronger for having shed them.

## *Betty*

On a rainy morning in April, my sister and I moved Mother to Mountain Ridge Home. She was ninety years old and had lived in Elm Manor, a congregate care seniors' residence, for five years.

A couple of years after she went to Elm Manor, we began to get concerned because she was going downhill. We phoned the health department, who did an assessment. They sent us to Dr. —, who diagnosed Mother with Alzheimer disease.

But now she was having increasing paranoia and hallucinations. She was hearing things that weren't there. She was missing meals and needing help with medication for glaucoma. Elm Manor couldn't deal with these things. Mother would have to move.

After touring a number of facilities over a year, my sister and I liked Mountain Ridge the best and put her name on the waiting list. We toured it twice, the second time with Mother. She did not really comprehend what it was all about, but it made us feel better that perhaps she was involved in the decision in some way.

Her name came to the top of the list once and we declined because we felt she wasn't ready to move. The second time her name came up, we felt the move had to be made.

I organized things by phone with my sister. I do not recall a meeting about the move or about Mother with anyone at Mountain Ridge. We moved a desk and chair and a large chair into her room the day before and put pictures and a bookshelf on the wall to make it welcoming for her.

The admission itself was confusing and chaotic, and it appeared no one was prepared for her. Reception did not know she was coming. I staggered in with boxes of clothes and had not been told I could park in the

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back, much closer than the side street where I had parked. No one helped me. The bed in Mother's room had not been made.

We had understood we would be meeting with the senior nurse and administration, but this did not happen. The recreation therapist and dietitian came into the room. They were friendly and welcoming and asked Mother questions about her likes and dislikes. The timing was not appropriate. She was too confused and was incapable of answering the questions.

That day was very difficult for all three of us. It did seem that not much effort had been made in preparation for a new resident. Mother's comment was, "Can I go home now?" It was heartbreaking for us, as you can imagine. However, we were invited for lunch, which helped us get a sense of the procedure for meals. Also it gave us a way to be supportive to Mother.

The first few days at Mountain Ridge were confusing and frustrating for my sister and me, as well as for Mother. We did not know who to talk to with our questions. We needed to know who the staff were. What were their roles? What was the daily procedure? How much care and attention was available for Mother? We needed to know what to expect from the home. Perhaps our expectations were high, but we didn't know because we had nothing to compare it to and no one to talk to about it.

From my experience, I would recommend that family members clarify expectations, such as: What can you expect the home to do? Who are the staff, and what do they do? Whom can you contact with your questions?

## CHAPTER 10

# Moving Day

### Stay Calm

Moving day can be as traumatic for you as it will be for your wife—and maybe even more so. The call will come to tell you a room is available. You will find out the day and the time of admission. You will hang up the phone. Then you may have a sense of panic, “Oh, oh, what do I do now?” You might forget everything that you were just told on the phone.

Sit down. Have a cup of coffee (or maybe a drink if it’s after lunch). Let yourself think for a minute. Let the feelings pass through you; you may have panic, fear, anger, sadness. Take some deep breaths. Give yourself an hour to do nothing but regain some equilibrium. Call the person who is going to help you with the move. This will give you someone to lean on as you go through the immediate crisis.

Reread the home’s information manual that you received on the tour. Although you may have read it once, you may have forgotten much of the information because you didn’t need to act on it right then. Now you do. Next, reread your plan and list of things to do that you wrote up earlier. The plan will make the task easier because it is something concrete.

### If Your Relative Refuses to Go

It may happen that your wife starts to hesitate. If she does and she is able to reason, remind her that she can try it for a month or two and then decide if it is the right place for her. The home is not a prison;

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the door swings both ways. I have had people move in gradually to a nursing home. For the first while, they may go back to their own home to sleep several times during the week. Little by little, they end up spending more time sleeping in their room at the home. People adjust and grieve at different speeds and in different ways. Some people hold their noses and dive in, and some put in their little toe to test the water first.

If your wife has dementia, it may be difficult to enlist her cooperation. She may refuse to go into care and insist that she doesn't need it. She may honestly not know that she has deficits and not understand what is wrong. It is part of the tragedy of dementia that one's ability to make decisions and judgments is impaired. Often, however, at some level, people do know, and are so frightened that they deny it.

There are a number of ways to approach someone with dementia about the move to care. You may say that it is for only a short time while you have a rest or while you go out of town. You may say that the doctor wants her there for some tests; she will stay until the doctor says she can go home. Some people have said that it is for financial reasons. With a parent, you may say that the apartment building has been sold. Think of what or who might make sense to her in her world, and use that as an explanation. Sometimes it is better if the doctor tells her. When it is the fault of someone or something else, she is not fighting you directly. If she is going to have a private room, you might see if you can spend the first night or two with her. Ask if the home can put an extra bed or cot in the room. That way, your wife has someone with her.

It is beyond the scope of this book to get into a discussion about ethics, coercion, and individual rights. Clearly there is often an element of coercion when someone has to enter a nursing home. When an individual has dementia, the coercive factor can be even more pronounced because of the individual's impaired ability to make decisions. You may have to *tell* your wife that she is going. You may bring her for lunch or an activity, and tell her then that she is going to stay for a while. You might tell her you are going for a drive. I have seen some elderly people who were living on their own deteriorate to the point that they were hospitalized for health reasons and from there were transferred to a nursing home. As I discussed earlier, be aware that,

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in most areas, people have the right to make their own decisions until they are deemed incapable by law—whether or not they are obviously and significantly mentally impaired. If your wife refuses to stay, it may be that legally you cannot make her stay, nor can the nursing home keep her. It could happen that the home will tell you after a while that she has to try again at home. Find out what the policy and laws are in your area, and with the home where your wife will be going.

### When You First Arrive

At the time of arrival, there is usually an initial interview with a nurse, who will take vital signs (pulse, blood pressure, etc.). He may also conduct a more in-depth interview and ask about physical health, emotional issues, and practical abilities such as going to the toilet, feeding, dressing, and washing. Your wife will probably be assigned a seat in the dining room and table mates. Other staff members will probably try to meet her at least to say hello. If too many staff and interviews are taking place, ask if some of them can be spread out over the next few days. It is easy to be overwhelmed by staff who think they need information right away.

During that first day there may be several administrative tasks that you have to complete. These can include signing preadmission agreements, reviewing payment options and plans, and receiving information that federal and state law requires you be given. The forms can be somewhat confusing. The details can take quite a bit of time. If your stress level is high, these things can feel onerous and you may feel pressured. That is why it is a good idea to know in advance what you will have to do that first day and to see if any of these tasks can be done beforehand.

See if you can stay for the first meal with your wife or at least sit with her in the dining room and have coffee during the meal. Stay as long as you can that first day, or stay for a while and come back. Someone will probably give you and your wife a tour. If they don't, ask for one. Although you may have been there before, things will look different this time.

Even if you have written down and presubmitted care issues that you think are important, talk to the admitting nurse again about

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them. Unfortunately, you cannot assume that the nurse and nurse's aides who are on duty that day have had time to read what you wrote, or, if they did, that they will remember. If you refresh their memories, there is a better chance that the important things will get done in the way in which your wife is accustomed.

In the United States a nursing home must inform residents of certain rights if their care is being covered by Medicare or Medicaid. These include what items and services the programs will pay for and for which the home may not charge and charges for additional services. They also include a resident's legal rights concerning a personal needs (comfort) account and information about state agencies, advocacy groups, and advance directives. (See Appendix 3, "Nursing Home Residents' Rights under U.S. Law," for more detail.)

## *Joan*

My mother's condition had been deteriorating for several years when we took her to the doctor. He gave us a diagnosis of Alzheimer disease and confirmation that she should not be living on her own. This finally made it clear that something had to be done. She was only seventy-two years old. We put her name on a waiting list for a nursing home and were told she would have to wait a year. The last few months of that year were by far the worst. Her memory was fading rapidly, and her inability to handle the basic needs of daily living had put her in physical danger.

As moving day grew closer, Mom would talk about how happy she was living in her own apartment. She had no idea she was on a waiting list for a care facility, but she knew something was up. Whenever we tried to broach the subject of moving, we were met with fierce opposition and a long history of how she had raised four boys and always been in control of her own destiny. "How dare you even suggest you know what's best for me?" she said. "I love where I am."

With less than a month to go, we received a call from the social worker. She said that our mother's name was getting to the top of the list and that a move could happen at any time. And when that time came, she said, we had twenty-four hours to accept the spot and another twenty-four hours to move her in—forty-eight hours for the entire move. We had a plan and were prepared for the move, but still, forty-eight hours seemed almost impossible. We had full-time jobs, small children, and no idea if we could pull it off.

"Are we talking about her name coming up in a week, a month, or several months from now?" I asked the social worker.

"We're not sure," she replied. A pending nurses' strike had made the uncertainty worse. It became a nervous waiting game.



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On the eve of the July 4th weekend, we were told that a bed was ready and that we should be moved in on the following Tuesday. Fortunately, we had a long weekend working in our favor, but the task still seemed beyond reach. My brothers and I had dreaded this day since we first put our mother's name on the waiting list.

We brought our mother to her new home, carrying only her most precious possessions, her family photos. Later we could bring a chair, a TV, and her piano keyboard. She had been a concert pianist, and her music was very close to her heart.

"I don't belong here. I wish I was a thousand miles away. It's like being in jail." Her words hit me deep inside. "It's a nightmare," she continued. "You can't make me stay. I'm going to run away."

My mother's condition in the days after the move deteriorated faster than we could have imagined. There was almost total confusion and disorientation about her surroundings and her whole existence as a person. She could not understand why she was there at a time when she had been so happy at her old place. Just one week earlier she would go for walks to the local coffee shop and return home safely. Now she couldn't find her way back from the elevator, just thirty feet away from her new room. I was told that this was typical and that within a week or so she would regain her sense of orientation. But after several months she has not returned to the level she was at before moving into the home.

Eight weeks after she moved in, the staff at the home scheduled a care conference with my brother and me to discuss our mother's progress. The staff at this meeting consisted of the head of each department. Each gave a report from her own perspective. The general thinking was that my mother had settled in very well and that the staff found it a pleasure to work with her. She got along very well with the other residents, they reported. This was great news to me and my brother, and we felt compelled to tell the staff how grateful we were for all their help and support.

But for the family members of persons with Alzheimer's, nothing is ever certain. Things are always changing as the disease progresses. You never know what is around that next corner.

I started receiving reports from the staff that our mother was exhibiting "unusual behaviors" and that a doctor from the mental health agency was being brought in to examine her. I couldn't believe she had changed so fast.

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The staff at the home would be the first to agree that my mother is one of the most passive, loving, and honest residents at the facility. This was evident from the reports at the team meeting. Clearly, she would not intentionally harm or even inconvenience anyone living at the home. Knowing this just made me have more questions than answers.

I received a call from the director of nursing, who informed me that the decision had been made to move my mother to another ward, the "Special Care Unit," for people unable to cope in the regular part of the facility. I had heard about this ward during my initial tour of the home, but few people had talked about it. The doors to the ward were locked and the people inside were isolated from the outside world. That's where Mom would live. It didn't seem like we had a say in the matter.

When I heard the news, I thought, "Not again. She was just getting settled." My brothers and I went to visit our mother that weekend. When we got there, she was looking better than she had in months. She was visiting a friend on her floor who was playing the harmonica. She was more oriented to her environment than she had been, and she even recognized someone sitting outside her window.

After personally touring the Special Care Unit that weekend, it was clear that the residents were at stages far beyond that of my mother. I thought that the staff at the home were rushing it. She may not have many years left before she reaches that point, but I didn't see any reason to cut those years short.

With the hope of delaying the move to this ward, I set up a meeting with the social worker and the head nurse for her floor. The staff at the home had been open and accommodating in the few months she had been there. Perhaps a meeting is what we needed. I wondered if I had been too demanding on the staff time. But then the nature of this disease requires as much participation from the family members as possible. I wasn't sure how the meeting would turn out or what my options would be, but I was sure it wouldn't be the last intervention I would have to make in my mother's care, or the final crisis left to solve.

In the meeting, we explained to the social worker and head nurse why we were concerned. They told us what they saw as problems. They agreed to try to do some other things. When they heard what my brother and I had to say, they reevaluated what they thought. They agreed to wait.

It is now several months after that meeting. My mother is still in the

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same room and she is doing well. I am just glad that we were able to ask for a meeting and didn't take what the staff told us as the only course. We had to have the courage to speak up and believe in what we saw and knew about my mother. But they also didn't act like they were the experts and we were "just the family." They listened and I think they learned something too.

When we deal with the home, the only consistent thread holding things together, it seems, is clear and open communication between us as the family and the staff. This open communication, and the sincere efforts of the staff to keep us informed, give us comfort in knowing that our mother is getting the best treatment possible.

## CHAPTER 11

# Settling In

## Resident Adjustment

A move for any elderly and/or ill person is extremely disconcerting and can be very confusing. As I mentioned, in times of high stress, people's coping abilities are often impaired.

For people who have memory loss, a new situation is particularly difficult because they have trouble learning. In their own home with familiar surroundings, they can use old habits to guide them in their daily life. In a new situation, such as a nursing home, they cannot use those old habits. The familiar cues are gone. Remember, people with dementia retain long-term memory, but it is short-term memory that people need first in new situations.

*For any new resident, whether or not he has some memory loss, adjustment to care can easily take three to six months. I cannot emphasize this enough.* After your husband has been in the home for four months, it may feel like a long time, but it isn't. Some of the complaints, behaviors, and emotions that you continue to hear about from your husband or the staff will be the result of trying to adjust, even though they may seem completely unconnected or may occur months after the move.

In some ways, coming into care is like moving to another town. There are new customs and new neighbors, new ways of having needs met and getting things done. Especially for someone who is memory impaired, finding the way around is like learning the streets in a new neighborhood. If you've ever moved, think about how many times

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you might have driven around looking for the turn into your new street or even driven right by your house.

### Changes and Differences in Behavior

You may be surprised to find that your husband is acting differently in the nursing home compared to the way he did in your own home. It may look to you like he has suddenly gone downhill and his confusion has increased. In fact, what you may be seeing is the real extent of his memory loss without the cues in your house that helped him hide it. The change could also be an increase in confusion due to the new situation, or it could be a fear reaction.

Unfortunately, depending on the home he is going into, your husband can go into a decline because the care is not very good, because he is being overmedicated or mismedicated, or because his needs are not being attended to. In a home that you don't know (say, for instance, it has been a fast or unsought transfer from the hospital) or one in which you do not have confidence, you will have to be there often to monitor what is going on and try to figure out why it is happening. If the care and caring are not good, you will not be able to depend on the staff to rectify the problem or help you figure out what it is.

It is possible that after a while, your husband's functioning will return to normal or improve. He may even start walking better, communicating more, or doing more on his own than he did at home. People sometimes pick up when their personal attendant (you) is not around. If it is a parent who has moved into a home after living alone, he may improve because he is receiving adequate nutrition, proper medication, social stimulation, or effective therapies.

Your husband may adjust easily or, for several reasons, he may go into a depression. Causes can include feeling abandoned, acknowledging the reality of his condition, and reaction to all of his other losses. The crisis of the move can activate a preexisting low-level depression. Even though this is a normal reaction to change, it still can be very painful for you to watch and may cause you additional feelings of grief and guilt. It may make you think you have made the wrong decision.

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It is very difficult to be a family member of someone who is depressed. It can make you feel particularly helpless or angry. Your response may be to try to cheer your husband up. The problem with that approach alone is that, to a point, it denies what he is going through. Keep open communication and talk about what he is feeling. Tell him what you are feeling. Remind him and yourself that it will get better. After you have acknowledged and talked, then you might want to find things to do or talk about that distract him. Come back to the subject when you feel or he feels it would help to talk.

Your husband may adjust to the move to a care facility by withdrawing. This looks like depression, but it isn't. It is simply his way of coping with an onslaught of new people, routines, and so on. He will probably gradually come out of it, sometimes starting in a week, sometimes starting in a couple of months. If after several months of withdrawal your husband has not started to come out a bit, and if he was a gregarious person previous to admission, then it is time to consider whether he has become depressed or something else is occurring.

If your husband withdraws, he may withdraw from you too. You may have a tendency to try to draw him out because the withdrawal leaves you feeling abandoned or rejected. That may even be how he wants you to feel, because that is how he is feeling. You can try to draw him out, but at the same time try to respect his way of coping by allowing him the emotional space to withdraw. If you feel your own anger rising, talk to the social worker or another staff member, a support group, or a family member.

At some point you may want to try to tell your husband to "snap out of it" or "stop feeling sorry for yourself." Sometimes this can be therapeutic. Just be careful about how and when you do it.

Your husband may go through a period of agitation on admission. This is especially true of people with some kind of dementia who do not have the skills to deal with a change in environment. They do not understand what is happening and they may not believe you when you tell them why it is happening. They may not like where they are and feel imprisoned. Often they are not able to express what it is they are feeling directly—the agitation is that feeling.

Sometimes a resident's agitation, anger, complaining, or aggression is part of the grief reaction and fear. Talk about the feelings that you

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suspect may be under the behavior, not about the behavior itself. If he is unable or unwilling to express the underlying feelings, you may want to respond by trying to change the subject, or even not responding. When he sees that his behavior is not eliciting a response from you, it may change. He may also talk more to someone else, such as the social worker, than to you.

Usually, someone who has become agitated due to the move will settle down. It may take some investigation to see how his environment can be adjusted. You may have to figure out if there is anything in particular to which he is reacting. This is where you need to work with the staff, because you know your husband much better than they do. You may even have to take some leadership in requesting that they do all the investigation possible.

If your husband is a younger man, his anger may be greater and more intense than that of an older person. It also may take him a lot longer to deal with his admission. Not only will he be dealing with the loss and grief, but also he is probably surrounded by people much older than he who have lived their lives much more completely. It will emphasize to him his situation, the unfairness, and what he hasn't had and most likely never will.

In turn, your guilt, anger, and distress may also be greater. As unfair as it is to him, it is also unfair to you. Even though you don't mean to, you may notice yourself directing your anger toward him, and not the situation. This is clearly a case in which a competent therapist would be helpful for you and for him. At some point, he and you both will learn to turn the anger where it should go and then move to come to terms with it.

A decline in functioning, changes in behavior, depressed mood, or withdrawal can be much more intense and take longer for someone who has come directly from the hospital or who enters the home in an emergency than for someone who has been adequately prepared. It can be a shock and a crisis. The feeling of loss of control is exaggerated. This is not to say that adjustment doesn't happen in this situation. It does. But the person is more fragile, both emotionally and physically.

Whether your husband exhibits depression or agitation, the staff may suggest some kind of medication to help with the transition. A

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word of caution. Medication is not necessarily a bad course of action if it helps the staff provide care. If they absolutely cannot get him changed or bathed or dressed or to sleep, then medication may be a win-win situation. Medication can also help your husband settle down if he is overwhelmed by fear, agitation, and panic. People suffer with those feelings. I have seen medication make a world of positive difference for a resident; what might have been cruel was *not* to use it.

There can be a thin line between using medication to help someone settle in and using it as a form of restraint. Keep your eyes open. Make sure you understand what the side effects of the medication are. Watch to make sure that your husband doesn't become overly tired or at risk for falls. Make sure that all options have been tried and all potential causes of the agitation have been investigated. For instance, if he is struggling when they try to help him change for bed, maybe he can just sleep in his clothes and change in the morning.

If medication is used, make sure that it is reviewed regularly so that it can be stopped when he doesn't need it any more. Find out for whose benefit the medication is being prescribed. Is it to help your husband or is it to make it easier for the staff, or both? (For more on this, see the "Medications" section and the "Restraints" section in Chapter 12.)

A resident's adjustment may seem different to family than it does to the staff. Often a resident *will* talk and behave differently with his family from the way he does with the staff. It is not uncommon for a resident to complain bitterly to her daughter but never open her mouth to the staff. Your husband may eat only if you feed him, or he may not be able to move without his wheelchair when you are there. Yet when you are not around he may be feeding himself and walking independently with a walker.

Your husband may complain to you but be reluctant to complain to the staff because he does not want to be a "troublemaker." He may be concerned about maintaining an image of "a nice person" and will not want the staff to think ill of him. He may be afraid of retaliation. It is hard to complain when you are feeling vulnerable and the people you wish to complain about are the ones who are taking care of you. Also, many elderly people are not used to being advocates for them-



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selves in the medical system. If your husband thinks medical personnel are the authorities, he will question, ask for, and complain less.

The reason for the differences between what you hear from your husband and what the staff sees can sometimes be found in your relationship. If he lets you know that he is unhappy with the situation, that is a way of retaliating for being abandoned by you. It may be a sort of angry gesture. Sometimes complaining can be a way of keeping you as his champion and involved in your relationship—if you are not there, something is going to happen to him; if you worry about him, you will be around more. All of these can be unconscious processes and not something that he is willfully planning. This is also not to say that his unhappiness or problems are not real. They are, but you need to look at some of the dynamics that occur between the two of you and their meaning as they relate to the three-way relationship (your husband, you, and the nursing home) in which you now find yourself.

You may have to stop responding to some of your husband's complaints. This can be very difficult, as it will feel like you are further abandoning him. Explain what you are doing by saying something like, "Honey, I know you are a little frightened and don't like being here, but you need to get used to it and I need to help you. So when I come to visit or when we talk on the phone, I want to hear the good things that are going on. I don't want to hear complaints from you unless they are very serious. I want you to try to solve them yourself by talking with. . . ." Then set up a system with the social worker or another staff member who will check in frequently with your husband. When he sees that the complaints are no longer eliciting from you the effect that he wishes, he may start to acclimate to the new situation. If you do this, you first need to be absolutely sure that there is no abuse or neglect occurring and that you have thoroughly investigated his complaints. If you are not satisfied, keep checking, digging, and monitoring. Agitation or withdrawal can also indicate abuse.

The second hardest experience you will have in the process of having your husband settle into care may be when you want to leave and he wants to go with you or doesn't understand why he is being left there. This can be heartbreaking. Until he gets used to it, he may repeatedly feel abandoned and angry. For you to continually go through

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this can be like picking a scab. I talk about how to handle this under "Visiting." Here, I want to emphasize that it will get better. Also, be aware that it is very possible that fifteen minutes after you have left, he may have forgotten that you were there, what he is upset about, or even that he is upset. Unfortunately, you are not around to see that part. The staff can tell you what he is like after you leave and how long it takes him to settle down.

One of the most troubling things that can happen is that your husband will call you constantly to tell you that he wants to go home. You can talk to him, he will forget that you have done so, and he will call you again in five minutes. Usually that stops after a while, but it can lead your guilt machine to kick on at high speed: you were right—you were a terrible person to do this to him. You may have to get some kind of call monitoring device, a specialized answering machine, or even a second line. You might want to put another message on your service temporarily, saying something like, "If this is Jack, I love you and am thinking about you. I will call you as soon as I can." You may have to stop answering the phone or turn off the ringer for a while. You can also get him a portable tape player and make a tape with a message that you will be visiting again soon or whatever you feel would be helpful. I recently heard of some people making videos of themselves and their families to leave at the home, which the staff would play after they left.

Keep reminding yourself that your husband is adjusting. That can be very difficult to do when he is calling, complaining, depressed, and agitated. The emotions that keep you involved are the same ones that make it difficult for you to step back and view the whole picture analytically. One way to help maintain this perspective is to make an adjustment calendar. To do this, take at least twelve sheets of paper and mark them Week 1, Week 2, Week 3, etc. When he enters the home, jot down during each week what he and you have been going through—complaints, emotions, and so on. At the end of each week, write up a short summary. Just the fact that it is a time-limited calendar will help to tell you this is a temporary situation. Most people are quite surprised at the end of twelve weeks to see what they have been through and how the process has been resolving. If things are not resolving, the calendar is data you may need later.

## Dementia and Behavior

It is not my intention or ability to educate you in geriatric medicine or psychiatry. However, there are a few essential things that anyone who is a caregiver for an older person needs to know about aging, dementia, and memory loss. I have said some of them above, but they bear repeating.

First, remember that “old age” is a description, not a diagnosis. If someone tells you that a change in your husband is due to old age, that is not acceptable. Dig deeper. Ask for a more precise reason. If no one can tell you, then ask what they need to do to find out. This is one of the reasons that you want a physician who has a knowledge and interest in geriatric medicine. She will go the distance for you. To find out why a change has occurred or is occurring may take some invasive procedures that you or your husband do not wish. It also may be that even if you find out what is happening, there may not be anything you can or wish to do about it (for example, chemotherapy for cancer). But that should be your choice, made with appropriate information.

Dementia is a syndrome (a cluster of symptoms) that is chronic, usually not reversible, and progressive. It is characterized by memory loss, personality changes, behavioral symptoms, and/or other cognitive changes. It affects about 5 percent of people over 65 and 20 percent of people over 80.

There are several kinds of dementia. Alzheimer disease is one kind of dementia and appears to be the major cause. So if the doctor tells you that your husband has Alzheimer disease, she is also telling you that he has dementia. But if she tells you that your husband has dementia, it doesn't necessarily mean that he has Alzheimer disease. As of this writing, it is difficult to make a definitive diagnosis as to whether someone has Alzheimer disease or another kind of dementia.

Strokes also cause dementia. This type of dementia is often called vascular dementia or multi-infarct dementia. It can occur from major strokes or it can be caused by many small, sometimes imperceptible strokes called transient ischemic attacks (TIAs).

Dementia can also be caused by Parkinson disease, Pick disease, chronic alcohol abuse, and many other diseases. As of this point there

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is no cure for most dementia, but there are a couple of medications that can sometimes slow its progression. A few causes of dementia are reversible. These include vitamin deficiencies and infections.

Often what looks like dementia is something called delirium. Delirium is a syndrome characterized by a sudden or fast onset, with fluctuating levels of alertness and impairment. *Delirium is usually reversible.* That means that the confusion and behavioral changes will be resolved when the underlying cause is treated. Delirium has symptoms such as memory loss and confusion. There are also behavioral symptoms, including falls, restlessness, agitation, listlessness, and aggressive behavior.

Some of the causes of delirium include

1. Urinary tract infection, or UTI (this is extremely common and recurs often in elderly persons)
2. Pneumonia and other chest infection
3. Electrolyte, thyroid, or potassium imbalance
4. Medication overdose and medication reactions
5. Chronic pain
6. Bowel impaction/constipation
7. Sleep deprivation or sleep disorder
8. Malnutrition and dehydration.

Dementia-like symptoms can also be caused by depression. It is estimated that 25 percent of the population in a nursing home has some level of depression. Delusions can also cause dementia-like behaviors. Delusions are a set of false beliefs based on an incorrect perception of reality. They are maintained despite all evidence to the contrary. You cannot talk someone out of delusions. Delusions can be a symptom of delirium or can be seen on their own. Depression and delusion are usually reversible and treatable.

Reduced hearing and eyesight can contribute to an older person's behavioral presentation. He may withdraw because of an inability to interact. He may try to mask the losses and end up answering questions or interacting in a way that seems to indicate that he has not understood. Once someone withdraws because he is unable to participate in the world, he can become isolated, which can lead to depression.

If your husband begins to exhibit any of the signs of dementia or

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if his behavior or condition deteriorates, it is essential that he be investigated to see if any of the above reversible conditions is occurring. Do not permit a continuing medication order that modifies behavior without investigating the causes of the behavior first. You do not know if something can be done until the tests have been completed. All of the causes of delirium can be tested for fairly simply with minimal discomfort. A physician and staff who are knowledgeable about geriatrics and who care enough to pay attention will automatically screen for reversible causes of problems before they prescribe or use medications.

Having given this warning, I want to emphasize that many of the causes of dementia are not reversible. You need to be willing to accept that. If your husband has Parkinson or Alzheimer disease, he will continue to decline. These are progressive diseases. People die from complications that arise from them. Many, many family members end up in denial because it is so painful to acknowledge this. But the pain and pressure of denial weigh more heavily in the end than the process of acceptance.

For more information on diagnosis of cognitive impairments, see the Web site of the International Psychogeriatric Association ([www.ipa-online.org](http://www.ipa-online.org)). Click on the AD diagnosis section.

## On Staying Healthy

There are three elements to maintaining good health in old age. These are good nutrition (including fluid intake), exercise, and social interaction. They are essential for all of us, but with elderly persons, deficits in any of these areas can mean a much shorter route to ill health or even death. Whether your husband is at home or in a nursing home, pay attention to all three.

Malnutrition and dehydration are common in elderly persons. Similar to many single persons living on their own, they do not eat as well. Women who used to cook for a husband or family may just “pick” at making food. A man on his own may not ever have cooked for himself regularly so he lets himself eat poorly. A medication can make food taste bad or funny. Elderly people often have reduced sensations of smell and taste, so food tastes bland. When food tastes

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bland or funny, people tend not to eat as much or as well. People with dementia may forget to eat even if a meal is placed in front of them, or they may forget how to eat. Older people may not take fluids for the same reasons that they don't eat well. Plus, if someone has problems with incontinence, especially nighttime incontinence, he may reduce fluid intake so he doesn't have an accident.

Both malnourishment and dehydration occur in nursing home residents. This can happen because a resident is not getting sufficient help with eating, he does not have enough time to eat, he has developed swallowing disorders, or for the same reasons that he may not eat or drink at home. It may be necessary to closely monitor intake. Do not assume that the nursing home staff is doing this, even though it is their job.

Exercise is one of the most important parts of care for elderly persons. Older people lose muscle mass and strength relatively quickly when they are inactive for even a short period of time. Activity has all kinds of physical benefit for elderly persons (as it does for the rest of us). It has a positive impact on bowel function, heart and blood pressure, and diabetes. With increased physical ability, people feel better about themselves. When they maintain their physical abilities, they maintain their independence and social life. If someone cannot get around, the ability to interact with others can be impaired.

Social interaction decreases for many people as they age. As they lose a spouse, their friends, and the ability to drive, their worlds shrink. They can become shut-ins. A couple of years ago, I was hired by a nursing home to do a study of people on the home's waiting list. Issues concerning social interaction were one of the major reasons for which people were going into care.

Social interaction is nourishing for most people, although not all. I am convinced that many of the behaviors that we see in nursing home residents are the result of loneliness, isolation, and despair.

Social interaction is not assured in a nursing home simply because there are activities. Your husband may not wish to make new friends, or there may not be appropriate activities. He may not have the competence to develop relationships. He may not want to come out of his room, even if the staff encourages him. If he is not independently mobile, he will have to depend on staff to be taken to activities or to be

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somewhere that encourages interaction. You cannot assume that he will even be gotten up and out of bed, never mind be brought to activities or helped to relate to others.

Be aware that social interaction means relationships, not activities. Relationships give people their sense of self and satisfy the need for intimacy. Relationships can develop and be nurtured through activities, but people can go to the home's activities without being involved in relationships. Relationships also develop outside activities in homes. For instance, people come to know their table-mates in the dining room and other residents in their rooms or hallways.

### Your Emotional Adjustment

Your first impression of the home may be that a bunch of old people are sitting around in a sea of wheelchairs. This can be very upsetting. That will change. Over time, you will begin to know the people and become friendly with them and their families. You also may react with a feeling of "My husband is not as bad as they are." This may be true, but it also may be that you know him and he is at his best with you. You don't see him as "an old person sitting around in a wheelchair" because you see the person he is. Other people are saying the same thing about their husbands.

When you come back to visit the first few times, you may be overwhelmed to see your husband sitting in a wheelchair like the other residents or wandering with a blank look on his face. You may experience him differently from how you did when he was in your home. You may have a feeling that this is a different person. This may be more of the feeling you have already had: "My husband is gone." In a sense, it is true; he is not the person who was able to talk to you the way he did or to function the way he used to. That doesn't mean that you are not important to him anymore or that he needs you any less. What's changed is the give and take. It is you who are doing the giving for the most part. Remind yourself that you are experiencing grief, and that it will get easier.

A family member's adjustment often parallels the path of the one who is in care. Partly that comes about because you will not feel comfortable until you have the sense that your husband is feeling com-

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fortable and that he is getting adequate care. So, your initial adjustment may also take three to six months.

Your husband may adjust better than you do in the beginning. Many people have told me that after the initial move occurred, their relative did fine—they were the ones who went through the crisis. People who were afraid to say anything to their spouse about the move to a home found that he accepted it very well. I know some family members who called the home every evening, after having been to visit every day. Their husband was fine; they were the ones who couldn't sleep.

### The Gap in Your Life

Even if the move to a nursing home is a relief and you are confident that you have made the right decision, it is still a major lifestyle change for you and everyone else who has been involved in the caregiving process. You will have to adjust not only to the home and to the change in your relationship but also to having a different life on your own in which you are not primarily a caregiver.

Many caregivers have given up part of their lives as they became more and more involved in caregiving. Sometimes they stopped going to a bridge club or bowling league, sometimes they let go of friendships. When your husband goes into care, you may suddenly realize how much you have given up and who is no longer around because you have let them slip out of your life.

Now there is a big gap in your daily life. You are no longer wondering “what is he doing?” when you are not around. You are no longer organizing medications, toileting, and monitoring for the majority of your day. Whether or not you feel relieved, you may also feel a loss. This can lead you to feel envious and be critical of the people who are doing the tasks you used to do.

You may also feel in some ways *at a loss*—what to do with your time and your thoughts and your energy. It will feel strange at first, like something is missing. To fill this gap, you may have a tendency to grasp onto visiting or becoming very involved in the home.

A couple of years ago, I admitted a ninety-three-year-old woman to a facility. Her son and daughter-in-law had been caring for her in their



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home for ten years. They had renovated the home and had arranged their lives around taking care of this severely and increasingly demented woman. When they had finally exhausted their resources and those of the system, they admitted her to care. The daughter-in-law had been the primary caregiver—she had become an expert in Alzheimer disease, medications, heart disease, local support systems, etc. When the woman was admitted, her daughter-in-law had a terrible time. She continually called asking about problems, medications, and so on. She told us that she wanted to ensure that her mother-in-law got the best care possible. But underneath that was an inability to let go. She had been on the caregiving train so long that she didn't know how to get off. She had an important role on which she could focus a lot of her energy. At some level, she was also getting what is called secondary gain—a lot of attention and admiration from people in her church and community because she was such a selfless, giving daughter-in-law. On admission, she lost that. Caregiving also diverted her attention from an unsatisfactory marriage. It wasn't until she was able to look at some of these underlying issues directly and honestly that she was able to shift her caregiving role.

Begin to think about how you want to fill the gap. Slowly start to plan things that are healthy, enjoyable, and functional for you. Make a schedule for yourself and put into it some activities you want to pursue or people you want to see even if at first it is only one activity or person per week. When you are feeling stronger, take a piece of paper and write down some goals for a year from now. Write down how to reach those goals.

Then start to do what you wrote, even though you may not feel like it at first. Activities can lift your feelings or change your emotional state. Once you are doing them, you will be glad you did. At first it may be hard for you to believe that you can feel better. It is like setting sail for another continent—you have to believe that it is there even though you can't see it and you have to get there before you can feel it. Activities and people will help contain your feelings and distract you from them. They will help you balance and regain your life.

There are a number of books written about loss, though there are fewer about the actual process of moving on. You might want to look through *How to Survive the Loss of a Love*, by Melba Colgrove, Harold

Bloomfield, and Peter McWilliams, or *To Begin Again: The Journey toward Comfort, Strength, and Faith in Difficult Times*, by Naomi Levy.

### Phases of Adjustment

It may be helpful to think of your adjustment as happening in phases. The first phase is the crisis. It occurs from the time when your husband is offered a bed through about the first week. This is when you first encounter the new system and experience the change. It is the time of highest stress and when your emotions are running high. During this period, you may feel abandoned, angry, and helpless. You may feel alone in having to deal with the institution. You may want to ask some questions and may not know where to turn. This is the time when your support needs can be highest, but you will be focusing your attention on your husband.

The second phase comes in about the second to fourth week. By then the initial crisis is over, and you begin to figure out some of the more practical things, such as to whom to talk, what times something happens, or where to find something. It is when you are doing your initial problem solving. You may begin to feel like you are able to come up for air. At the same time, you may feel that one day everything is fine and the next day nothing is right. Expect that this is a time of ups and downs for both you and your husband. This is also the time when you may begin to feel very sharply your own loss and separation. As the initial crisis settles, you realize what “this” is going to feel like.

During the second phase you begin to establish relationships with the staff. You both are figuring out what the others are about. It is also when the staff begins to get a feel for what your needs are and how to help you. Look for the people you feel could be helpful to you.

Establishing relationships with the staff and the home is the development of trust. Developing trust takes time and in some ways you will need proof that your trust is justified. This happens through a series of small events and interactions over the initial period. It would not be normal for you to have that trust from the first day.

After having been a caregiver for so long, it will be hard to let someone else take over. Partly this relates back to guilt, and partly it relates

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to the grief process. But partly it is fear—fear that no one can take care of your husband the way you have, fear of what is going to happen if you are not around to take care of him. If this comes up for you, ask yourself what you are afraid of. Write it down and then look at each item you have written. Ask yourself if the fear is realistic or not. If it is, talk to the nurse or social worker about your concern.

The care your husband receives in a nursing home *will not* be the same as the care you gave him. But that doesn't mean he will not receive good care. There are very often glitches in the first few weeks, but even that does not mean that the care will not be good or that you have done the wrong thing. It means that the system is learning and routines are not established yet. In fact, it may turn out that his needs might be met better in the home.

The third phase goes from about the second to the fourth, fifth, or even sixth month. It is when you start to figure out some of the subtle but important details about the home and the care, such as what to do when your husband has an outside appointment, when the podiatrist comes, and how the whole system really functions. During this phase, you are really learning what your role as a family member is. You learn what your expectations are, and what others expect of you. You learn what the home really does, as opposed to what they say they do.

In the third phase of adjustment, your trust in the staff should grow as you see that they are competent. This will happen as you see your husband settle. That is why your adjustment parallels his. If you do not ever feel that you can trust the staff or the home and it is honestly because of the quality of care, then it is time to move your husband or become an active partner in a process of change. (See Chapters 12, 13, and 16.)

Although the beginning of this phase may be marked by the continuing pain of your loss and separation, it is often during this period when you may begin to let go. You start to face living without your husband and without caregiving as the central role in your life.

The final stage is when you and your husband have developed a routine for living. You have a routine for visiting. You have at least begun to reestablish your life outside, with some new habits and daily patterns.

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The fourth stage does not mean that you're smoking a cigar with your feet up on the desk. It means that you have surfaced with a feeling of equilibrium in your life. You may still feel some guilt and depression. You may still feel some emptiness or anger.

To help you through your adjustment, you might want to see if there is a family member of another resident who has been in the home for a while who can act as a "buddy" or mentor for you. Or try to get to know some of the other relatives who are visiting at the same time you are. These people can become a type of informal support system. They know how the home really works and have learned to get things done. They know what you are going through. I have always found that family members are very willing to help other family members.

You should also go to the family council or the family information nights. There may also be a family support group, often run by the social worker. These can give you an opportunity and a forum to figure out the system. So even if you feel you do not need the emotional support, you may benefit from the practical information that these meetings provide.

## Acceptance

Some people have told me that, in fact, they never fully come to peace with having their relative in a nursing home. They always have a feeling of sadness when they walk out the door. What they have been able to do is accept it. They say that the feelings of guilt and loss become manageable and they have been able somehow to move on. They have to keep on working at letting go and accepting their feelings in order to come to whatever stage of adjustment they are able to manage.

You may have to work at acceptance. You can do this in the same ways you worked at the resolution of guilt. Talk with your husband about what the two of you are experiencing. Write down your feelings in a diary. Write letters to your husband about what you feel and are going through. Post a note on your mirror that tells you what you need to hear.

The staff in a nursing home understand what you are going through as you adjust. They may not understand it the way someone

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who has been there would understand it, but they do know. In a good home you can talk about it with the social worker or one of the nurses. It is their job to take care of you also.

If the care and home are acceptable or better, then what you must learn to do in that first year is to come to emotional terms with the situation as it is. Know that it may change or may be changing. Know that there will be ups and downs. Take and give what you can, and let go of your expectations. In some ways, this is an attitude of "one day at a time." Acknowledge your anger and your grief and acknowledge how and where they are coming out. Try not to be ashamed of your feelings or to hide them. Let them be a signal to you that you need to work on and take care of yourself.

## New Relationships

There may come a point after your husband has been in the home for a while when you have made a new life for yourself in the community. For some people, this means developing romantic and intimate relationships. Especially for people whose spouse has dementia, this becomes a possibility because you have truly lost not only physical intimacy but also emotional intimacy. Becoming romantically involved with someone else can bring up tremendous conflict and guilt. It goes against your marital vows. Your children may be extremely upset. You may feel your community is judging you.

A new relationship does not mean that you are abandoning your husband or that you love him any less. It means that you have adjusted in a way that is right for you. You are the only one who can decide what is right for you. It is not uncommon. Let me tell you that many people who have walked in your shoes will not judge you.

## *Bill*

We came together in midlife from vastly different worlds. "Soulmates at last," we said. Our joy was indescribable.

We lived the good life for a few years, my Bill and I. We had each devoted a great deal of time and energy to our respective careers, and it had paid off well. We enjoyed meaningful work and an enviable lifestyle with exotic travel, interesting social events, and, most of all, each other. We had waited a long time for this and thought we deserved all we had.

But our dream was cruelly interrupted a few short years later. Slowly but surely, this proud man of dignity and intelligence was thrown into the neverland of dementia and disability, and I became his caregiver.

I began to pray and bargain with the cruel God, who, I decided, was responsible for this devastating turn of events. I begged for a nice predictable stroke, something that people don't survive. I forced my confused husband to visit every quack up and down the coast, drink unpalatable potions, and swallow pills that made him choke.

Although I kept a journal for most of the four years of my husband's illness, there is a painful void in the record once placement had become imminent. My last entry for almost a year was: "This all seems so hopeless, I can only watch him deteriorate further, but I want him with me anyway. My intellect tells me I am deranged for wanting to continue living this way, but it seems to be the only thing that has any meaning."

Etched in my conscious forever is the dark, rainy day I sat sobbing in the parking lot after viewing the chosen facility. In hindsight, I can see that this was the point of acceptance: acceptance that I could no longer cope and that I had to release my love to the care of others and to a simpler world.

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It was so painful to know I would be placing Bill in care. I felt bound by promises: ones I had made to him and to myself, and ones he had made to me. It made me wonder about who I was, about how I had formed and shaped my life to this point. I felt I was being untrue to our relationship and to the things we had built together. When I made the decision to put Bill into care, I was filled with feelings of guilt, loss, failure, and self-doubt. I thought that maybe I was not loving enough, that I was being cruel and heartless. I was sure that there was a way to avoid doing this if only I kept searching and trying.

The day Bill was admitted to the nursing home was both the worst and the best day of my life. It wrenched me away from the destructive path we were on and signified the end of my life as it was. Despite all my feelings, or maybe among them, I knew it was also a relief to turn him over to people who were trained and equipped to care for him. Although Bill couldn't speak, I think he was able to cope better in this new world of routine and simplicity.

Several months later, when I was offered a job, I wrote in my journal, "My love, I am leaving you behind, and that makes me so sad." Then a few passages later I wrote, "I can't handle it. What used to be most important to me is now insignificant. Bill, I am lost in the same neverland as you are."

Eventually when Bill's physical condition began to deteriorate, I decided I wanted him to die at home. Because he was not able to get up and down stairs, I began the process of modifying our two-story home to accommodate him on the main floor. When my plan became known at the nursing home, the head nurse cautioned me about the time and energy it would take, and what that would take away from Bill. She pointed out that I would be too exhausted to give him the same attention I now could when the staff was bathing him, preparing his special food, changing and dressing him, toileting him, etc. I hated her for her honesty, but I was thankful someone had helped me see the folly of what I was trying to do.

Now as time has softened my wounds, I can see that placement is sometimes a predictable and practical step as we near the end of life. Current lifestyles do not accommodate home care in the way that they did in my mother's generation. I know that although medical advances have extended life, people are older and sicker than they were then too.

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During the years Bill spent in the facility, I had a ringside seat from which to observe others and myself. I heard people complain about the most trivial oversights as though they were life threatening. I saw healthy seniors spend their remaining years focusing on a relative who no longer knew them. I noted the ones who dealt with their loss by staying away. I came to understand that if I let caregiving become the focus of my attention, then giving it up and moving on would be extremely difficult.

For me, letting go was a gradual process. Eventually, Bill's placement provided me with the space to grow and move back into the mainstream of life. What I perceived as the worst day of my life was actually the first day of moving toward a new and interesting segment—one of appreciation and thankfulness for the experiences I had, and of greater understanding about the passages I would have to go through in life.





PART IV

BEING THE FAMILY  
MEMBER OF  
SOMEONE IN CARE



## CHAPTER 12

# Care and Care Planning

### Basic Standards of Care

Care should be about enabling and allowing people to have their individuality, dignity, and respect. I think there are certain basic standards and rights that should never be violated. When I started out as a geriatric care manager I wrote the following list as a response to how I saw elderly people being treated, and allowing themselves to be treated, as they went through the health care system. I would like to see people use this list of rights as a guide to obtain adequate care from their health professionals, whether or not they are in care. If any of these standards are violated as you work with the health care system and health care providers, it is a signal to demand a change.

1. You have a right to be valued as an individual.
2. You have a right to a physician who is knowledgeable about geriatric medicine.
3. You have a right to a diagnosis for a problem.
4. You have a right to information about your treatments and medications.
5. You have a right to be spoken to, not about.
6. You have a right to be treated as an adult, not a child.
7. You have a right to live at risk if you have the capacity to make that decision.
8. You have a right to be consulted about decisions that affect you in any way and to make decisions about yourself for as long as you are able and competent to do so.

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9. You have a right to determine who will make decisions for you and in what situations when you are unable to do so.
10. You have a right to make advance directives and have them carried out.
11. You have a right to say when you have had enough.
12. You are responsible to make sure your rights are respected and to use your rights appropriately.

### How Care Is Organized

Usually, the provision of care is organized around what is called a care plan. A care plan is a document that identifies an individual resident's problems and strengths. For each problem a resident has, the staff will identify a goal or objective. The care plan then lists the actions to be taken to achieve those goals.

The basic components of a care plan identify a resident's level of independence in the areas of eating, dressing, washing, grooming, bathing, walking, and transferring (the ability to stand up, go from the toilet to a wheelchair, etc.). These are known as activities of daily living (ADL). The staff will determine through observation and, one would hope, through talking to you and your mother how much help your mother needs. Abilities such as dressing are categorized as, for example, "independent," "needs partial assist," or "needs total assist." With walking or transferring, the care plan will identify whether your mother uses a walker, wheelchair, and so on. If she needs help to transfer, it will say if she needs one or two people to help. Sometimes a chart will be posted in your mother's room identifying what kind of help she needs. It is almost always kept at the nursing station as well.

A care plan also addresses more complicated needs, such as medical, social, nutritional, recreational, psychological, and spiritual needs. This is the part where special diets (such as diabetic, low salt, etc.) will be identified. The plan may note skin integrity, tendency toward depression, and behavioral issues. It may also identify family needs or issues such as caregiver stress or if there are conflicts in the family that could affect the resident's care or decision making.

The goals describe an optimal level of desired functioning and list the actions to be taken to attain those goals. These are based on a re-

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alistic view of what is possible for each resident. For persons with diabetes, a goal may be simply to maintain appropriate blood sugar levels; the actions would be appropriate diet and exercise. For depression, the goal may be that your mother express contentment. There may be several suggested courses of action, such as a mental health assessment, medication, appropriate activities, pet therapy, and bus outings. For walking the goal may be that she is able to walk fifteen feet safely with her walker. Courses of action may include physical therapy and new shoes.

In nursing homes with Medicaid-funded beds, an initial assessment must be done within fourteen days of admission. A care plan must be developed by seven days after that. The facility must use what is called the Minimum Data Set and a Resident Assessment Protocol. These are fairly complicated instruments that create a problem-solving path for the staff as they examine all areas of a resident's functioning. If used well, these instruments are an excellent guide for the provision of good care and for problem solving when something is amiss.

The care plan is one of the areas in which the social history that you wrote will be important. It tells the staff what your mother was like before all this started, so they have a basis for determining what success will look like and what is normal for her. For example, if she was always somewhat underweight, her care plan would probably not have as a goal that she reach her ideal body weight.

Unfortunately, sometimes staff members do not read care plans, write down changes, read the changes that have been noted, or pay attention to them if they do read them. First of all, some staff members are illiterate. Second, a nurse's aide with fifteen people to take care of every day might not have the time to be aware of all the changes. If it is casual staff or agency staff, remembering the care plans for all those people is hard. These problems should be addressed, but remember that the setup of the system can mean communication and continuity problems among departments, staff members, and shifts.

You should try to involve yourself in the development and monitoring of your mother's care plan, and you may want a copy of it. (For more about care plans, see *Nursing Homes: Getting Good Care There*, from the National Citizens' Coalition on Nursing Home Reform.) The best way to involve yourself is through a care conference.

### Care Conferences

A care conference is the occasion during which you, your mother (if she is capable), and representatives from all disciplines meet to talk about care. Usually it is attended by a nurse, nurse's aide, recreation worker, social worker, dietitian, and other therapists employed by the home. Ideally, a physician and pharmacist will be there as well. Often a housekeeper, dietary aide, and pastor will also attend. During the conference, people from each discipline will discuss issues that they have identified and look at ways of meeting needs.

If your mother is unable to sit through a meeting or would be too threatened or confused to handle one, you can talk to her beforehand and see what her views are. Ask the social worker to do the same. Some people who are nonverbal or who have dementia can make very clear some of their needs or problems. Your mother is the “team leader” and you are the co-captain. Make sure her voice is heard.

Some family members feel intimidated in a care conference. The process is new to them, there can be many staff members there, and unfamiliar medical terms are used. Just think of the staff as people who happen to have knowledge in a specific area. You do too, in other areas. You are not stupid if you don't understand their terminology. They are rude for using terms that you might not understand without explaining them to you. Ask them to explain, speak up, slow down, and go over something again. Keep on asking until they get it. If you have a feeling about something, you can state it—your opinion is valid, and your feelings deserve to be heard.

The care conference is your chance to give and receive information. Your mother and you are the experts on your mother—you know how she has responded, what she used to be like, what was normal for her. You know her limits and the meaning of some of her behaviors. You know her psychological strengths and foibles. You have the right to ask questions about what is being done and why. You are the one who can give some insight as to how and why the goals that the staff sets can or cannot be met. You should discuss the goals and hopes you have.

You also have the responsibility in a care conference to listen with

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some respect to what the staff says. They may see the picture differently from you. They may not feel that the goals you have are realistic. They should be able to tell you why they believe what they do and present data to support it. You may not like what they have to say, but that doesn't mean that they are wrong.

You may still believe that the goals you have for your mother are realistic. I have many times seen people achieve goals of rehabilitation or improvement after a stroke that no professionals thought were possible. The people did it through willpower and perseverance. If you disagree with the staff and believe that your goals are realistic, you may have to find the evidence yourself. You also may have to work with the staff to find ways to try to achieve what you hope. There may be limitations on the staff and budget that will interfere, and you may have to accept that and find another way around it.

You may also have to look at your goals and ask yourself if you are hanging on because of the grief of seeing your mother deteriorate. If that is what you are doing, then you need to take a look at your grief, anger, and other feelings. Dealing with them by denial is not helpful to you and can be difficult for your mother. I have seen people hang on long after realistically there was no hope of improvement and long after even their parent wanted it to stop.

This is not to say that substandard care or practices are acceptable. It is saying that you must be honest with yourself as to what is going on. It is not easy to do. Letting go of some of your goals may mean accepting that your mother's condition is progressive and that she will die. This means that you will have to accept that you will lose her; that you will have to go on with your life without her.

At the end of the care conference, you should feel that you are working with the staff and your mother in a team. You should understand what the staff feels they are doing for your mother and what they need to do. You should also have confidence that they understand both you and your mother and that they know how she is experiencing her life in the home. Even if your mother is deteriorating, you still can look for a quality and comfort of life free from pain.

There should be an initial care conference about four weeks after admission and not later than eight weeks. It is good to check in with



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the staff informally before then, but it can often take four weeks for the staff to develop a clear idea of what your mother's care needs and abilities are. There should be a care conference yearly after that.

It is also a good idea to have a care conference when there is a marked change in your mother's condition, either for the better or for worse. This gives everyone the opportunity to sit down and revise plans. It also gives you a chance to talk over how you and she would like to handle this phase of her care. Maybe you would like to be more involved. Maybe you would like more aggressive tests to be undertaken, or maybe you don't want anything more to be done.

### Charts

A chart and records are kept for every resident. In the chart should be the care plan, medical history and medical examination notes, as well as results of blood work, X rays, and so on. Usually, each discipline will do an assessment, which will be written up in the chart as well. The form of the main body of the chart varies, but usually it is a historical narrative that highlights problems and actions taken by the staff. It includes discussions with the physician and will document different incidents: for example, if your mother has had a fall, if she has had some behavioral problems, if there was a particular family interaction. The doctor also writes in the chart.

Sometimes the staff will also keep records similar to flow charts that document a resident's pattern in regard to a specific problem, such as sleep, pain, or behavioral disturbance. These are particularly effective in determining what the cause or specifics of a problem may be. For instance, if your mother is agitated, the staff can look for a disturbance in her environment and see if it corresponds to a certain time of day. They can then look for clues as to what may be happening at that time. Maybe her pain medication has worn off and she needs a higher or more regular dose, or maybe she is tired or hungry.

You have the right to read your mother's chart (if *she* has given you permission). If you do so, it may be helpful to sit down with someone who can go through it with you rather than to examine it yourself. The staff may insist that they be present, but you can also ask your own physician or other consultant. If you do want to read it yourself,

don't jump to conclusions about what is said in the chart. Although charts should be written with the idea that they will be read by the family or resident, often they are not. It is easy to misinterpret what is in a chart. I heard of one family member who got very upset when reading that her husband was SOB. She thought the staff was saying he was a son of a bitch. Actually, he was short of breath.

### Medication and Care Planning

You should pay particular attention to the issue of medications. Older people react differently to medications from younger people. Their bodies do not eliminate medications as easily as a younger person's, so it is especially important that your mother be on the minimal medication possible.

It may be that medications have been gradually added to your mother's routine over a couple of years as different illnesses or conditions have arisen. All of the medications may make medical sense individually, but they may have interactive effects that can cause problems. Or they may help one problem but cause another. If they were added slowly, she may not ever have had a comprehensive medication review.

It is also possible that medications that were appropriately prescribed and taken have built up in your mother's system. This can happen slowly, and when it begins to have some adverse effects the medications might not be diagnosed as the cause because they have been stable and effective for so long. It may happen that they need to be cut back or stopped or another drug prescribed in their place. People who needed certain medications at home may not need them now. If your mother needed medication to help settle in the first month, she may not need it in the third month. A medical condition may have changed and the medication may need to be adjusted. Sometimes at home people aren't taking their medication as prescribed. When they come to a nursing home and it is dispensed properly by a nurse, the medication can start to affect them differently. Medications need to be reviewed regularly and discontinued when they are no longer needed.

You should know not only what medications your mother is on but

also how they are prescribed, especially those prescribed for behavioral concerns and for pain. Medications can be prescribed on a regular basis (for instance, twice a day, or two tablets once a day in the morning). Or they can be prescribed on a PRN (as necessary) regime. “As necessary” can mean it is up to the discretion of either the resident or the nurse. If a medication is prescribed PRN, find out how often it is in fact being given.

Sometimes medications have lifestyle effects. For instance, if your mother is on a diuretic (water pill), she will have to use the bathroom more often. If she is slow on her feet with a walker, she may be afraid that she will have an accident before she can get to the bathroom. This will cause her to stay in her room and decrease her social interaction, which can lead to depression. Or she may be on some medications that affect her sense of taste. This will have an impact on her eating, so her nutritional status can be affected. Some medications can increase the risk of falls. Some medications or combinations can cause delirium or other changes in behavior.

The above are the reasons why it is so important to have access to a good pharmacist. Drug interactions and effects are their area of expertise. A good pharmacist will be able to say whether medications and dosages are appropriate for the diagnoses. He should also be able to advise you if behavior you are seeing could be related to medications. If you suspect that medications are inappropriate and/or are having an adverse effect on your mother, try to find a good pharmacist or ask for another medical consultation. To find a pharmacist, go to your local drugstore or call the professional body in your state or province.

### Medication and Pain Control

Studies have shown that up to two-thirds of all nursing home residents are undertreated for chronic pain. There is no need for this to occur. Pain management has changed and improved greatly over the past decade.

The approach to pain control today is to give medication so that the pain does not “break through,” as opposed to giving it only when the pain becomes too great. When a medication has been prescribed

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for pain PRN (as needed), the result may be that your mother is not getting it often enough, especially if she has dementia and is unable to tell someone when she is having pain. One result can be behavioral disturbance: she will “act out” her pain.

Many residents don’t want to bother the nurse or believe that they should be able to stand a little bit of pain. They will ask for something only when it becomes unbearable. By then it is harder to control. Also, if a nurse is busy she may not be able to respond to a request for medication. If it is prescribed on a regular basis, there is a greater likelihood your mother will receive what she needs when she needs it. If your mother is reluctant to ask for pain medication or tell the nurse when she is experiencing discomfort, you might want to ask the doctor to prescribe it regularly throughout the day. If she is reluctant to take it that way, it should be her decision, but perhaps she would be willing to try it for a month and then reevaluate.

Different types of pain medication are administered in different ways. For example, some are delivered gradually by wearing a patch. If one kind of pain medication isn’t working, find out what options are available. You may have to do your own research and suggest something.

A word of caution: most medications have some side effects on some persons. Don’t read a physician’s desk guide to medications, have a panic attack when you read about all the potential side effects, then insist that all your mother’s medications be stopped. The point is to be aware of the potential for problems and to be able to discern if a condition or a change in condition is caused by medication.

## Restraints

I remember walking into the nursing home where my grandmother was living in about 1972, before people understood Alzheimer disease or dementia care. When I walked into the lounge the people were lined up in rows as though they were at a theater performance. They were sitting quietly, staring straight ahead. Some were slumped over the side of their chairs or wheelchairs. My grandmother was in the front row, secured to her chair by a restraint that immobilized her whole upper body. This was how they stopped her from running out

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of the home into the street. When she saw me, her face shattered like a mirror and she started to cry.

Restraints are still in use today. A restraint can be chemical—medication that alters a person's personality or mood, or slows her down to the point where she is immobile. Physical restraints restrict someone's mobility or movement; for example, she may be tied into a wheelchair or confined to bed through bed rails.

The reason a home usually gives for restraining a resident is that it is for the resident's own protection or to protect the other residents or staff. Research shows that restraints do not generally prevent injuries such as falls; in fact, they may increase the likelihood of injury. Restraints end up being used sometimes because there has been an inadequate problem-solving process. It takes time and effort to figure out why some behaviors are occurring. Once figured out, it can take considerable staff time to meet the needs that cause the behavior.

Ideally the staff will go through the steps necessary to understand and intervene in a problem. Don't fool yourself. The reality is that limitations on staff and resources may prevent them from doing so. The reality is that they may not have the education to figure it out. The reality is that they may see your mother every day and not recognize when her behavior is abnormal or has changed. Even if they do try to do all the problem solving, they still might not figure out what is wrong or why a behavior is occurring.

In the United States the law specifically addresses restraints under resident rights: "The right to be free from . . . any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms." The law also says when restraints may be used. Although Canada does not have a similar law, many homes have a no-restraint policy and will apply restraints only following a physician's order. Despite the laws and the policies, you still need to keep on top of this issue.

There is absolutely no excuse for basic problem solving not to be done. You may have to be the detective. If the home tells you that your mother needs some help with her behavior, you may have to step in and prepare a checklist of everything that should be tried and all the tests that need to be done. You may be able to tell the staff what

the problem is because you know your mother—you may understand what she wants, what is bothering her, or what she is missing.

It may make you uncomfortable to see your mother at risk for falls if she is trying to walk instead of using a wheelchair. You may wish for her to be restrained. But she may prefer taking that risk. If she is not mentally aware at present, you need to ask yourself what she would have done. Your mother has the right to live at risk if she chooses, or if this is something that she might have wanted. The fact that you are her caregiver does not give you the right to make decisions that go against what she would want because of your own needs or fears. If she makes a choice that leads to injury, you need to accept that it was not your fault.

The National Citizens' Coalition for Nursing Home Reform has two excellent guides that discuss restraints: "Avoiding Physical Restraint Use" and "Avoiding Drugs Used as Chemical Restraints," by Sarah Greene Burger.

### Toileting and Incontinence

Many older people have some kind of incontinence problem that leads to the wearing of pads or diapers. If you think about it, one of the first symbols we have of being "grown up" is when we are toilet trained. To lose control over bladder or bowels brings us back to being a child. It is a shame-inducing problem. It can also cause someone to limit social involvement for fear of smelling bad or having an accident.

Bladder incontinence is a complicated problem and often misunderstood, even by well-trained staff. For example, your mother may constantly feel that she has to urinate, but when she is on the toilet be unable to do so. When she asks to go to the toilet often and the nurse's aides see that she has not voided, they may think your mother is malingering or trying to be difficult. Some people also have continued dribbling. Your mother may have a bladder that doesn't empty completely, so she has to urinate frequently. The staff may think, "She couldn't possibly have to go so often; she is just wanting attention."

If your mother starts to have problems with incontinence of either bowel or bladder, pay particular attention to how the home is han-

dling this. A resident who becomes incontinent may do so because of neglect. The staff may not respond to her needs to use the bathroom and may find it is easier to put her in diapers. Incontinence can be indicative of a urinary tract infection, changes in medications, side effects of medications, or other medical problems. See if the staff or doctor can diagnose the cause of the incontinence. There is often something that can be done. This includes bladder retraining and exercises, surgery, and medications. Once again, however, to be able to use some of these solutions can take staff time and money. Often the staff does not have the training or time to be able to implement some of the behavioral solutions. Also, your mother may not be able to do the necessary exercises. (For more information on urinary incontinence, look on the Web at: [www.agenet.com/incont\\_caregiver\\_guide.html](http://www.agenet.com/incont_caregiver_guide.html).)

If there is an ongoing problem, see if your mother is on a toileting schedule and an appropriate bowel protocol. Maybe she needs to be reminded to use the bathroom more frequently. Maybe she needs more help in getting there. Sometimes confused residents simply cannot find the toilet or need more directional cues to go to it. If they are helped with this, the incontinence will clear up or decrease.

Toileting routine should include nighttime. It is generally not appropriate to have someone sleep through the night if he is wet or soiled. This leads to skin breakdown and infections. It is also a loss of dignity. Diapers or pads are not an excuse for the staff to ignore a resident who needs to be changed.

If your mother was wearing pads or diapers and managing on her own at home, make sure that she is able to manage by herself with the ones she is wearing at the home. A change of system can make it difficult for her, hence decreasing her independence as well as making her incontinent.

Be aware that the staff can be excellent about changing your mother on time and you will still come in and find her wet or soiled. Sometimes someone is put on a toilet, then fifteen minutes later she has an accident. Caregiving is not one-to-one, the way it might have been when your mother lived in your home or when she had someone with her all the time. It can be very upsetting to come in and see your mother soiled or wet, with the accompanying loss of dignity.

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Your first reaction may be, once again, guilt and then some anger and frustration with the home. Investigate the circumstances, but you must understand that there may be times when she will be soiled or wet.

### Falls

Falls happen for a number of reasons, some of which are preventable and some are not. Some of these reasons are

- malnourishment or dehydration
- osteoporosis
- arthritis
- limited vision
- general weakness
- a problem with balance or gait
- dizziness when going from sitting to standing
- medication problems
- large or small strokes (TIAs) or seizures
- illness
- improperly fitting shoes
- being pushed or abused.

If your mother is falling, find out why. This may entail the staff's keeping a record of when and how she falls, which will illustrate a pattern and may help to find a means to prevent it. It can also pinpoint it to a staff member if it is a case of individual abuse.

Have a physical therapist do an assessment, even if you have to hire one from outside. Try to find one who is knowledgeable about geriatrics. Once she assesses the problem, she may be able to develop a strategy to prevent or lessen the incidents occurring. If your mother is getting some rehabilitation or strength training to improve walking and prevent falls, make sure that strength training is included for her upper body as well.

Sometimes people just fall from weakness, because their condition is deteriorating. There is no abuse. There is nothing that can be done except take away their independence, their dignity, or both.



### Bedsore

Bedsore (pressure sores, or decubitus ulcers) occur when the skin has been rubbing against something like bedsheets or the seat of a wheelchair for too long without being able to breathe. They also occur from contact with irritating liquids, such as urine. After a while the skin turns white, then red, and eventually breaks down, opens up, and festers. The bedsore can be so deep that it goes right to the bone. Gangrene can set in, eventually leading to amputation and possibly death. Pressure sores generally should not occur. If they do, a good home with a good nursing staff will catch them early, and under most circumstances they can resolve the problem. There are creams, lotions, and medications to help prevent them and there is equipment such as special mattresses and coverings to protect the skin.

An older person's skin may be fragile and can bruise easily. Problems such as dehydration and poor nutrition can make it even more fragile. A bruise does not necessarily mean that your mother was abused or that the care is bad. If she is in bed or uses a wheelchair or is otherwise stationary for long periods of time, she is at risk unless she is turned or moved regularly. You may want to check her skin frequently. If you find that your mother's skin is bruising easily, speak to the nurse, physician, or dietitian to see if there might be measures you can take to improve it.

### Roommates

I don't know about you, but when I think of the word *roommate*, I think of summer camp, college dormitory, or maybe my first apartment. I do not think of the situation I would like to be in when I am eighty or ninety. Yet more than likely your mother will have to have a roommate at some point if she goes into a nursing home.

The good news is some people like to have a roommate. If they are immobile, if they are lonely, or if they are frightened, it can be comforting to have someone in the room with them. If it is someone with whom they get along, a real bond can develop. They can watch out for each other, or one can watch for the other. If one or the other at least has a certain level of awareness, it will cut down the opportunity

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for abuse or neglect because it is not going to happen so easily while someone else is watching. Roommates may share family visits. The other family and you may help each other monitor the care and condition of each other's relative.

The bad news is that a roommate can be horrendous. If your mother's roommate is cognitively impaired, she may go into your mother's belongings and take them, wear them, or even try to eat them. Certainly she may lose them. She may have different sleeping patterns, she may be incontinent, she may be loud. She may be deaf and turn up the television so loud that your mother can't sleep, or may demand that your mother turn off her television so that she can sleep.

Whichever of the above situations occurs, if your mother has one or more roommates, she will certainly have minimal privacy and no place for intimacy. She will have no real place to entertain you, and no place to call her own.

You may want to try to be creative in establishing some private space by the way you arrange furniture. Maybe you can bring in a nice room divider, or if there are curtains between the beds, make some nice new curtains yourself. Can you put up shelves or hang things from the ceiling (like a bead curtain)? If she can't entertain you in her room, see if there is somewhere else she can be your hostess. Is there a kitchen where she can get you or make you coffee or tea? Is there a corner where she can take you that is out of the way, so that you can sit and talk?

Find out what the policy is on switching rooms and roommates if there are problems. If there is a waiting list for a private room, make sure you understand how it is made up and how people move up it. Is it by need or by date of request or by funds available? Also find out what the home's procedure is for resolving roommate problems.

If your mother is having trouble with her roommate, make sure you hear all sides of the story and look for all the possible reasons for it. Is it to keep you involved? Is she jealous because her roommate's family visits more than you do? Is she jealous that you spend time with the roommate when you are supposed to be visiting her? As with any other problem, you must be a detective and keep your mind open.

How your mother accepts her situation is similar to so many other

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aspects of nursing home care: it is influenced by how you deal with it. If she is upset, acknowledge her feelings. Make sure, however, that you are not projecting your own feelings and upset onto her or encouraging her to feel upset because you are. Stay aware of your own feelings. Guilt can be worse for you if your mother is in a multiple-person room because it may emphasize to you how much she has lost.

In the end, your mother may accept the situation better than you do. Often, older people are very good at being stoically accepting, especially if they know that, in time, the situation can change.

## *Louise*

My mother had multi-infarct dementia, the result of frequent small strokes that affected her memory and reasoning abilities. We realized that there was something wrong when she began having memory lapses and time became a problem. During a summer vacation we went on a boat trip one morning, returned to our cabin for lunch, and then set off in the other direction down the lake in the afternoon. Mum remarked that we had gone the other way yesterday. She didn't remember it had been just that morning. We said nothing to Mum but at least, with some humor, we saw the positive when Dad remarked that Mum would have a longer holiday than the rest of us.

We knew we could not change her perception of time. We could easily adapt and, of course, we hoped that this was all that Mum would confuse. It was not. It soon became apparent that she was unable to remember things that had taken place just a few minutes or hours before. When we traveled, she forgot where she was all the time. At the end of a trip, Mum would have no recall of it. However, she loved all kinds of things in the moment.

As time went on, Mum lost more functioning. Her walking became quite unsteady and she could no longer sign her name. Gradually, she was not able to manage daily tasks that had been part of her repertoire all her life. She needed help with food preparation, bathing, dressing, going to the bathroom, and other things. Someone had to be with her always. At first, my father cared for Mum largely on his own with some help from my sister and me. But we soon found ourselves overwhelmed. We added services like adult day care and home help.

The amount of care Mum required was gradually going beyond our

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ability to cope. We began talking about a nursing home as opposed to supporting Mum at home. Despite realizing that we were beyond our ability to cope, we gave it the old college try. We set up an elaborate system that involved Dad and homemakers in the day.

My sister and I juggled full-time work, families, and all-nighters with Mum. Sometimes, it was truly exhausting but sometimes it was truly funny as well. We compared notes about how many times we got up each night. It was frequently at fifteen-minute intervals. Mum, of course, had no idea that she had just been in to see us and was perfectly cheerful throughout. It was impossible to be angry with her because she was either happy to see us or as fearful as a young child might be in the night.

When we made the decision to look for care for Mum, she had to be further assessed. That was when we discovered that she had added Alzheimer disease to her multi-infarct dementia. After the assessment was completed, it was clear that Mum needed to be in a locked area of a nursing home because she had no idea where she was and she was wandering outside. As it happened, there was a placement available in the secure unit of the Royal Care Center almost immediately. Had Mum been more alert, she would probably have had to wait as long as two years. The bed's being available was a godsend because we were all getting tired. I don't know how much longer we could have kept on. But it was also hard that we had to make a decision so quickly and live with it. We had no time to prepare ourselves emotionally.

When we come to see Mum, she always knows us and is thrilled with our visits. She searches for my father when he is not there. She constantly asks to come home. We can explain where she is and why and she is accepting in the moment, but then the question is repeated over and over. It is immensely sad not to be able to help Mum when she becomes upset and confused about a situation that she cannot explain and that cannot be explained to her.

Living with Mum's being in a nursing home has probably been the most difficult thing we have had to do as a family. We know that it was the right decision, but having Mum separated from the family unit is very hard. Our parents had been married for over fifty-five years. They fully expected that death would part them at some point, but they did not think that something like Alzheimer disease would.

In many ways, Mum's dementing illness is like death. She is not the

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person we once knew. But at the same time, aspects of her character and personality continue to shine through. We can't walk off and leave her behind as if she had died, but we don't have her with us anymore either.

Many staff members at Royal Care Center, where Mum lives, have helped us in this very difficult situation. They are used to seeing residents and their families learning to live in this new world. However, they don't seem to gloss over the feelings, but take time to listen, to reassure, and to make suggestions that might help.

I cannot say enough for the support of other families at Royal who have shared this journey too. Once a month we attend a support group and in between we often see other relatives on the ward. It is very helpful to be with others who are experiencing similar problems. This gives us a variety of solutions or at least ways of tolerating the issue. You begin to see families as whole units with a history that didn't always include Alzheimer disease. Now they are learning to include this disease and their relative in their continued functioning. Somehow, that continuing becomes the focus instead of the disease.

In some ways, my family has been strengthened by what we have been through. We clearly see the love between our parents. As daughters, we have been given the opportunity to be really useful and caring to both our parents. Our husbands have demonstrated their respect and commitment to the family they joined through marriage. The grandchildren, who range in age from teens to adults, have not shied away and are much more prepared for helping their own children through tough times as well as us as we age. They have helped both their grandparents at home, have visited Royal Care Center often, and have attended support group meetings. Even the first great-grandchild in this clan has come halfway across the world to be the best hug therapy that Mum (and the rest of us) could have had.

I don't want to minimize the pain that we all feel in this situation. There are times when it is unbelievably sad to see our mother in her separate existence. It is very hard when she cannot understand and we cannot make it better. Not to be able to take her home when she asks or, worse, cries is dreadful. However, Alzheimer disease does not mean that we stop being a loving family or that we cannot laugh. It does mean that we have to find new ways to do things together and to support one another.

## CHAPTER 13

# Communication and Problem Solving

### Working the System

Because a nursing home is a complicated system, you need to learn how to navigate it. You probably learned to do this with the hospital system or home care system before your mother was admitted. Although there are ways to speed up your “learning curve,” it will take time, just as it took you time to learn to be a caregiver or to learn how to maneuver in other systems. For one thing, before you can ask a question, you have to figure out what it is you don’t know. For another, you will have to be involved in the system to learn its gaps. Until you have figured out the system, you may experience a good deal of frustration with both it and yourself. Try to be patient with yourself and remind yourself that it takes time.

As mentioned earlier, it is helpful to sit down with the staff before admission to talk about expectations, both yours and theirs. However, it may not be until you actually have your mother in care that you realize that you had some expectations that are not being met. You may expect the physician to call you or come in when she hasn’t. You may expect that the home will be using the same kind of incontinence pads that you did. You may expect them to provide shampoo and soap, and so on. Some of these issues can be discussed at a care conference. You can also discuss them with the director of nursing, the social worker, or the nurse on the floor.

## Communication

Communication in a complicated system is difficult. You need to learn how to make your communication effective so that the system works for you. You may tell a nurse that your mother hates orange juice, and three weeks later she is still getting orange juice in the dining room. After you have said it five times, you may feel like tearing your hair out.

Monitor care especially closely in the first few weeks after admission. There is a lot for the staff to learn about a new resident. This is the time when you are passing the torch to the staff. You may want to make sure that they have grasped it firmly before you let go. Don't let yourself feel bad if you feel like you are "checking up" on the staff. In a good home, that isn't what you are doing. What you are doing is tracking the system. (If the home is not so good, checking up is exactly what you are doing, and you will have to continue to do it carefully as long as your mother is there.) There will always be gaps in a system's functioning. That is often where problems occur.

There are tricks to make information flow more easily. The first is to ask the staff how *they* make sure information is communicated through the system. Different homes have different systems. You need to learn what works in the home where your mother is. When you want the staff to have some information, write it down. Keep a copy for yourself and date it so that you have some notes to refer to. If it is information that affects more than one department, such as nursing and dietary, give a copy of the note to each department. You may also want to give a copy to the director of the department. Let them know that you are doing all this simply because you know it is easy for information to get lost.

Even after you have written down what you want the staff to know, don't assume that what you wish to happen is going to get done. Track things for a few days and follow it through a few shifts. In the dining room, for example, check to see that the weekend and week-day staff have received your concerns and followed through on them.

I recently admitted a resident with a hearing difficulty. After a couple of days, the daughter told me that her mother had two hearing aids and they weren't being put on. Her mother, ninety-six and very



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forgetful, was unable to do it for herself. First I had to find the hearing aids, which her mother had misplaced. Then I went to one of the nurse's aides and asked her what happened. She said the woman dressed herself and didn't need help in the morning. I explained that she did. I wrote it down in the communication book and told the nurse. The next day, the woman still wasn't wearing her hearing aids. I went back to the nurse's aides. A different one was on that day. This happened on three days before it got into the system. Two weeks later I again saw the woman without her hearing aids. I asked a third nurse's aide where they were. She told me that the woman must have forgotten them and that she dressed herself. This aide hadn't worked with this resident before. I just had to keep working and tracking this until the information became part of the system.

When you are giving information, make sure you give it to someone who is there on a regular basis, not a casual staff member or someone from an agency. Ask the person to write it down in the communication book. This is a book for the staff that documents changes or needs in residents which do not go into the resident's chart.

If your concern needs an active response, don't wait for the staff person to call you back. Let the person know that you will visit again or call her back, then wait a few days and do so. If she hasn't gotten the answer, tell her you will call back in a few days. If you keep calling back, it puts you at the top of the list.

There is a good time and a bad time to talk to the staff. Bad times tend to be at change of shifts. This is when people are going home and trying to finish up their day. They usually are trying to communicate to the next shift staff what has happened during the day. You will not get their full attention. (On the other hand, it might be a good time to schedule a *very brief* meeting—maximum five minutes—if you do so in advance. That gives you the advantage of being able to talk to two shifts at once. The key is to make it brief and focused on information. It is not a time to problem solve.)

It is also not a good time just before, during, or just after meals. These tend to be labor-intensive times when the staff are focused on helping residents into or out of the dining room, dispensing medications, or helping people to eat. Other labor-intensive times are when

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residents are being made ready for the day: nurse's aides are toileting, dressing, washing, grooming, and so on.

Ask the staff when is a good time to talk to them. Usually they want to help. If you communicate when you have people's attention, there is a better chance that what you say will go into the system.

Be very clear to the home about who is to be the spokesperson in your family. If there is a spouse and three children, it is not reasonable to expect that the home will send everybody notices of conferences or call everybody when your mother has a fall. I remember a very frustrated daughter calling me to complain because the family had not gotten notices of conferences or meetings. When we investigated, we found they had originally told us that the mother was aware enough to be given notices directly. She had not been passing on information to her daughter. When we discovered this, we started sending notices to the resident and her daughter.

If there is some conflict in your family about how decisions are to be made, see if you can work that out, or at least let the home know, so that they are not contacting one person and asking for a decision or giving information, and then having a backlash from other family members because they weren't included. If one person, usually a son or daughter, lives out of town but is very close to the resident in care, try to keep that person in the information loop.

### When Things Go Missing

It is amazing what goes missing in a nursing home! Beyond valuables, people lose glasses, toothbrushes, dentures, and telephones. Sometimes things are stolen. Sometimes a staff member will accidentally break something and be afraid of the family reaction so he cleans it up and doesn't say anything. Sometimes possessions are misplaced. Sometimes the resident will throw them out. It is very common for a confused person to take out dentures, wrap them in toilet paper, and throw them down the toilet or into the garbage—or drop them into an unfinished bowl of soup, which then is collected and thrown down the sink by the dishwasher, who doesn't notice something at the bottom of the bowl. It is also common for a confused resident to walk

into someone else's room and put in that person's dentures, sit in his chair, and sleep in his bed.

It is true that things get stolen. That is why you want to have a list of the possessions and clothes that you brought in, and you want them clearly marked. But don't jump to the conclusion that something was stolen. Investigate. Learn the lost-and-found policy of the home. Search for things that are missing. Ask the staff if they have seen it somewhere else or on another resident. Go look in the laundry.

### Your Role

As I indicated earlier, the most important aspect of your role as a family member is to provide your mother with the love and attention that makes her feel valued and important as an individual. No one else can do that. It is your history, trust, acceptance, and intimacy that make your relationship irreplaceable. You are the only one who can “anchor” her—give her a sense of her place, history, and importance: in short, an identity.

Sometimes family members describe themselves as an advocate. I prefer to think of them as partners, because the word *advocate* can take on an adversarial tone. You want to work with the staff, not against them. Even when you do not like what is going on, I think that when you are changing things for the better, you are still being a partner in care. The result may be conflict, but the goal is the partnership and supporting the staff to do their jobs as they should be done.

As a partner in your mother's care, you need to continually monitor how the home is affecting her. Continually does not necessarily mean frequently. When you have a certain trust level, you will find you need to monitor things less frequently. Is your mother getting back her laundry? Was she missed when the podiatrist came to see the other residents? Has she had falls or bruises? Is there a subtle change in her behavior? Does she really need all the medications she is getting? How is she eating and drinking? Is she participating?

Remember that systems and people change. What was working at one time may stop if there is a new nurse or nurse's aide who wasn't privy to the conversations you had with the one who was there for

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the two years previously. With so many different staff members providing care over the course of a week or month, they may not have the consistency to pick up on the things you would. Casual staff especially will be less aware because they are on site less frequently.

Keep things in perspective when you notice that something hasn't been done—if toenails haven't been cut, they can be next week. If you cannot take this stance, you will never sleep. You will feel that you are continually at war with the home and will never be satisfied. You need to trust that the major issues and most of the care is being done properly. As I said, if you really can't, then think about finding a place where you can.

On the other hand, there are many homes where you will have to be constantly on top of things, where the care does not meet very high standards, and where some of the staff, the management, or the corporation is either incompetent or uncaring. Then your role can go from a partner to a police officer.

If your mother is in a home where you have to be more police officer than partner, you will need to learn how to do this effectively so that you don't burn out. (Reread the section on abuse in Chapter 6, see below on "Making Complaints" and "Throwing Bouquets," and see Chapter 16, "Making Homes Better.") Here are a few things to remember.

- Pay attention to your feelings and what you sense. If you think something is wrong and the answer is unsatisfactory, keep looking.
- It is your right to read the chart. Do so if you are suspicious.
- Rely on outside experts if you must—pharmacists, physical therapists, and specialists in gerontology.
- Not all the staff will be incompetent or uncaring. Search for the ones you can trust; rely on them, and ally yourself with them.
- Visit at varying times during the day and at care times so that you can develop a total picture of what is happening and how care is actually done, and done by different staff members.
- When you find the staff members who are competent, see if

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there is any way you can make sure they are providing care to your mother, or at least are in the same unit or area as your mother.

- Build bonds with other family members and work together to monitor care.
- Talk to residents whom you feel are competent and able to stand up for themselves and listen to what they have to say.

### Making Complaints

After your mother has moved into the home, you may find yourself criticizing how care is given or continually feeling that care is not up to standards. Sometimes, you will be very accurate in your criticisms; sometimes, maybe not.

As I mentioned above, during the first phase of the time in which your mother is in the home, it is important that you keep focused on your feelings and what you are going through. This is especially important with regards to complaints or problems.

When you have a complaint, take a minute to look inside yourself and ask what else is going on for you. Often people find that their anger or distress about an occurrence in the home is really tied to their feelings about their mother's being in a home. It can be less painful to criticize someone than to accept your own feelings. Have the courage to ask yourself if your criticisms or concerns are really about the care or are they the result of your trouble accepting or even acknowledging some of your feelings? Sometimes it is both. Solve the problem, but don't let the system or staff become the whipping post for your guilt. It is easy to let this happen but it is not fair to the staff, nor ultimately are you being fair to yourself.

You may need to be able to talk about your criticisms with someone. If there is a social worker, that is her job; if not, it is often the director of care's responsibility. Verbalizing your criticisms to someone can help you take another look at them and see them differently. It doesn't mean that you are a bad person because you are critical. Nor does it mean that the care is not good care because you are critical. It may be that you are right about the care or the incident but the way you have approached trying to solve a problem is inappropriate be-

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cause of your feelings about the situation. When you can separate the two, you will find that it is easier for you to communicate and you become a better partner in your mother's care because you are more able to listen.

If you have a complaint, make sure that you have gathered all of the information and you know exactly what the problem is. If it is something your mother has complained about, remember that you are getting only one side of the story. Try to find out from the staff or even a couple of people what they know about the incident or issue. It can look a lot different when you have all the information. For instance, you might think that the recreation staff is not bringing your mother to baking. When you talk to them, you may find that she wanders away before the activity is over. But because you have come in at the end of the activity, you think that she has never been.

Sometimes your mother may honestly have problems with the home or staff. Yet even though you encourage her to say something to them directly, she may not be willing to do so. Form a good picture of why not. Make sure it isn't because she is intimidated by the staff, has been threatened or abused, or has seen other residents abused.

You may have to teach your mother that it is all right to voice what she wants or doesn't want. One very good way of doing this is to have a small meeting with the appropriate staff member and your mother. When you meet together, you can support your mother and model for her that it is all right to say something. If she has the experience of voicing her concerns a couple of times, she may be more willing to do it for herself.

If you want to know what is going on when you are not around, or if you are an out-of-town caregiver, you could go so far as to set up some kind of video monitor and even connect it to the Internet, so that you can tune in anytime. This is similar to what is being done in children's day care. If you do this, remember that it also can be an invasion of your mother's privacy. Video monitoring can also cause some resentment from the staff, even those who are doing their work (and who theoretically have nothing to hide). How would you feel about being video monitored during your working day?

On the other hand some homes allow video cameras in residents' rooms because they can protect the staff from false claims of abuse

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or neglect. Staff who are confident about the care that they provide may have little objection to being on film, and might even welcome the occasion to show that they are doing a good job. I would suspect that cameras reduce the incidence of abuse just because people know they are being watched. If you do wish to use a video camera, it may help if you present it in a positive light, saying, for example, "My mother has been complaining and I am worried. I know you have a good staff in a difficult situation with a lot of residents and limited funding, so I would like to use a video camera to help you show that her care is good."

In the end, if something is bothering you or your mother and it is not solved by talking it out with the staff, you may have to gear up for a harder time. Going "higher up" can be intimidating for some people. You may fear that the result will be worse care for your mother. You may feel that you don't have the skills. If you are tired from caregiving or are pulled from your work or your home life, you may feel you don't have the time or the energy to take on what needs to be taken on. You may feel confused about where to turn and become more confused by a system that seems unresponsive. The longer the problem goes on and the further you have to go, the more helpless and unsure of yourself you may feel.

I want you to know that you do have what it takes. You can learn to advocate using the same skills you learned to be a caregiver. Talk to other people, find another family member who feels as you do, be part of a support group. Join an advocacy for the elderly group or the Alzheimer's or Parkinson's association. Go on the Internet to communicate with other caregivers who have done what you have to do ([www.jeffdanger.com](http://www.jeffdanger.com); Association for Protection of the Elderly, [www.apeape.org](http://www.apeape.org); in Canada, Caregiver Network, [www.caregiver.on.ca](http://www.caregiver.on.ca); or others).

Do whatever you can to make sure you have the support for yourself that you will need so you don't burn out as you take your complaints higher in the system and government. Use your anger and your sense of justice to keep your goals clear and your end in sight. You will find yourself with strength and resolve that you did not know you had.

Keep on forgiving yourself. You did not choose the situation, and

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you would not have chosen a poor home if you had the choice or the knowledge. It is not your fault that problems are occurring. Don't feel guilty about shaking things up if you must. Reread Chapter 4 on guilt and follow those exercises once again. Remind yourself that the energy you expend on guilt will take away from the energy and purpose you need to obtain the best care possible.

Your first step beyond the floor staff, social worker, or director of care will be the administrator. Be clear about what the problem is, what you expect, and what you have tried to do. Come up with some possible solutions. When you are making a complaint, present it calmly and rationally. Tell whomever you are talking to that you are angry and frustrated instead of blasting her. If you think you are too angry, take five minutes, or an hour or a day, until you can talk about the anger, rather than act it out. You may want to write a letter and then put it aside for a day or two and reread it before sending it. The goal is to solve the problem. Set up the conditions under which that can be done.

In the United States every facility must have a formal procedure under which someone can make a complaint. There should be a staff person designated to hear complaints. The home must respond to your complaints within a reasonable length of time.

If the home is owned by a chain or larger company, find out whom you can talk to in that company. Let the administrator know that you will be doing that. You may also be able to become a shareholder in the company. This will permit you to attend the annual general meeting. If all the families in the home and many in other homes become shareholders, this can have quite an impact on the company.

If you feel that you have not received an adequate response after going through the home's formal complaint procedure or if you feel that the issue is still not being dealt with, seek out the health department or agency on aging, or, in the United States, the ombudsperson or adult protective services. The ombudsperson will help you negotiate with the system. This office also reports to the licensing office. You have the right to go to those people or agencies. You can find them through the Eldercare Locator (800-677-1116) or online at [www.aoa.dhhs.gov](http://www.aoa.dhhs.gov). They will have the most up-to-date names, addresses, and telephone numbers.



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If the situation is one that you feel constitutes abuse, you can go to the police. They may tell you that this is not appropriate for them, but abuse may constitute assault, and that is a matter for the police. Better that you should go to them when you are concerned about assault than when you have to report a death from abuse or neglect.

You can also go to the local media, picket the home, or talk with a lawyer. These may be necessary, but they do carry consequences. If you are going one of these routes, take one more look inside to try to ask yourself how much is attributable to your own feelings or other issues. You owe that to yourself and the home. Ask other family members or go to the family council to learn what they think. Listen carefully to the ones who disagree with you, because they are giving you information that you might not want to hear, and this makes it more valuable. Remember, you can destroy people's lives if you go after them by mistake.

If you do go outside the home, make sure you have documented everything that has happened concerning the issue and the efforts you have made in trying to solve it within the home.

The Association for Protection of the Elderly (see Resources) has a Web site ([www.apeape.org](http://www.apeape.org)) that gives information on how to file a complaint with the state. It also describes how to monitor what is going on in the home and how to be an advocate. The National Citizens' Coalition for Nursing Home Reform (see Resources) can also give you some guidance on whom to call and how to proceed. Call both APE and NCCNHR if you wish. Obtain as much support and information as you can.

### Throwing Bouquets

Working in a nursing home is physically and emotionally draining for several reasons. Staff do get attached to residents and families; at a death they experience grief. Limited staff to provide care means they often work overtime (on their time; it is often unpaid). It also means that sometimes they are not able to provide care as they would like or as they should, and they know it but cannot do anything about it. They often do not get their breaks because of emergencies and paper-work requirements. Lifting residents in and out of bed, on and off the

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toilet, and so on, is tiring and can easily lead to back and other injuries. The staff receives the brunt of the family's emotional turmoil in the form of anger and criticism. The pay is minimal.

Nurse's aides, laundry assistants, and dietary aides are often seen by residents (and sometimes family members) as servants. They are often treated that way. If they are of a different racial or ethnic background, they are often the recipient of covert or overt racism and prejudice.

I know some residents and families have awful experiences. I know that some staff of nursing homes have absolutely no business being in a position of responsibility anywhere near another human being. But there are many, many dedicated and caring people out there. Many of the staff in the worst homes would desperately like to give better care. It is agony for them to see what is going on and to be part of it. It is wrenching for them to have to make decisions based on limited staffing and lack of support. It goes against their sense of humanity and against their professional integrity and code of ethics. There are many who are intimidated by their employers but who need a job. These people are as caught in the system as you and your mother are. Find them, and help them to be the staff they want to be and the caregivers you want.

Remember to throw some bouquets. Treat all staff as professionals or as experts in their field. See if there is some area or actions for which you can give them some respect. A simple "Thank you" is extremely rewarding. It means that you have noticed what the staff are doing for your mother. It can give them the energy and impetus to keep on making an effort to provide good care despite the trying conditions of their work. Ask after their families or activities. Get to know them as people. When you notice someone doing something positive, go up to her right away and reinforce that with a "Thank you" or "I really admire the way you handled that." This will increase the likelihood of the behavior happening again.

If I can make a completely unscientific statement with no research to back it up, I would say that, from what I have seen, the ratio of complaints to bouquets is about twenty to one. This may be because of genuine problems with care and funding, but think how you would react if, for every time your boss told you "Good job," he made twenty

## COMMUNICATION AND PROBLEM SOLVING

complaints. If you are already feeling stressed and overwhelmed in your work, this does not make for good incentive.

Write a note to the staff and send a copy to the administrator. You don't have to wait for a significant event or for Christmas—just a note to say that the efforts are appreciated can go a long way with the staff. Send flowers to a nursing station.

It is appreciated if you ask if you can do anything to make it easier for the staff to help care for your mother or someone else. It may be something simple like including another resident with your visit. Usually it is appreciated if you help feed your mother if she needs help. The simple fact that you asked shows the staff that you care about them.

Remember, you are in a relationship with the staff too. In some ways the relationship is separate from the one they have with your mother, but if it is a positive one, it can positively influence the relationship they have with her. Relationships are two-way streets. Care about the people you want to care about you and your mother, if you can.

## *Alvin (part 1)*

When my husband, Alvin, became depressed over the murder of his son, over losing his vision, and other tragedies in a short period of time, he was placed in a convalescent home and given an antipsychotic drug that was not monitored. The effects of the drug, combined with his Parkinson disease, left him “frozen” stiff eighteen hours of each day for a month, winding up a virtual vegetable. To save his life, a G-tube was inserted to feed him and he was sent to another convalescent home as a full-care patient. He was unable to move, push a call button, scratch his nose, or turn on the TV. All he could do was talk, and he was so brain damaged from the drug that he often didn’t know anyone or anything. I was told there was nothing they could do for him except keep him calm and as comfortable as possible. Since they also discovered inoperable lung cancer, no one, including the doctors, expected him to live six months.

I realized that if my husband was going to be anything more than a vegetable, it was up to me to find the solution. Thanks to our faith in God, and my insisting to the doctors that he have certain treatments, and surreptitiously sneaking some to him on a daily basis, there was a remarkable difference. Even the doctors and staff could not believe it. Gone was the depression; Alvin began recognizing people and talking, singing, whistling, playing his harmonica, telling jokes, beating the others at trivia—he became his old, happy self. It took several months, but it was worth being a bulldog. At the same time, he was off his Parkinson medication with no symptoms and his lung cancer started shrinking.

I became known as “the doctor” (they didn’t want to call me what they really thought), but I did gain a reputation for being persistent and loving, not only to Alvin but to the staff as long as they did a reasonable job.

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That was the problem: most of them wanted to do their jobs but they were so overwhelmed by the workload that it was impossible. Because I was nipping at their heels when I arrived in the afternoons or weekends, Alvin got better care, but still it was appalling much of the time. I found if I backed off, they did take advantage, so I didn't dare; however, I also made sure I helped whenever they needed it. Alvin and I entertained often, and I tried to be a "nice" person, if a bit dogmatic.

Alvin was very musical, and we were fortunate to be in a facility that had many retired professionals performing for the residents. I had to insist that they get him up and out to activities. Since he was also blind at this point, it was all he had to look forward to. He enjoyed every minute, singing, whistling, smiling, and participating in all activities, and he made everyone else happy as well.

I was fortunate to have good health, which held up in spite of long hours and hard work after my daytime job and forty-mile commute to the home. I found that checking on Alvin en route to work at 5:00 A.M. and coming in unexpectedly caused panic, as well it should have. The staff's neglect almost caused Alvin's death several times and did cause numerous hospitalizations. I wanted to transfer him, but because of the entertainment and the convenience, I put this off. Also, it would have meant moving him out of town, as there was no other facility in this town that I wanted him in.

After a CNA taught me how to lift Alvin, I started to take him everywhere I could. Using a portable wheelchair that folded up like a stroller and with just a little help from Alvin, we would sing "Hold Me" and he would grab me around the neck while I lifted him into and out of places. We were able to again be a part of things on the outside. Had I not learned to help him and insist that he go out, he would have been left to vegetate in the facility.

During the next two years the facility became a "House of Horrors." We had life-and-death incidents constantly, primarily due to lack of staffing. The last year of his life included:

1. A tube feeder that never lay down flat, a large hiatal hernia, and a lot of congestion. Had I not taken off work that day, he would have drowned in his own vomit. As it was, he ended up in a hospital due to aspiration pneumonia and internal bleeding.

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2. I checked him every night, but one morning I came in to find that his scrotum was totally burned, looking like a piece of raw meat. He had been fine the night before but had been allowed to sit in his feces for hours. He was on Vicadin for the pain for a week. You don't just visit your loved one; you'd better do body checks regularly.
  3. My life was threatened at one point and, in the presence of Alvin, I was threatened with not being able to visit him if I visited anyone else in the facility. Not only was my life threatened, I was told it took only a minute to put a pillow over my helpless husband's face. Because of these threats, I had to watch a resident literally die of starvation and malnutrition across the hall without being able to do anything except report it.

I began the process of trying to move Alvin. I felt it was no longer safe. Even though the nurses and nurse's aides liked me (except for those few who were causing the problems), the power people felt I was a threat to them, as I knew and saw too much. So when I asked that he be transferred, the blackballing began. I learned that you do not request a transfer; you go to the facility where you want to move, make the arrangements, and let them send for the records. The old facility will still try to make the care seem much more than it is, but you have a better chance.

At this point, again due to lack of care, Alvin became very ill, but the facility refused to transfer him in spite of high temperatures for days, congestion, brown urine, etc. I finally had to insist they put him in my car (unhealed broken femur and all) and I took him to the hospital, where the hospital staff had some unmentionable things to say about a facility that would allow a car transfer and not know a person was so desperately ill. Alvin was hospitalized with tubes suctioning his lungs for ten days. When they felt he was stable enough to transfer, we could not find a bed within a fifteen-mile radius, thanks to the blackballing by the House of Horrors. I even visited facilities, taking his actual medication list and care list.

We were fortunate to have someone on staff on our side and were able to get the director of care of the best facility in the area to come to see him to see why he couldn't be placed. She couldn't believe it, stating he was such a sweet person and his care was no more than many others. So we got him into our first choice and the best facility in the area.

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Alvin spent seven wonderful weeks in the new facility before he joined the angels. We were so thrilled finally to be where it did not stink, did not look like the typical facility (even had lounge chairs in the rooms and only two beds per room instead of three). It made us realize there are still some great facilities out there, even if you're on Medicare and Medicaid. But you have to look hard to find them.

The two main things I learned from my husband's time in care facilities are that you'd better visit regularly, if not daily at least a couple times a week, and at irregular hours, and do a body check or have someone do it for you whom you can trust. Bedsores quickly get away from you and are killers. You must stick up for your loved one; there's no one else to do it. There really are great places out there, but you have to be willing sometimes to go the extra miles to see that the person is happy and comfortable. Alvin told me shortly before he died that he couldn't believe he'd had such a nice day. He finally felt safe, cared for, and loved, and I was able to relax for the first time in three years. We felt we'd finally gone from Hell to Heaven, right here on earth.

## CHAPTER 14

# Visiting

How often to visit, what to do when you are visiting, how long to stay, and how to leave are important issues that may trouble you. They certainly bear some discussion as you try to balance your needs and those of your wife.

Some people do not want to visit at all. For them, it is too upsetting to see “all those people in wheelchairs.” Or it is upsetting to see their relative in his present condition. Sometimes people are frightened; the thought in their minds is that “this is where I could end up pretty soon.” You can move beyond those feelings if you are willing to confront them. They do subside. This is another situation in which you may wish to seek some professional help. If you avoid visiting, the guilt from doing so can be overwhelming. After the death of your relative, you could feel intense regret that will stay with you for a long time.

Just as in every other aspect of care, there is no one right way to do your visiting. Your situation, relationship, needs, and time schedule are different from those of the daughter of the lady whose room is next to your wife. Unfortunately, your wife might not take those differences into account when she tells you that Mrs. Smith’s daughter is here every day (implying, therefore, “Where the heck are you?”).

Your tendency in the beginning may be to do what you think your wife needs; at some point, you will have to figure out what your limits are. If you don’t, you might as well have kept her at home. What is it that you honestly feel you can and want to manage? Write down your limits. It can help you stick to them. It is kind of like writing a care plan for yourself. If you trust the home enough not to have to do



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surprise visits to monitor care, tell the staff how often you will be visiting. That way, they can tell your wife, when she starts to worry, that you will be in soon.

Remember that at the end of the adjustment phase—both yours and your wife's—the goal is for her to be integrated into the facility. So when you think about visiting issues, remember to ask yourself the question, Is this going to help or interfere with her adjustment to the home?

### How Often to Visit

It is fine to visit the home every day for the first couple of weeks or so, up to a month. There is a psychological assurance for both or all of you in that kind of pattern. It also helps you begin to see how the home works on a day-to-day basis and to know the staff. Because it is also the time when the staff is getting to know your wife, they may have questions for you or they may be missing some part of her care that you wish to review with them.

It is good to vary the time of your visits so that you see different staff and different routines, and so that your wife doesn't get dependent on "this is the time when he comes to see me." The more she depends on you for reassurance, social interaction, and so on, the less reason and willingness she may have to integrate herself into the home. Remember, you are fostering adjustment—for both of you.

You might also find that a shorter visit, done more often, is better for both of you than coming for a whole afternoon. Just dropping in for half an hour can be meaningful. If there are several family members, set up a schedule so that you are coming on different days. This will help you avoid burnout.

Sometimes shortly after admission, the staff may recommend that you stay away for a week or even longer. Usually when they do this it is because your visiting is actually interfering with your wife's settling in. It is a little like when you leave a child at school or camp for the first time. Without you there to hang onto, she will get used to it more easily. The difference, of course, is that your wife is not a child. If you think you can trust the home and they recommend this to you, you may wish to consider it.

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There can actually be less agitation when families don't visit frequently in the beginning. I have seen many people who were quite calm throughout most of the day end up being very upset after a relative's visit. It seems to bring up their feelings of being abandoned and alone and reminds them of their home. It can also be a bit of a manipulation so that you feel guilty or so that you change your mind. Is it better to visit and have your wife be agitated and upset when you leave, or is it better to stay away for a while? I think it varies with the individual and situation. Generally, however, I think it is better to come and pay the price of the agitation when you are leaving. You will have to discuss the situation with the staff, then try it and see.

Before you decide to stay away for a week, do some in-depth problem solving with the staff to see if there is anything else going on that is causing the agitation, or if there are any other ways of dealing with it. If you do decide to stay away, see if a friend can come to visit in your place. Often, a friend's visit will not stimulate anxiety the way a family member's visit does.

Generally, most professional people recommend that after two weeks to a month, you stop coming every day. This is done to protect you from burnout. It also says clearly to you—and you might not want to hear this—that you need a life outside of your relative in the home. If you are unable or unwilling to do this, at least give yourself permission to take a day or two off every now and then, at least once a week. If you don't, you can burn out.

The first time that you skip a day may be hard; you may have to make yourself do it. It will be easier if you plan something to do rather than sit around at home and wonder how your wife is doing. Visit friends or other family members. Fix the roof or clean the house; do some of the things that you have put off doing. This is another situation in which a friend could visit in your place. A "no visitor" day could be a second step.

Some family members *do* come every day. Depending on the home, you may feel that it is the only way you can monitor for abuse or neglect. But maybe visiting every day is how you want to express your commitment to your wife. Just because she is in a home does not mean that she cannot provide you with love, affection, and companionship. You might enjoy coming in and just sitting and reading or

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watching television with her. Even in a good home, you might want to help her eat dinner or walk. Your marriage does not have to be over because she is in a home. You need to do what is best for you in your situation. The trick is figuring out what is really best as opposed to what you want. Sometimes the two are different. Take some time and ask yourself what you are hanging onto and why. Ask yourself if there is anything you are avoiding because you don't want to face it.

Visiting can be difficult for practical reasons. There is very little private space in a nursing home, especially if your wife has a roommate. This is extremely difficult to get used to because close relationships are not lived solely in public. If your wife liked to entertain, in a home she may not have a place to do so, and even if she does, it is not hers. If you think about it, the act of "visiting" is symbolic for both of you of a power difference—she is in an institution and governed by its rules—and of a change in your relationship.

### Visiting Someone with Dementia

Even if your wife is very demented and, two minutes after you leave, she is phoning to ask when you are coming, your visit has been worthwhile. People who have dementia can experience the moment and they may be living only in the moment. If your wife is nonverbal, she may understand a whole lot more than she is able to respond to. Talking, hearing, and comprehension are different functions in the brain. Also, the fifteen minutes you spend holding her hand is important even if there is nothing said or she is unable to respond.

You might want to leave a guest book in your wife's room and sign it when you and other family members come in. This gives your wife a visible reminder of who has been to visit. If you have worked out a visiting schedule with more than one relative or friend, this lets you know if it is working. You might also want to write down what you did together and to whom, including staff members, you spoke.

If you live out of town, or even if you are in town, sending a letter or postcard is nice because your wife can look at it when you are not there and the staff can read it to her over and over.

American culture tends to view social interaction as conversation. This idea can make visiting difficult because conversation with per-

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sons with dementia is often limited and frustrating. Family members often say they don't know what to do when they are visiting.

Your visiting may be more satisfying if it is activity based. Activity can be something as simple as holding hands while watching television or listening to music. You may want to bring in some old photographs and make albums, or review the albums. If the home has a resident's kitchen, maybe you can make some cookies together. See if you can find some games that are within your wife's ability range, such as a simple jigsaw puzzle. Do her nails, or do a craft. See if the home has any activity boxes that they can lend you. Maybe there is a book of old photographs of the city where she grew up. Take old family photographs and make them into videotapes you can play and watch together. Bring in a book of songs and sing together. Sit together in a chair and watch the people go by in the main hallway. See if the kitchen staff will let you set some tables for dinner. Clean the room together. Do a simple woodworking project together. Schedule your visits with other families, so you can all visit together. Remember, there are many ways for people to be together; talking is just one of them.

## Going Out and Going Home

Older people living on their own often experience a withdrawal from the larger community due to physical limitations or losing their driver's license. When they move into a care facility, this interaction decreases even more. Your wife is still a member of the community. Think about ways in which she can continue to be part of it. Maybe bring her to church on Sunday for at least part of the service. If she had a bridge club, see if she can continue to go, or see if the bridge club can meet together in the home. Your visits don't have to be in the home; take her out for coffee, lunch, or a walk.

Younger people particularly need to see themselves as part of the larger community. The more connected they are, the more normal they feel. This connection validates their worth and identity as persons, and it counteracts the feeling of uselessness that the disabled can experience.

If you do take your wife out, it might be wise to limit the stimula-

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tion that she has, especially if she has dementia. People with dementia often do not do well in situations with many people, multiple conversations, or a lot of noise (which is why sometimes a well-run dementia unit is a good idea). So even though you want to bring her to a family wedding or dinner or to the club, it might not work out very well. Try it and see, but be prepared to bring her back early.

If you are wondering if you should bring your wife back home for a visit, try it after a few weeks. This can be especially important if she was discharged directly from a hospital into a nursing home. She never had a chance to say good-bye to her home, possessions, or pet. See what happens while she is there, and then ask the staff to monitor what happens after she comes back. It is not necessarily a bad thing if she is very upset on returning; it is part of the grief. You and she will have to judge whether taking her home is like “picking a scab.”

If you do decide to make a clean break rather than the slow transition that visiting your home would entail, wait a significant amount of time, even two to three months, before taking your wife back home. A good guideline indicating that someone has settled is when the person begins to talk about “my room” or being “at home,” and means the nursing home.

Remember, too, that you can bring your wife out for vacations, even if it is just a weekend or overnight. Many hotels and resorts will accommodate a disabled person. I have known residents who have gone to Las Vegas with other residents they met in the home and on cruises to Alaska with their families. Some have hired a companion to go somewhere. Everyone needs a vacation.

## Ending a Visit

Ending a visit can be harder than the visit itself. Your wife might not let you go. She might be angry with you and tell you never to come back. Even if she is not agitated, the look on her face may intensify your guilt. Especially in the beginning, you may feel each time you leave that you are abandoning her and may experience a twinge of pain knowing you are going home to an empty house. It will get better, and you both will get used to it. It just takes some time. That is

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hard to remember when you are in the middle of it, but just take one day at a time.

If your wife has dementia, you might have to experiment with what works and what doesn't. For some people, it is helpful to say, "I have to go to work now" or "I have to go have my hair done / go grocery shopping / go to the doctor's" rather than to say that you are going home. You may just be able to say, "I have to go to the men's room" and she may not remember that you have gone. Sometimes it is helpful to say right at the beginning, "Honey I can stay only for an hour today," and then remind her after forty-five minutes that you will have to leave soon. If there is a hairdresser, bring her there and you can leave while her hair is being done. Take her to an activity and sit with her for a while. When she is involved in the activity, you can leave. Maybe you will want to visit just before a meal so you can get her seated in the dining room, and then say good-bye. Or ask the staff to take over and distract her for a minute.

Monitor your stress level if visiting and leaving are hard on you. Try to have people in your life with whom you can debrief when you come home, especially at first when you are adjusting to the changes. It can be helpful just to be able to say to someone, "That was a hard visit."

## Companions

Family members often hire a paid companion for their relatives. There are both advantages and disadvantages to this. The advantage is that a companion gives extra, individual time to your wife. This helps provide the individual relationships that can be lacking in a home. It gives added stimulation and encouragement. A companion can help you monitor the care your wife is receiving. Sometimes a companion can help with exercises or other rehabilitation if she is trained and/or monitored by a physical therapist. She may be able to give an extra bath. However, a companion can prevent your wife from integrating into the home if she doesn't take her to activities or if she prevents her (either intentionally or not) from interacting with other residents. Companions can also create a dysfunctional dependency. Sometimes they do this because they are afraid they will work themselves out of

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a job. If your wife has a companion before admission, this person should maintain involvement for at least a little while after.

If she is able to participate in the decision, ask your wife if she would like to try a companion. She may want someone to alleviate the boredom. You may have to explain that you will not be visiting any less; that you need a break but you will still be coming; or whatever is true for you and reassures her. You can also discuss it as an experiment: "Let's see if you enjoy having someone else come to visit."

If you do decide to hire a companion, the decision can be part of the overall care plan. Consult with the staff or have a care conference to discuss the goals and objectives of the companion. What do you expect the person to do? What would the staff recommend in terms of hours per day or week and time of day? Find out what the rules of the home are concerning companions. Rules can include sign in and sign out, not taking work from union personnel, and issues of insurance and liability. Although the home will not supervise the companion, someone, perhaps the nurse on the floor, the social worker, or a recreation worker, should be able to give you feedback on how the relationship is functioning. The home will also have a good idea of the pay scale for a companion in your area.

You can hire a companion privately or go through an agency. I would not generally use a staff member from the home, even if they have some extra time. It is a conflict of interest for them and seriously divides their loyalty to you. If you want to hire a private companion, ask other family members whom they use or ask the home if there is someone whom they would recommend. Some people have success through notices in community newspapers. Or you might see if there is a local school that trains nurse's aides or LPNs and ask if they can recommend someone. If you hire privately, look into your responsibilities concerning paying taxes and benefits. Screen the person carefully and check references. If the person says she has worked for someone else in this capacity previously, call the home where this other client lived as well as the family who was involved.

If you hire a companion through an agency, the agency will take care of screening, payment, and insurance. You should still interview the person. Ask the agency about the companion's training. Make sure

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the agency will send the same person consistently, not a different person each time. You should meet with the companion or call the agency supervisor regularly, at least once a month.

Whether you hire privately or go through an agency, follow specific procedures. Have the companion sign in and sign out. You might want the person to keep a notebook in your wife's room of what they have done each period. There may be a staff member in the home who is willing to countersign the companion's sign-in book. Specify to the companion (and the agency) what you want the companion to do and write it down. Make sure that the companion is taking advantage of the activities and that she is assisting your wife to adjust and integrate with the community. You may want to start off by having the companion be there when you are visiting. This helps your wife become accustomed to her and can teach the companion some of the ways in which you interact with your wife.

## A Few Words about Sex

Just because your wife is in a nursing home does not mean that you have to stop having sex. There is also no reason for you to stop holding hands, cuddling, or having your arms around each other. Younger and/or disabled people can also still have sex, but they may have to learn to work with or around their disability. They may also need to know that you still want to have sex with them.

Much of our society associates sex with young people. The implicit message is that older people are not sexual, or they should not be. They are and they should be. Our skin is a sense organ. Touch, whether sexual or not, is one of the most important means of communication. It is important to our mental and physical health. This is true if you are twenty or if you are ninety. Long after someone's memory has gone, touch and intimacy are still valuable.

If your wife has her own room, you can lie down on the bed together and watch television. You can cuddle up and listen to music. You can make love and you can nap together. A good facility will try to accommodate you in that way. If they are unable to because there is a roommate, then allow yourself to have as much intimacy as you wish



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within what is available. To have more, you may have to go home. You can also go to a motel or a nice resort that is equipped for disabled people. Many people do this, although they do not talk about it.

If you are using your wife's room for sex or other intimacy, tell the staff that when you are visiting you want some privacy. Sometimes they use a pass key and enter a room with only a cursory knock, or simply knock on a door and enter. This happens because often a resident is unable to respond or cannot hear (or because the staff member is rude or in a hurry). Emphasize to the staff that when the door is closed, they are to knock. Put a "Do Not Disturb" sign on the door.

## *Jane*

My father cared for my mother in their apartment for several years. During these years, Mom traveled down that terrible path we all hope and pray won't happen to a loved one. Even now, writing this is so painful, tears stream down my face as I recall the heartache and the decisions we had to make.

As the only child and a nurse, I think I expected more of myself than I ever expected of client families. I've worked in the long-term care setting for over twenty years. Distressed, loving families were people I saw on a daily basis. My heart went out to them as I tried to ease their guilt and anxiety. All the objectivity is gone when you have to deal with your own situation.

My father, dear stubborn man that he was, decided that he and Mom would be better off in the country. Against all advice, he bought a house in a small town an hour's drive from any medical services. Of course, it wasn't long before it was very clear that without family and friends they were very alone and isolated. My father's workload as a caregiver increased dramatically with no support.

Many frantic trips followed, and I admit I was resentful at having a six-hour return trip to see them. By this time, I had been suddenly widowed and was feeling ticked off at everyone, especially at my father for having taken Mom so far away when she needed a lot of care.

The decision to move Mom to a care facility wasn't difficult to make when Dad became ill. It became obvious to him that her physical care needs far exceeded his ability to cope. After my mother had another operation for cancer, my father agreed that I should make immediate arrangements to have Mom placed in a nursing home. Unfortunately, this

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was all happening so quickly that I chose the first facility that would accept Mom. The plan was that I would view other facilities, and Dad and I would eventually decide what facility we wanted to become her “home.”

Mom died only a month after we brought her back to the city. That month was one of the most difficult periods of my life. Thankfully, Mom and I had often talked about her wishes and she had made her feelings very clear to me: when the quality of her life was bad and only going to get worse, she did not want any active treatment that would only prolong an existence that she would hate.

The night Mom died, I stayed late at the home. I worried that she might not survive the night. With the nurse’s assurance that she would call if there was a change, I went home. To this day it bothers me that I was not there when Mom died. My mother was in a coma and, rationally, I know she wasn’t aware of my presence, but in my heart, I wanted to be with her when she died.

The whole process of placing your loved one in a care facility is heart-breaking. If I can offer any advice, it would be try to get into the “system” as early as possible in your parent’s illness. Call the local health department. Get a case worker and search out for yourself where you feel your parent would be most comfortable. Never be intimidated by the caregivers or the administration. Interview and inspect. Do remember that no matter how high the standard of care, it can never replace one’s own home.

If your finances permit, it is wonderful to employ a “companion.” Staff are very busy, and it is often the small, personal things they don’t have time to do that make such a difference in the quality of life. I think this goes a long way to easing the guilt that all children feel. If a companion isn’t possible, arrange with other members of the family to form a team, to visit and spend loving, quality time with your family member. Don’t be afraid to call on them. In the end, they will be glad they helped and participated in caring for grandma or grandfather. It gives them a great foundation and enriches their lives. Sometimes they just need a good nudge—but do it.

The most difficult decision you might have to make is if you want to be present when your parent dies. This is a very personal decision. Some children can’t be there at the end and that is the only way they can handle it. If you can, for your own peace of mind after it is over, I would urge

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you to be there, physically touching your parent. I remember a daughter who actually lived in her mother's room for days. She used to lie in the bed, holding her mother close to her. Her mother died in her arms. The spiritual connection was so strong. It was an experience that I've never forgotten, and I often wish that I could have had this experience with my mother.

No matter what you do, you will feel guilt. Don't beat yourself up when it is over. Remember the love and good times. Know that you've handled one of the hardest situations you will ever face in the best way you could at the time. Take heart and courage knowing that parents' love is unconditional and if the circumstances had permitted, they would have supported your decisions with love and understanding.

## CHAPTER 15

# Out-of-Town Caregivers

If you are an out-of-town caregiver, you face some unique practical and emotional challenges. This can be true even when there is a family member in town. Basically, the problem is that you can't see for yourself what is going on. The information you receive is secondhand. You have to put a lot of trust in the person or system giving you the information.

Long-distance caregivers do not have the opportunity to do a thorough preadmission process of visits and interviews or postadmission monitoring. This means you need to be especially diligent about checking out homes and selecting one or two that you feel you can trust.

Trust is naturally more difficult for long-distance caregivers. Generally, trust is an emotion that increases with information and through relationships. It decreases in a void. Fear and mistrust, on the other hand, grow in a void because we fill in the gaps with our own thoughts and fears. What we make up is often much worse than the reality. You will be especially prone to fill in the voids with worry and worst-case scenarios because the process of care is so emotional and because of the stories that we hear. (And maybe because of what you read in this book.)

It seems to me that degree of caregiver guilt increases with distance from the care receiver. Be prepared for this. It may show up in added worry because you can't drop by the home to find out what is going on. You may end up being overly critical of an in-town caregiver, of the home, and/or of staff. You need to accept the fact that you live where you live; don't beat yourself up because of it.

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Make sure that you understand the long-term care system in the area where your brother lives. Try to know all the rules about nursing homes, placement, and funding. If something sounds funny or you are told that something can't be done, find out why and if there are any exceptions. It is harder for out-of-town caregivers to make decisions if they cannot be right in the area.

After you have selected a home, find someone who lives in the same vicinity as your brother who could be your representative. This may be a more distant relative or a family friend. Just make sure it is someone who knows you both. The person should understand your values and be able to make decisions based on them. Let the home know that this person is the primary contact and is authorized by you to make decisions, monitor care, and so on.

If you are able to spend a week or two visiting after admission, try to get to know some other family members and the family council. Ask them to keep an eye on your brother. Give them your phone number and take theirs. The more you feel you know the community of the home, the safer you will feel.

Arrange to call the facility every week for an update, until you feel comfortable. You may have to search to find a staff member with whom you feel comfortable and whom you trust to be honest with you. It may be the music therapist, it may be a nurse, it may be a dietitian.

Long-distance caregivers need to be very clear with the facility about their expectations. What information do you want, and how often do you want it? To what do you want the home to pay attention? If you can't put a phone in your brother's room, see if the staff can arrange that he talk to you once a week. Try to visit at least once if not twice a year, and set up care conferences in advance. Make sure you have at least one conversation a year with your brother's doctor. If you are not able to attend a care conference, make sure the home is having one annually and ask for the results. Learn about his medications. I have had care conferences in which the out-of-town caregiver is hooked up by telephone so he can listen in and participate to some extent.

One practical reason for ongoing communication is that you may recognize a change in your brother's condition before the staff does. They are with your brother every day. From a distance it is sometimes

## OUT-OF-TOWN CAREGIVERS

easier to notice changes that are occurring so slowly that they are evident only at intervals. Not that they wouldn't be picked up, but you may notice them sooner.

Out-of-town caregivers especially might wish to employ a companion. This is further insurance that there is someone who is reporting directly to you and does not have any kind of obligation to the home. The person doesn't have to be a spy, but can certainly be your eyes and ears.

If there is a primary caregiver in the city where your brother lives, you need to have some trust in her and what she does. It is not fair for her to have the burden of the tasks but not the permission to make decisions that arise from them. Make sure you do not take out on her your guilt for being far away. While it is all right to discuss major decisions, if you are going to second guess her all the time, then you need to develop another decision-making process. This doesn't mean that you don't keep informed; you do. But do it in a way that supports that person. When you talk about decisions she has made, ask if she is feeling that you disapprove or are critical. Even though that may be the farthest thing from your mind, remember that she is under stress. She may perceive what you say much differently from what you meant.

One of the best ways you can be supportive to your brother is to be supportive to his primary caregiver. This can be as simple as phoning her weekly to ask how things are going. Spend some time listening to her and what she is going through. This will help her feel she is not all alone. If you are willing to do more, ask her what you could do. Maybe come stay with your brother for a week or two, or, if you can afford it, hire someone to come in to give the caregiver a break.

It is particularly helpful to the primary caregiver if you can be there when your brother has to move into the home. Stay for a week after the admission, to support her as she (and you) go through the initial phase of adjustment.

It may or may not be a good idea to have your brother come stay with you. If your brother has dementia, it could be confusing and upsetting to be in a strange place. It will take him a while to get used to being with you and then when he returns to the home, he will have to become used to that routine again.

## OUT-OF-TOWN CAREGIVERS

If you are thinking about moving a parent to a home near you, consider several points. A long-distance move is hard physically and emotionally on a frail, older person. She may miss old friends and the familiar climate, landscapes, or daily newspaper. In a home near you, your mother may expect a daily visit; your idea may be different. A move can affect your work and family life. If your relationship with your mother was difficult, old conflicts can arise again. Before making the move, honestly look at all the repercussions: on you, your family, and your mother.

### Professional Geriatric Care Managers

In many areas you can hire a private professional geriatric care manager. This is someone who specializes in working with the elderly and their families. (This is what I do.) A geriatric care manager has expertise in arranging and monitoring systems to help people stay at home rather than enter care. If you are out of town, we can act as your surrogate. If you are in town, we act as your partner. We know your brother's medical problems, his background, etc. We usually know his finances. We know his values and yours.

We also are very involved with people in nursing homes. We can help your brother choose a nursing home, make the move, and follow him while he is there. We monitor the care he is receiving. We will read his chart, go to his care conferences, make sure he has clean clothes, good food, proper social and recreational opportunities. We will help "interpret" him to the staff. We provide counseling to him if necessary (and to you if you need it). It is often easier for us to be the one working with the nursing home staff because we are also health care professionals and can relate on an equal footing. Certainly we are not intimidated by the jargon or the systems.

To find a geriatric care manager you can call the National Association of Professional Geriatric Care Managers at 520-881-8008, or find them on the Web at [www.caremanager.org](http://www.caremanager.org). You can also try the phone book. As in hiring anyone, make sure you verify references and experience.



## *Lloyd*

I am an only child. I am fifty years old and have a husband and two teenage sons. Two years ago, my dad, eighty-seven, and mom, eighty-four, were living in another city. I used to visit for two or three days a month. During my time with them, we would be busy doing errands and visiting—generally taking advantage of the fact that I had a car and could help them get around.

Dad started “failing” and having “bad days.” We were unaware of the cause. We knew there had been “one or two small strokes,” but his declining health was inconsistent and the reasons for his difficulties—what we now know is multi-infarct dementia—were never explained to us. I spoke to the physician several times, but I was never given a clear diagnosis or an indication of what to expect.

What I didn’t know at the time was that Mom, the caregiver, was beginning to have some problems with dementia too. She was losing the ability to reason. She could not always be relied upon to give me the facts. She couldn’t cope with Dad’s declining health and was always trying to make him be what he used to be.

Over the next year, my visits became more frequent and lasted longer. By telephone, I arranged for in-home help twice a week to give Mom a couple of hours home alone or time to go shopping. I also arranged for Dad to go to an adult day center. I wondered at the time if I was forcing something that my parents were not ready for, but I am fortunate that they have complete trust in me and did not oppose the steps I took.

I also put Dad’s name on a waiting list for a facility. Nine months later, his name came up for a double room. By that time, Dad had lost most of his sight. The small strokes had made him almost totally confused, espe-

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cially with regard to space. He shuffled slowly. But he could still reason. He was really a sad, lost soul.

The facility was within walking distance of their apartment, so Mom could visit. She braced herself and coped well with his move. She enjoyed her walks to see him. Even with him in a home, she could look after herself but not after him. New batteries for his radio, new socks, his desire to have a phone in his room—all were insurmountable hurdles for her.

It didn't take me long to realize that I had to take charge. I remember that moment so clearly. The parents who had for so long been a strength for me now needed my strength. I was now the sole source of emotional support for Mom and Dad. At the same time, my teenage boys were learning to drive. Not good timing!

Against Mom's wishes, I bought a large-number telephone and had it installed in Dad's room. But being blind and confused, he could not always find the phone, let alone the memory button. He pressed other buttons and often erased my number from the phone's memory. Mom couldn't fix the phone. When I telephoned the nursing station, it was clearly explained to me that fixing telephones was not the responsibility of the nurse or the nurse's aides. When Dad's telephone did work, his calls to me tore me apart. He was so confused and knew that Mom was not able to help him.

Soon after that, I got a call from the social worker. She said that it wasn't working out in a double room. Dad was becoming agitated. She recommended a change to another facility.

So I had to shop around for another facility. This time we got one in the city where I live. After a short wait, he was admitted. We were happy with this facility and thought he would be able to stay there.

Then I had to deal with Mom, who was still seventy miles away. She became the major problem. She was unable to understand how the move had come about, even though she had been present for the discussions. She stayed in her apartment, afraid and overwhelmed at the thought of moving. I had Dad phone her every day, I brought her here for visits, and I showed her apartments in our area. But she always went away afraid and unable to make a decision. After a year, we had a call from a neighbor and then one from the physician. She was not coping.

I knew it was time to take over even more. We couldn't let Mom keep saying no to moving. We found her a small, assisted living complex where

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she was independent but had company and all her meals prepared. This filled the bill. I thought things were going smoothly.

Then soon after Mom moved we had a call from the facility where Dad was. He had been declining and needed more care. He was now confused, blind, and totally helpless. They were not licensed to provide additional care at that level. He had to move again. I had to start searching a third time. It did not help that many facilities offered tours only on Thursdays.

It has been just two years since my dad had his original assessment. He is now in his third facility. He still tries incredibly hard to keep the different staff members straight in his mind and to be socially correct. Three times now I have tried to help the staff understand who he was and what he has done in his life. I have tried to touch base with the nurses, the nurse's aides, the social workers, the recreation staff, the physical therapists, and the meal-time aides to tell them about this wonderful man who had such a rich past.

My parents are now, I believe, in situations that are suited to their needs. My sons have learned to drive. My husband continues to be a constant source of support and encouragement. Me, most days I keep my sanity!

## CHAPTER 16

# Making a Home Better

Whether your brother is in a good home or one that is not so good, you can try to have an influence on what goes on there. It takes some time and effort. There are actions you can take by yourself or with other families.

Your efforts at change can be aimed at the structure of the system itself or at the various groups or individuals in the home. Working with the structure of the system would mean, for example, targeting the philosophy, the communication patterns, and the policies and procedures. Ideally, work at this level filters down to affect the individuals. Working with groups or individuals would mean working with nurse's aides on improving care skills or working with dietary personnel to change serving habits in the dining room. Working with individuals or groups may be extremely effective and, ideally, will filter up, but it may or may not have an impact on how the home functions as a larger system.

When I spoke earlier about good homes, I spoke about good caring, which at the most basic level comes through the quality of relationships that are available and fostered by the home. The groups involved in those relationships include residents, families (including children and pets), staff, administration, and community. Whether you are working with a family council or on your own, and whether you are working with the structure of the system or with individuals or groups, try to answer the question: What can I/we do to build relationships among all of these parties?

## Include the Resident in the Change

I know this will sound silly, or like a given, but I want to remind you to involve the residents in making changes. It is their home. Their viewpoints should guide you. They are your allies. Cognitively aware residents and especially younger residents are valuable resources. Use their skills. Involvement in change helps give them a sense of ownership and of being needed and useful. It allows them to be leaders and in control of themselves. Encourage them to take control of seeking change.

As I have tried to point out throughout this book, sometimes family members have different needs from residents. What the residents see may differ from what you see; what they want may differ from what you want. If you don't know what they want or see, do a survey or help them do one. Think of yourself as supporting what they want in order to make their home better while working to meet the needs of families at the same time. Ask how to allow yourself to be used by residents.

## Individual Actions

The easiest solution to making a difference is money, of course. Donations are always welcome. You can make a one-time donation and earmark it for something special or let the home choose what is needed. They may wish to add it to other funds, such as an education or Christmas fund. If you wish to purchase something, look around and/or ask what kind of equipment is on the wish list of the residents council, staff, or administration. You can also set up a fund and direct it toward a certain project or department. If you don't trust how the money will be spent, buy the gift yourself and donate it.

Most homes also usually need volunteers. If there is no volunteer coordinator, talk to the head of recreation. Maybe you can come in half an hour early or stay half an hour late and use that time to do something as a volunteer. Or maybe you can make one of your weekly visits a group visit in which you run an activity or small group—it can be something as easy as reading to two or three residents or playing cards with your mother and one other lady. If you take your mother

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out for ice cream, take another resident. This will also help your mother develop a friendship (although she may be jealous and not want to share you).

You can act as a buddy to family members of new residents. Maybe you can answer phones, give tours, etc. Look around and see what is missing or what you would have liked when your brother first came in. If you have an old computer, bring it in and teach some residents how to use it. Donate an Internet connection. Get an e-mail address for different residents. Maybe you can bring in plants and make watering them part of the activity that you do with your mother. A warning: Make sure what you are doing does not take away from a union position. If you start doing union work, that can lead to trouble.

If you have a pet or grandchildren, bring them in and share them with the residents. Children and pets provide some of the best stimulation possible. Warmth, caring, and love hold on and can be felt to the very end, when everything else is gone. It is remarkable to see the joy on a resident's face when she sees and holds a small baby. Seeing the same ones regularly will help residents develop a relationship with them. All they need is ten minutes, and it can make a difference. Even cognitively impaired residents will hold a child correctly and be able to talk to him.

## Working with Other Families

Sometimes the most effective changes will occur when you work with other families as a group. You can start with just one other family if you have to. This can also help you develop a sense of what is an individual problem that you have versus what is a systemic problem. If something is bothering you but no one else feels the way you do, this could indicate that it is your problem, not the home's. If a number of other families have experienced the same difficulty, this is information that you can take to the administration and present as a problem to which the home needs to pay attention. If the administration resists making changes, you can offer to do a more systematic collection of the data. When you have information about when the problem occurs, who else is involved, what else is occurring, etc., this becomes a powerful and irrefutable tool for instigating change.

## MAKING A HOME BETTER

Many homes have formalized family input through a family council. In the United States, a nursing home must provide meeting space for a family council. A family council is a group of family members and friends of residents whose focus is improving the quality of life at the home. They should be organized or at least run by family members and be legitimized by the administration. A family council is not a forum for a witch hunt, nor is it a forum to take revenge. Especially in the beginning, families often use it to “get” an individual staff member. If it is used that way, it will accomplish nothing and will cause increased friction and mistrust between staff and families. On the other hand, if the staff sees that the family council is working with them, they will come to see it as a valuable tool. Care can improve.

Family councils can do incredible things—raise money, run activities, put on welcome teas for new residents and new families, problem solve, mediate between individuals and the home, set up libraries with books, films, and videos, start a day care or an after-school program for the staff’s children, and bring in outside resources such as speakers. They can bring warmth and hope to families, staff, and residents.

In most homes there is a huge need for education and upgrading. A family council can be instrumental in funding education and upgrading programs for staff. Or they can fund a consultant who comes in and works with the staff on the floor to help them develop their skills. There is often either overt or covert illiteracy in a home. A family council can fund literacy programs or the members can help teach reading and writing.

The family council can be an effective forum for going to the state ombudsperson or state or provincial licensing agency. If you are noticing neglect or abuse in the home and it is not being addressed by the administration, use the family council’s strength in numbers to begin to go outside the home. The council can do an informal (or formal) gathering of data on the problem to present to the state agencies.

A family council can help implement an ethics committee, or, conversely, an ethics committee could be a precursor to a family council. Ethics committees in health care started in hospitals to deal with issues such as the allocation of resources, which research to fund or allow, when to allow a patient to die, etc. However, in a nursing home

they can be expanded to help decide a much broader range of issues. How do you decide whom to move if roommates are having difficulty? How do you decide when a home is no longer appropriate for a resident? When is a family member becoming unreasonable? When are the home's regulations becoming too onerous? When staff and families sit down together to look at these questions from an ethical viewpoint, it helps shift them from a source of contention to a source for learning, so it takes away the power struggle. An ethics committee gives you the opportunity to develop some understanding of how other groups in the system think and what they see as important. It helps you see each other as people and work together.

The decisions made by ethics committees are complicated, and it may take some training time to get one off the ground. During the training time, you are building some trust among committee members—families and staff—and developing a common framework for viewing problems. This will help the committee to function effectively.

### Working with the System

If you start working to change the system, you will be working with the administration, staff, and possibly unions. They can be extremely wary of working with family groups and of where family-led initiatives will lead. They are often afraid that groups of family members will come together only to criticize the home, personnel, or care. This is especially true of the nursing staff, who usually end up receiving the brunt of complaints because they provide the primary care and because they are the largest department. Remember, the staff is one of the family council's client groups. If you do not have their support, they can sabotage what you are trying to do.

Staff members and groups will have to accept the changes you want. This may entail going to staff or department meetings. Explain what you are doing and ask them if they wish to have input. You can also let them know what is in it for them. If all they see is more work, they will not support what you are proposing.

Anyone working for change in an organization needs to be aware of the culture and history of the organization. This includes developing an understanding of the corporation or society that may own the



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home. When you understand this, you understand how the organization really works and why. If you understand the organizational culture and history, it helps you understand the reasons for what people do. It will enable you to see the personnel as real people who often are as unhappy with the system as you may be. This understanding helps them feel validated and accepted. It sets up the conditions for positive change.

One of the questions you can ask when working with a family council and the system is how to help create a home in which the residents are more responsible for their own lives. When people come into a nursing home, they give up all their responsibilities and tasks. Everything is done for them. I think this is very destructive. Residents often say they want to feel useful. Having responsibilities and tasks gives structure, meaning, and normality to life.

Look at all the tasks that are done in the home. Figure out which ones the residents can do. Can they help in the kitchen, the laundry, the office? You may have to make some shifts in job descriptions, insurance, etc. For instance, a housekeeper may help a resident to wash his sink, rather than washing it herself.

Changing job descriptions may involve unions and negotiating, so be realistic and be aware that it will take some time. This is why people need to understand how it will benefit them. You may start in one section of the home or on one floor.

Start your efforts for change positively by finding what is right with a home. Building on the positive can help set the stage for working on the other parts. What do you see people doing that is positive? Under what circumstances are they doing it? How can you increase these circumstances so that the positive actions occur more often? For example, when is a nurse able to spend psychosocial time with a resident? Why at that time? What needs to shift so that those conditions can be replicated at other times? What can you and other families or resources do to help make that shift possible?

It is helpful to have an overall vision of what you would like to see happen. Work with the staff and administration to develop a common vision. Jeff Danglo at his Web site, "The Truth about Nursing Homes" ([www.jeffdanger.com](http://www.jeffdanger.com)), says, "If I heard someone say, 'I can't wait to go live in a nursing home,' I would recommend they receive psychi-

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atric help.” Perhaps the question you could ask is, “What can we do to make this a place where people would want to come to live?” You might not achieve your ideal, but it is a good place to start.

Another question you need to ask is, How will the changes affect the company’s bottom line? Sometimes, the answer can be as simple as the change will increase staff satisfaction, which can lead to increased efficiency. If you can demonstrate that it will help or not add to costs significantly, the administration will be more receptive to change.

Be creative. What would you like to see happening? Children in day care? Pets and plants? After-school programs? What can be done to make the house a home? What is life at home really like? What can be done to replicate that life in the nursing home? What can you do with the rooms and the hallways?

Think of the home as what it could be beyond a nursing home. Could it be a community center, a shelter, or an art gallery? Can the dining room become a small café for the community? Is there a yoga teacher who is looking for a space to teach a class? a night school looking for space? See if the American (or Canadian) Legion will hold a meeting or chapter there. Bring the community to the home, because so often the residents’ access to the community is limited. They don’t have to participate; often they like to watch activity. That in itself is stimulating. (For more on changes and vision, see *Life Worth Living: How Someone You Love Can Still Enjoy Life in a Nursing Home—The Eden Alternative in Action*, by William Thomas. It is an inspiring guide to what a nursing home could be.)

Once there is a vision that is validated by all parts of the system, you are ready to create the methods to achieve it. Take a look at what it would take from you, the staff, and the administration to make it happen. Does it mean money? Does it mean a time commitment? Look around for other homes that have tried what you would like to do. How did they do it? You may want to consider hiring a consultant to help manage the change.

Remember that for most people and organizations, change doesn’t happen overnight. It is a slow process. There are always staff in a home who will resist change and who will feel threatened by it. This can be for a number of reasons. They may have a vested interest in

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keeping things as they are or they may be lazy. Sometimes they are afraid because they think they don't have the skills or capability to do something different. They may have tried to change things in the past and have been thwarted, threatened, or undermined; now they are so discouraged they don't have the energy to try again. A home may not want to be exposed. Sometimes the administration doesn't want to spend the money or is afraid of what the costs will be. If there is a union involved, the union can resist the change out of concern for loss of employment.

*Don't allow yourself to be discouraged or put off!* I was recently working in a very good home, where the care and the caring were wonderful. It was a beautiful facility, small, homey, clean, and bright. But there were no pets. Well, to try to bring a cat into this place was like trying to buy New Zealand. We had to have a committee to examine how it would affect the staff, how it would affect the residents, who would feed it and clean it. We needed a policy about it, we needed family meetings. Discussion about this cat took months. I was ready to tear my hair out. But we just kept working, went as slowly as the system needed, and kept our eye on the goal.

If you need a guide for managing change, follow these questions:

1. What is your vision?
2. What would it look like concretely if it were to happen?
3. What and where are the resources you need to make it happen?
4. Who are the people or groups, inside or out of the home, who need to be involved to make it possible?
5. What are the steps you need to take to make it happen?
6. Where are the potential problems, and who are the people or groups who could derail it from happening? How will you meet those challenges?
7. How will it affect the company's bottom line?
8. Will there be any unintended results because of the change?
9. What do you have to do to make sure the changes become part of the system and are functioning effectively?
10. What will the signs be when the change has occurred and been implemented? What kind of evaluation and follow-up will you do?

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11. What will you do to make sure the change is working in the way that you planned it?

When you have answered all of these questions, make a flow chart to document the path you are going to take and the various issues that could take it in different directions—the “if this, then this” part of flow charts.

Good luck! When you feel that you are working positively, it will give you hope, energy, and enthusiasm. When you feel that people are working together, it will already start to make a difference.

## *Ann*

The move to the nursing home came at a time when Mom's condition precipitated a crisis. She had been forgetting to eat, and her food would be left in the microwave to spoil. My sister was going over there every day to check on her and make sure she was taking her medication. But one day Mom wandered away from her apartment. Only through a miracle was she able to tell the police that her son worked at Divine Providence Hospital and give his name.

The home was just opening, with a dementia wing that had access to a closed-in yard and was secured so the residents could not get out. It was a beautiful new home and very tastefully decorated.

The first few months were painful not only for Mom but also for us as a family. It took many months for her to adjust to the home, to begin to make friends, and to join in some of the activities. The guilt, pain, and frustration of not knowing if we were doing the right thing caused differences of opinion and separation within the family. This was probably the hardest time for me, as Mom would ask to come home with me and I knew I could not take her. I dreaded having to say good-bye and explain why she could not come with me. I assured her that I would be back very soon.

After almost a year, we finally felt that Mom was adjusting and seemed happy. My sister called and told me Mom went on an outing to Riverside Park and rode the carousel! The home took a picture of her; she was smiling and seemed to be enjoying herself. This was the first time in about four years that we had a feeling of contentment about Mom.

Our period of calm came to a halt when Mom started having falls for no apparent reason. One resulted in our taking her to the hospital for X rays. We took her to the doctor to see if there was a medical reason that

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she was falling. We purchased new shoes that were flat and easier on her feet. We ordered a walker to help steady her. We talked to the owner of the home about the falls and what could be done. She suggested putting a monitor on her at night. This monitor was to ring if she got up, and the staff would go in immediately to assist her.

Shortly thereafter, one of the employees said to us they were not treating Mom very well there. We asked what she meant by that and she would not explain—just that they weren't treating the residents very well. We then had several talks with the owner. We explained what we heard and tried to get some answers as to why Mom was all of a sudden falling.

The owner was at first not receptive to our concerns and seemed to think that we were trying to make trouble. She intimidated us by telling us that she had asked a lady to leave the home because her daughters were making trouble. We learned later that other families had had the same threats. At the time, we did not understand that this was a tactic used by nursing homes to keep residents' families from asking too many questions.

When we brought to the owner's attention what the employee had told us, she was very defensive and said she did have some employee problems but that she would never allow them to mistreat the residents. She reassured us that Mom was well taken care of. She wanted to know to whom we talked because she had some troublemakers.

Mom continued to fail both physically and mentally. She could not communicate with us, was lethargic, had difficulty eating, and was losing weight. We took her to the doctor again and again. He put her on a high-calorie drink to give her more energy and to supplement her diet. There were numerous visits to the doctor; at one point he thought she might have had a stroke. We talked to the owner again. She reassured us that Mom was doing okay. We did look into other homes at this time and put her on a waiting list for one, but it was a year long and we were concerned about having to move her again, as her dementia would have made the move frightening and devastating.

In November Mom took what we were told was a fall. They said a staff person tried to take her to the bathroom but she did not want to go and pulled away, falling face down to the floor. She was unconscious for five minutes and had severe bruising from the top of her head to her neck. My sister rushed her to the hospital.

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We didn't find out what really happened until four months later, when we had a birthday party for Mom. She was like her old self again, smiling and laughing with the family. She was able to talk to us and seemed happy. She said, "Life is good," which was joy to our ears. When we were leaving the party, one of the nurses made the remark, "Isn't it nice that your Mom is beginning to talk again?" We said that we thought it might be one of the new medicines. The nurse said, "No, that is not it. I would like to talk with you. Please call me at home." This was the beginning of a nightmare for us.

Later that night we called the nurse, who told us the reason Mom was talking was that she was no longer fearful because the two employees who had been abusing her and other patients were gone, and that Mom now felt safe. She went on to tell us that the fall Mom took in November was probably not a fall. She was the nurse on duty. When summoned, she found Mom on her back, knocked out. She also commented to us that the first thing Mom said when she regained consciousness was, "He hurt me," and pointed to the aide who was taking her to the bathroom. The bruising was on Mom's face; the nurse's concern was why she was on her back.

The nurse told us that she reported this incident to the management of the home and to the state department of health. Neither one did anything about it or said anything to the family. The employees, including herself, were threatened with their jobs if they talked to any of the families. We asked her if she herself had ever seen anyone abuse Mom or any of the other residents. She said she had not, but gave us a list of employees who had either turned the abuse in to the state agency or brought it to the management's attention. All this time we thought that Mom was falling. We thought we had done everything to help her.

After hearing from this nurse, we immediately took Mom out of the home and placed her in a nursing home, where she died three weeks later. We filed criminal charges with the city sheriff's office, which in turn sent it to the attorney general's office. The investigation revealed that records were hidden from the investigators. It turned out that there had been numerous complaints from employees who had witnessed abuse not only to our mother but to other residents as well. They started to investigate only when we told them we were going to the media. After the investigation was completed, we initiated a lawsuit against the home and the department of health.

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In hindsight, we found out that we trusted a precious life to those whom the investigation revealed were concerned only with making money. We see that we were too trusting and believed that they genuinely cared for the elderly. We learned that you have to trust your own feelings and question any action by caregivers that makes you suspicious. It is our right and obligation to do so. We were not of the mind-set to look for problems, nor did we go there to visit the staff; we went there only to spend time with our mother.

In looking back at this painful time in our lives, we have searched our souls, beat ourselves up, and read everything we could about nursing homes, trying to see what we could have done differently. We will spend the rest of our lives living with, and being haunted by, the guilt and memory of the pain and suffering that Mom went through.

Four years have passed. We are still involved in a lawsuit. Aunt May, my mother's sister, having suffered the knowledge of what happened to Mom, told us, "You have to fight for us old people because we can't." Those words give us the fortitude to keep fighting for justice. We have agreed to tell all, do all, and be all we can to see that the elderly are treated with the respect and love they deserve. We want to make positive use of our experience by advocating for continued improvement in care for the elderly.



## CHAPTER 17

# Difficult Decisions and the End of Life

### Living and Dying

Many people feel that admission to a nursing home means they are going somewhere to wait until they die. They believe it is the last stop. Your husband may say, “The only way I am coming out of there is feet first.” That may be where the resistance and sadness come from. A frank discussion of what he thinks is going to happen to him, how long he is going to live, and whether he is scared can be helpful to both of you. This may be an opportunity for you to talk about your feelings of living without each other.

At the same time, it is important to remind your husband and yourself that he is going into the nursing home to live, not to die (unless, in fact, he is in palliative care). While there is the process of loss and grief in the transition to living in a nursing home, the resolution of that grief is that life is going to go on. He needs to remember that, and you need to remember it, too. However painful at first, your life will go on. In the beginning you may not feel that way and it may not help you to hear that from me, but we are remarkable beings and people do adjust.

Even though your husband is going into the home to live, there may come a point at which he is truly dying and you will lose him in the near future. When a family member is dying, in some ways the death is a part of the relationship and the relationship too will die. You are going through this together. There is no “right way” to “do death”; there is only what is right for you, for him, and for your relationship.

## DIFFICULT DECISIONS AND THE END OF LIFE

In our society we don't talk about death easily, or at least not about our own. Perhaps even less do we talk with someone we love about his or her own death. We hush it up and close it off. The problem with that approach is that it robs us of the opportunity for a unique, intimate, and meaningful part of a relationship.

My mother died, after two years of fighting breast cancer, when I was twenty. One of the biggest regrets I had was that I had never said, "Thank you. I love you." I forgave myself by letting myself think that she knew how I felt. What I learned from that and since then in my professional life is that the experience of saying good-bye to someone as she is dying is healing for both of you. It can be a moment of incredible love, sharing, and intimacy. It can be a time when you forgive what happened to you and in which you ask forgiveness for what you have done, even the small things. Allowing yourself this opportunity for forgiveness allows you to let go of whatever you are holding onto and what is eating at you. It can give you and the person dying some peace. It can set you free for the rest of your life.

### Talking about Death

My experience has generally been that the person who is dying is willing to talk, at least to some extent. People who are dying have told me many things—sometimes they are ready, sometimes they are not; sometimes they are frightened, sometimes they just want to talk about their lives. Sometimes people talk about their sadness at leaving their family or the feeling of being cheated. Sometimes they talk about their worries about what will happen to their wife and children after they are gone. Sometimes they do not want to talk at all.

It can be easier for the person who is dying to talk about death than it is for those around him. Often, it is the relatives who are not ready to talk. By various means they let it be known to the person who is dying that they don't want to talk. Not talking helps people avoid the pain. You may say that you don't want to upset your husband by talking to him about death, but it may be that you do not want to upset yourself.

So you need to think about, and maybe test out, whether it is you who needs to talk or doesn't want to. Is it your husband who wants

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to talk or doesn't want to? Are you ready to listen and/or is he ready to listen? Who is avoiding and who is willing?

It can be frightening to talk about death. That doesn't mean we shouldn't do it; it means that we need to face the fear. The fear may be harsher than the conversation itself; not talking about it may take more energy than talking about it. Ask yourself what you are afraid of, or what are you afraid will happen during the conversation. Once you can verbalize this, it may help you realize that you don't have to be afraid. You may want to write down what you want to say, maybe just in outline form, to help you face this.

The way to talk about death is to start. It can feel clumsy and awkward, but just start. I have started sometimes by asking people, "Do you know what is happening to you?" Sometimes I ask, "Do you know what your diagnosis is?" or "What have you been thinking about your condition?" Sometimes I ask directly, "Do you think you are dying?" You can also talk about your feelings. You can say, "I am afraid I am going to lose you," or "Can we talk about what is happening to you?" (For more on this, you may want to read *I Don't Know What to Say: How to Help and Support Someone Who Is Dying*, by Robert Buckman.) You have to feel and grope your way through the best way to have this conversation.

If you really cannot bring yourself to talk with your husband about his death or dying, try talking to the home's social worker, nurse, or another professional first. They can tell you if they have already talked about it with him. Also, once you begin to talk about your fears and feelings, you may have the strength or courage to talk to him.

If you feel that you simply cannot talk about it at all, do some reading about death and do some of your own writing. Keep a journal. Write a letter to yourself, to your husband, or to God. A first step in writing may be to write about what you still have instead of what you are going to lose. You don't even have to write directly about death; it may be easier for you to talk to yourself in metaphors. Write about endings, about how summer turns to fall, then winter, and how leaves fall off a tree. Write about yourself standing on a railway platform, watching the train move away down the tracks; about when you left your child at school on his first day; or about closing up the summer house for the last time. Read what you have written, maybe the next

day or a few days later. The writing can be a first step and can prepare you to talk more directly.

When you talk with your husband, talk about what *you* feel and think, about your fears and sadness. That is how you go through this together. Recently I had a friend who was dying, and I listened to her talk a lot about her illness. I kept having the feeling that something was missing or unbalanced in our conversations. Finally I realized that I wasn't participating. I was listening, but not giving of myself. I started to tell her of my sadness when I thought of not having her around and what a gap there would be in my life. I felt very vulnerable and sad when I was telling her, but it put us on the same footing in a way. She was able to help me with my feelings. We felt much closer afterward.

When a loved one is dying is not necessarily the time to "be strong." Doing so may be robbing your husband of the opportunity to be strong for you. He may be able to comfort you, and that can be good for him.

Sometimes people are afraid that if they "break down" they won't recover. That is not true. Actually, the ability to let go will make you stronger. If you start to cry, you will stop.

### Facing Death

To be the relative of someone who is dying can bring up feelings of helplessness, failure, and guilt. When my mother was ill, it was like watching her slowly slip away and, no matter what I did, there was no way to stop it. You may find yourself asking again if you did all you could or reviewing what happened and thinking, "I should have taken him to the doctor" or "I should have had them give him that medication." You may find yourself angry with your husband for leaving you by yourself or with problems. You may be short-tempered with your children and at work. You may also find yourself angry with the nursing home and the staff, thinking, "They should have done more" or "If they had sent him to the hospital earlier" or "The doctor should have paid more attention." These are the same grief stages you went through around placement. They are all normal. If you ask other people who have lost a husband in a similar situation, many of them will tell you they felt the same thing.

## DIFFICULT DECISIONS AND THE END OF LIFE

Unless your husband's condition is a result of abuse and neglect, you need to be aware that probably nothing you could have done would have changed things significantly. People die. People are left behind. You know that.

If your husband has not signed an end-of-life document, and sometimes even if he has, there still may come a point where the home wants to talk to you about his condition and ask you how you want to proceed with his care. They may tell you that if they take certain actions, his life will be prolonged; if they take another course, it will not be.

There are a number of fairly common circumstances in which these end-of-life decisions arise. Your husband may develop pneumonia, and the home will ask if you want them to treat it with antibiotics or by sending him to the hospital, or just to allow nature to take its course. He may go into congestive heart failure. Do you want to let him go, or treat it? He may be diagnosed with some form of cancer, for which an operation is possible. Do you want them to operate? He may have symptoms that tell the physician that something is wrong, but it's not clear what it is. Do you want them to do some investigative procedures to find out what it is so that they could possibly treat it? If your husband has stopped eating or drinking, do you want a feeding tube inserted?

These decisions in some ways mark the turning point at which someone is or will be actively dying or will be allowed to start to die. At this point, if you decide to let your husband go, the home will begin to provide what is usually called palliative or hospice care. Palliative care is an approach to care in which the goal is to make someone's dying and death as comfortable and pain free as possible. Aggressive or experimental treatments will not be used. Care will include a great deal of emotional support for the person who is dying and the family. It may entail moving to a hospice facility or having special hospice workers come to the home. Sometimes a nursing home has a palliative care room. Many homes will keep someone while he is receiving palliative care until he dies.

It is up to you how you handle this, unless the situation is clearly written in your husband's advance directives and those directives are legally binding. What the home and physician are asking you to think

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about is “Do you think your husband’s present quality of life is such that he would want to go on living?” They are also asking, “If we do this procedure, what quality of life will he have afterward, and is that something he would want or you want for him?”

These are life-and-death decisions, and they are immediate. With one choice, your husband will live longer; the other will allow him to die, probably shortly.

Having to make this kind of decision can be a painful experience. When my father became acutely ill after having a chronic condition for many years, he ended up in the hospital. The staff told us that if they took certain actions, his life might be prolonged for a while, but that he would ultimately die from the condition. One of the hardest things to do was to tell the staff to let him go, even though some of us in my family weren’t ready to do so. They were hanging on, but for their sake, not his. My sister, crying, told me, “Peter, I’m not ready to let him go yet.” This is another reason for having advance directives and conversations about death with your relative. They give you permission to do something that otherwise would be too painful.

I have known some families who insisted that their mother be taken to the hospital several times and given intensive care even though she was clearly not having any quality of life, was in pain, and did not wish to live any longer. They were not able to let her go. To me that seems a little cruel and selfish. I don’t know about you, but if someone were acting out of love for me, I would want them to do what is best for me, not what is best or easiest for them or what would make them feel good. We have to die of something. It was an incredible act of strength and love when my sister agreed to let my father go. Is it better to let your husband die of pneumonia in a few days or weeks, or is it better to let him continue for a year or more, becoming ever more disabled and confused from dementia? Would you want to continue if you were in his situation?

Think about what he would want. What kind of quality of life is he having now and will he have later on? What would he want for you and for the family? When you can answer some of these questions rationally, the decision may come more easily for you. This is a very good time for you to talk to your pastor, priest, or rabbi.

The decision to let your husband die can be one that will provide

you and him with the relief that either one or both of you have wanted for a long time. This may be because he is in pain, because he has no quality of life, because he is completely unaware of his surroundings, or because you are exhausted from being a caregiver. Having made the decision can give you some serenity out of acceptance for the outcome, although it might not make his death easier on you.

Because you have wanted the relief, you may feel guilty about making the decision to let him go. Let me assure you that many relatives have a part of themselves that is “hoping” their loved one will die. Many people have seen a relative come close to the point of dying, get well, go downhill, then get better again. This can occur several times. The impact of having to prepare oneself several times is very hard; this is another time when people think to themselves, “I wish he would just get it over with.” Sometimes people hope a relative will die at a certain time because they have holiday plans. I know of one family member who was by her dying mother’s bedside for hours during the days. When she got home in the evening, she would stomp around her house yelling, “I wish you would die already.” All of these are normal and common feelings.

You are not a bad or evil person for wanting an end to a difficult situation. Your feelings are your feelings. It is all right to have them. It just means that you have conflicting feelings—you can love someone and not want him to leave you and at the same time wish that he would die. What you want for your husband and the feelings you have for him can be different from what you want or need for yourself. This is another time when it is good to have a support group or just someone else with whom you feel comfortable enough to share these harder feelings. That person can support the part of you that knows it is okay to feel that way, so you don’t get tripped up by the part of you that thinks it’s not.

### Younger People and Death

In some ways, the younger your husband is, the harder the issue of death can be. It can be more difficult to talk about with him or face it yourself. There are often much greater feelings of anger, and certainly there are much greater feelings about the unfairness of the sit-

uation. With an older person, at the very least there may be the comfort of knowing that he has had a long life; with a younger person it is as though something is being stolen from him, and from you. At the same time, your feelings of wanting relief from the strain can be greater because some of the practical issues—issues of payment or of juggling a growing family and career—can be greater, which can give you an even greater sense of guilt.

The younger a person is, the harder it is to make the decision that you are not going to ask for another operation or to decide to turn off life support (or not to start it). This is why it is especially important that you try to have a discussion with your husband about the possibility of this situation and what to do if it arises. It is also when the advance directives have greater value.

### After Death

After someone dies, the nurse on duty has to call a physician or official to have a person declared dead. If you were not present at the death and you would like to view the body, you will usually have a chance to do so. Make sure the home knows that you want to do so. If you want someone to be there, ask a friend or a pastor, one of the nurses, a social worker, or another staff member if there is someone to whom you feel close.

After you have stayed with your husband for a period, the home has to call someone to remove his body. You will have to know where you want the body to go. So you will have to know what kind of funeral to have or whether you will have one, where it will be, and all the other complicated and sometimes expensive decisions that have to be made about death. This is why it is a good idea to have made arrangements beforehand—it is very upsetting to have to do it when you are in shock or in new grief. As I said earlier, when you are in a very emotional state, it is hard to make decisions; it is easier to be influenced or let someone else make the decisions for you.

When someone has died, the nursing home usually wants the person's effects to be removed as soon as possible. They will want you to remove your husband's things from his room that day or the next. In a period of grief, that may seem to you to be selfish and cold. In some



ways, it is. However, no matter how much grief the staff may feel at the resident's death, the functioning of the home—the care they provide to residents—is usually based on beds being full close to 99 percent of the time. Without this income, staffing would be lower.

One of the homes where I worked made it a habit to send a staff member to the funeral of residents when they died, but many places do not do that. Please do not think that this means that they do not care. What it probably means is that they do not have the luxury of sending staff.

### Saying Good-bye to the Home

The death of a relative in a nursing home often means the loss of a number of relationships. As I have mentioned, during the time your husband is in the home, you will come to know the staff, the other family members, and many of the other residents. Even though he has died, these people are still there and they may have come to mean a lot to you. If you have been in a support group or part of the family council, you have developed a role for yourself in the home. In some ways, these people and groups have become your family. The hallways of the home have become more than just hallways; they have become the pattern of your life.

With your husband gone, you may feel that you have no place in the home anymore. In a sense, that will be true. Just as you took on the role of “the family member,” you are going to have let go of that identity. Once again, there will be a gap in your life. The adjustment that you will have to go through is similar to the one you went through when your husband first went into the home. It will be like finding a new life pattern for yourself.

It may take you some time to withdraw emotionally from the home. Partly this will be because it will be hard to let go of some of the relationships. Partly it will be because keeping involved in the home is a way of holding onto your husband. Partly it will be because it is hard to develop a new life pattern and role for yourself. This is why it is important for you to cultivate some activities, friends, and support outside the home even while your husband is there.

Some people do stay involved in the home for a while as a mem-

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ber of the family council or as a volunteer. If you have been a member of a support group, you can go a couple more times to say goodbye and talk about what you are going through now. This will be helpful for you and for the people who have not lost a relative. Some homes have memorial services or allow family members to have memorial services for their relatives in the home.

At some point you may want to do something that signals to you emotionally that you are leaving the home behind. Many people send flowers or a small gift to the staff to thank them for the care they provided. Some people set up a small fund or buy a piece of equipment as a memorial to their relatives. It does not mean that you are letting go of your husband's memory; it means you are allowing yourself to go on with your life.

## *Donald*

My father was admitted to a nursing home in September. He had a diagnosis of Alzheimer disease and had developed something called sun-downing syndrome. His confusion and agitation became worse at night, and no one could care for him at home, since his schedule was different from everybody else's. We were afraid he was going to hurt himself or wander off during the night.

My mother called and toured several facilities, but she finally decided on the one facility that told her they had a "special Alzheimer unit." In reality, this turned out to be nothing short of a jail, where mostly old people, but some younger people, were warehoused together in a locked unit, with the barest of custodial care. At the time, it sounded good, and we were naive enough to believe that this place really did offer "special services" and was a "special" place for Alzheimer patients.

I think that *naive* is actually the right word. When we look back on it, we ask ourselves how we could have accepted this, but I guess in a small town in rural Arkansas there wasn't much choice. We knew how it smelled in there, we knew that there was only one orderly and one licensed nurse, but they were the experts. My mother was eighty-one, my brother had no idea about care for an elderly person, and I was living far away with a young family.

Within a month after Dad went to the home, little things were happening: Dad would have a bruise on his arm; Dad was in bed because he had had "a fall." Sometimes my mother would call me and tell me, but sometimes she didn't want to worry me. When she visited, he would ask her, "Why am I in jail?" and "Why won't you take me home?" My mother

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would bring him food because he wasn't eating the food there. She thought he just missed her cooking—he had been eating her food for fifty-five years.

The staff always had an answer for us. His skin is fragile, he hit his arm in the shower, and he was forgetting to eat or couldn't sit still long enough for them to get him some nutrition. They would say that Alzheimer's patients often get confused about where they are and that it was common for them to think that they were in jail. To my family, all of those explanations made sense. We always had the feeling somewhere inside that things weren't the way the staff said, but we had no way to prove it. We are not a wealthy family; if we were, we would have hired private help to watch while we weren't there. That also meant that we couldn't move Dad easily—we couldn't pay \$4,000 a month for another home.

If I were reading this, I would be wondering, "How could they not know?" The hard part is, like I said, we did know if we listened to ourselves. We were in crisis—about my mother and dad having to split up after fifty years, about how my mother was doing. It is like being in a nightmare and you don't know where to look first to try to make some sense of it all.

Finally in May we decided that we had had enough. My mother decided to try to sell some family property and use the money to move Dad to another home. But land wasn't selling very well, and it didn't sell fast enough. If it had, Dad would still be alive. If it had, he would have been somewhere else on October 4. If, if, if, . . .

My journal starts from here. I omit some of the passages describing the horrible complications he suffered because of the injuries.

#### OCTOBER 4

Dad either fell or was pushed down at the home, at 7:30 on the evening shift. He says he was pushed; the staff, of course, knows nothing. He wasn't seen at the emergency room until noon the next day. The ER doctor ordered X rays, and discovered that Dad had a severe fracture of the left hip, a broken forearm, a puncture wound on the forearm, and a bone bruise on the knee. The home never had to explain these injuries because we couldn't see them. Dad was also dehydrated to the point of kidney

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failure. The surgery to repair his broken hip was delayed until the 7th. The orthopedic surgeon said Dad would never survive the surgery due to his weakened condition, so it had to be delayed until he stabilized medically.

#### **OCTOBER 16**

Dad is having a feeding tube placed in his stomach, to keep him from starving. I object to that strongly, but the doctor wins. And everybody else is listening to him.

#### **OCTOBER 22**

This morning Dad couldn't breathe, I called respiratory to come ASAP. X rays show Dad to have pneumonia, doctor says bacterial, but I know better. Too much fluid, but who will listen? The doctor says Dad is hanging by a thread, won't make it through tonight, but again he is wrong. You will make it Dad, you won't die in this stinking, god-forsaken place.

#### **OCTOBER 23**

I heard you screaming from the chapel at the end of the hall, where I went when your nurses removed the fecal impaction. Oh God, help me. Help Daddy make it out of here, he wants to go home. No one wants another feeding tube now for you, Dad, except that doctor of yours. I should have been stronger and demanded you not have one in the first place. You'd be home by now, eating. We've made another bad decision for you this time, Dad.

#### **OCTOBER 25**

Your doctor, case manager, and social services worker have all said how unrealistic it is for us to expect that we can manage you at home. The doctor suggested you go back to the nursing home. He wants to place another feeding tube in your stomach before he sends you, since once wasn't enough for him to learn. "How are we going to make sure he doesn't pull this one out, Doctor?" "We'll put him in restraints." Tied down, for how long? "Well, we'll have to keep him tied pretty much 24 hours a day." No thanks, doctor. He is not going to be in that nursing home again. We're taking you home, Daddy, which is where you always wanted to be, anyway. Did you have to do this to yourself to get there? No one should have to live, or die, tied down.

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### **OCTOBER 27**

Well, you're home now. Do you know that you're home, Daddy? See the trees are all changing colors, Scorpio is in the yard, look at the pictures of the babies, Dad.

Now I know what happened to you at the nursing home. I got Mother to demand the chart. They didn't want to give it to me, they didn't even want to give it to her. At least we knew the law about that. Now I can see what really was happening there, how you got pulled out of bed by the staff. They pushed you around because in your confusion you were feisty with them and fought when they were trying to make you do something you didn't want to do. I can see how they lied to us. Where the bruise on your elbow was, one of the LPNs said that you got it in the bathtub but the nurse charted that you caught your elbow on the bedrail.

### **NOVEMBER 10**

You have a UTI infection, as I suspected. We are at University Health Center now. I hate this feeding tube, and so do you. It won't work, will it? Is that why you asked today to have it cut out of you? Why won't you eat? Why do you tell me, "I don't do that no more"?

### **NOVEMBER 23**

Daddy talked to me today. He was lying very peacefully in bed, and said out of the blue, "I'm not afraid to die." "Do you want to die, Dad?" "No, but I'm not afraid to die. I'm at peace." Please, not yet, not yet, we have some things to do, Daddy. Not yet, please, please.

### **NOVEMBER 26**

As I was rolling Dad over in bed today, he said, "Don't push me out of bed." Why, Dad? You're in bed, you can't fall. "I know I'm in bed. Please don't push me out of bed."

God, I'd never do anything to hurt you. Pain, Daddy, pain, how bad was it in that filthy nursing home? That's what they did to you there, isn't it? They pulled you out of bed.

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### **DECEMBER 13**

I took Daddy out in the mid-December sunshine today. He actually laughed at Scorpio's dumb dog antics. I love you, Daddy. I'm so sorry, I didn't know. Please forgive me. Please live for a while for me. I didn't know how bad it was for you there. What is killing you? Why do you say, "This is killing me." Let me help you, please.

### **DECEMBER 25**

Daddy's dying. There's no doubt that hospice is right. We have to come to terms with it. But I can't, not like this. He wants the feeding tube out.

### **JANUARY 3**

Your blood pressure is bouncing around, you're not breathing right, I've called the hospice nurse. I sit here at 3 A.M. watching you and remembering what you have done for me. Remembering the last two months of this nightmare, watching you recapitulate your life. Listening to you talk of the babies, who will take care of the babies? The babies will be fine, Dad. Please don't worry about the babies, I'll take care of them. You did good with the babies anyway, and they love you very much. You can do whatever you need to do now.

### **JANUARY 4**

Daddy broke down tonight at 9 P.M. and started crying. I pleaded with Michael to tell Daddy that it was okay for him to die, that he would be okay with it. Michael did. It won't be long now. He has released our father, whom we both loved and will always love.

### **JANUARY 5**

Daddy died today at 4 P.M. He had been in a coma since 2 P.M. I know you heard the final words, didn't you, Dad? Peaceful death, no trauma. See you later, Daddy.

How will I fill this hole in my soul?

### **MAY 8**

As I copied these paragraphs from my diary, I cried again. I thought that I had quit crying, but now I see that I never will. But, I have learned a lot

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since my father died from the abuse he received at the hands of an orderly. First, I learned that we gave my father a gift—if life is a gift, then a peaceful and tranquil release to death must also be a gift. My father left this awareness knowing that his children knew he was leaving and could cope with it. He wasn't afraid, and he was surrounded by all of us in the last hours, at home, where he wanted to be.

I don't think what I feel, and will always feel, is guilt. Guilt is something you feel when you've done wrong and know that you've done wrong. I feel regret, so much regret, for the horrible twelve months that my father spent locked up in conditions worse than what criminals in jail live in, regret for my and my family's naiveté and ignorance.

I am not ignorant now, and I devote a good part of my life toward nursing home reform. Our system needs to be changed, in so many ways. My father's story is being played out all over the country every day, and I can't walk away from it, now that awareness has been dropped on me. If I had to offer one piece of advice to anyone looking to place a parent in a nursing home, I'd say this: Always, always, trust your heart. If something doesn't seem right, it isn't. Listen to your feelings, and not what the staff or administration, or even the state enforcement agency, tells you, but that tiny voice that somehow most always seems to be overridden.



## *Alvin (part 2)*

Even though Alvin was at another facility, the staff at the House of Horrors was there for me during his last few days. One in particular told me she felt that she was part of our family.

In the end, Alvin made a beautiful exit. We were making a brain donation, and since none of his family lived in the area and his friends were from the staffs at both the House of Horrors and the new facility, we decided not to have a memorial, flowers, donations, etc.

For the next six weeks I worked on a memorial book for Alvin that would stay with his family and friends for a long time. I included pictures of our wedding seven years before and of our life together. Then came pictures of his life with his parents, children, and grandchildren. There was a letter I wrote to friends describing his last few days. The last section included pictures of his “new life” in the new facility, showing him playing his harmonica, attending a St. Patrick’s Day party, with his favorite nurse’s aides, and next to me at the piano. In the last pictures I took of him, shortly before his death, he looked wonderful and was still smiling.

This memorial was absolutely beautiful. It was all I needed to do.

## APPENDIX 1

# State Ombudsperson Offices

For the latest information, see the list of ombudspersons on the Web site of the National Citizens' Coalition for Nursing Home Reform at [www.nccnhr.org](http://www.nccnhr.org), or call 202-332-2275.

Alabama State LTC Ombudsman  
Alabama Commission on Aging  
770 Washington Avenue  
RSA Plaza, Suite 470  
Montgomery, AL 36130  
phone: 334-242-5743  
fax: 334-242-3862

Arkansas State LTC Ombudsman  
Division of Aging and Adult  
Services  
P.O. Box 1437, Slot 1412  
Little Rock, AR 72201-1437  
phone: 501-682-2441  
fax: 501-682-8155

Alaska State LTC Ombudsman  
Older Alaskans Commission  
3601 C Street, Suite 260  
Anchorage, AK 99503-5209  
phone: 907-334-4480  
fax: 907-334-4486

California State LTC Ombudsman  
Department on Aging  
1600 K Street  
Sacramento, CA 95814  
phone: 916-324-3698  
fax: 916-323-7299

Arizona State LTC Ombudsman  
Aging and Adult Administration  
1789 West Jefferson 950A  
Phoenix, AZ 85007  
phone: 602-542-4446  
fax: 602-542-6575

Colorado State LTC Ombudsmen  
The Legal Center  
455 Sherman Street, Suite 130  
Denver, CO 80203  
phone: 303-722-0300 ext. 217  
fax: 303-722-0720

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Connecticut State LTC  
Ombudsman  
Department on Aging  
25 Sigourney Street, 10th Floor  
Hartford, CT 06106-5033  
phone: 860-424-5200 ext. 5221  
fax: 860-424-4966

Delaware State LTC Ombudsman  
Division of Services for Aging  
and Adults  
1901 North Dupont Highway  
Main Admin. Bldg. Annex  
New Castle, DE 19720  
phone: 302-577-4791  
fax: 302-577-4793

District of Columbia State LTC  
Ombudsman  
AARP Foundation—Legal Council  
for the Elderly  
601 E Street, N.W.  
Washington, DC 20049  
phone: 202-434-2140  
fax: 202-434-6595

Florida State LTC Ombudsman  
Florida State LTC Ombudsman  
Council  
600 South Calhoun Street,  
Suite 270  
Tallahassee, FL 32301  
phone: 888-831-0404  
fax: 850-488-5657

Georgia State LTC Ombudsman  
Division of Aging Services  
2 Peachtree Street, N.W., Suite  
36-233

Atlanta, GA 30303-3142  
phone: 888-454-5826  
fax: 404-463-8384

Hawaii State LTC Ombudsman  
Executive Office on Aging  
Office of the Governor  
250 South Hotel Street, Suite 109  
Honolulu, HI 96813-2831  
phone: 808-586-0100  
fax: 808-586-0185

Idaho State LTC Ombudsman  
Commission on Aging  
3380 American Terrace, Suite 1  
P.O. Box 83720  
Boise, ID 83720-0007  
phone: 877-471-2777  
fax: 208-334-3033

Illinois State LTC Ombudsmen  
Department on Aging  
421 East Capitol Avenue, Suite 100  
Springfield, IL 62701-1789  
phone: 217-785-3143  
fax: 217-524-9644

Indiana State LTC Ombudsman  
Division of Aging and  
Rehabilitation Services  
402 West Washington Street  
Indianapolis, IN 46204  
phone: 800-545-7763  
fax: 317-232-7867

Iowa State LTC Ombudsman  
Iowa Department of Elder Affairs  
Clemens Building  
200 10th Street

## STATE OMBUDSPERSON OFFICES

Des Moines, IA 50309-3609  
phone: 515-242-3327  
fax: 515-242-3300

301 W. Preston Street, Room 1007  
Baltimore, MD 21201  
phone: 410-767-1074  
fax: 410-333-7943

Kansas State LTC Ombudsman  
Kansas LTC Ombudsman Program  
610 S.W. 10th Street, 2nd Floor  
Topeka, KS 66612-1616  
phone: 785-296-3017  
fax: 785-296-3916

Massachusetts State LTC  
Ombudsman  
Executive Office of Elder Affairs  
1 Ashburton Place, 5th Floor  
Boston, MA 02108-1518  
phone: 617-727-7750  
fax: 617-727-9368

Kentucky State LTC Ombudsman  
Division of Family/Children  
Services  
275 East Main Street, 5th Floor  
Frankfort, KY 40621  
phone: 800-372-2991  
fax: 502-564-4595

Michigan State LTC Ombudsman  
Citizens for Better Care  
4750 Woodward Avenue, Suite 410  
Detroit, MI 48201-3908  
phone: 313-832-6387 ext. 250  
fax: 313-832-7407

Louisiana State LTC Ombudsman  
Louisiana Governor's Office of  
Elderly Affairs  
412 North 4th Street, 3rd Floor  
P.O. Box 80374  
Baton Rouge, LA 70802  
phone: 225-342-7100  
fax: 225-342-7144

Minnesota State LTC Ombudsman  
Office of Ombudsman for Older  
Minnesotans  
121 East Seventh Place, Suite 410  
St. Paul, MN 55101  
phone: 800-657-3591  
fax: 651-297-5654

Maine State LTC Ombudsman  
Maine State LTC Ombudsman  
Program  
1 Weston Court  
P.O. Box 128  
Augusta, ME 04332  
phone: 207-621-1079  
fax: 207-621-0509

Mississippi State LTC Ombudsman  
Mississippi Division of  
Aging/Adult Services  
750 North State Street  
Jackson, MS 39202  
phone: 601-359-4929  
fax: 601-359-4970

Maryland State LTC Ombudsman  
Maryland State Department of  
Aging

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Missouri State LTC Ombudsman Division on Aging Department of Social Services P.O. Box 1337 Jefferson City, MO 65102 phone: 800-309-3282 fax: 573-751-8687	Concord, NH 03301-3857 phone: 603-271-4375 fax: 603-271-4771
Montana State LTC Ombudsman Department of Health and Human Services Senior and LTC Division 111 Sanders P.O. Box 4210 Helena, MT 59604-4210 phone: 800-551-3191 fax: 406-444-7743	New Jersey State LTC Ombudsman for Institutionalized Elderly P.O. Box 807 Trenton, NJ 08625-0807 phone: 609-588-3614 fax: 609-588-3365
Nebraska State LTC Ombudsman Health and Human Service System Division of Aging Services 301 Centennial Mall South P.O. Box 95044 Lincoln, NE 68509-5044 phone: 402-471-2307 fax: 402-471-4619	New Mexico State LTC Ombudsman State Agency on Aging 1410 San Pedro NE Albuquerque, NM 87110 phone: 505-255-0971 fax: 505-255-5602
Nevada State LTC Ombudsman Division for Aging Services 445 Apple Street, #104 Reno, NV 89502 phone: 775-688-2964 fax: 775-688-2969	New York State LTC Ombudsman Office for the Aging 2 Empire State Plaza Agency Building #2 Albany, NY 12223-0001 phone: 518-474-0108 fax: 518-474-7761
New Hampshire State LTC Ombudsman Division of Elderly and Adult Services 129 Pleasant Street	North Carolina State LTC Ombudsman Division of Aging 2101 Mail Service Center Raleigh, NC 27699-2101 phone: 919-733-8395 fax: 919-715-0868
	North Dakota State LTC Ombudsman Aging Services Division Department of Human Services

## STATE OMBUDSPERSON OFFICES

600 South 2nd Street, Suite 1C  
Bismarck, ND 58504  
phone: 800-451-8693  
fax: 701-328-8989

Old San Juan Station  
San Juan, PR 00902  
phone: 787-725-1515  
fax: 787-721-6510

Ohio State LTC Ombudsman  
Department of Aging  
50 West Broad Street, 9th Floor  
Columbus, OH 43215-3363  
phone: 614-644-7922  
fax: 614-644-5201

Rhode Island State LTC  
Ombudsman  
Alliance for Better Long Term  
Care  
422 Post Road, Suite 204  
Warwick, RI 02888  
phone: 401-785-3340  
fax: 401-785-3391

Oklahoma State LTC Ombudsman  
Aging Services Division  
Department of Human Services  
312 N.E. 28th Street, Suite 109  
Oklahoma City, OK 73105  
phone: 405-521-6734  
fax: 405-521-2086

South Carolina State LTC  
Ombudsman  
Division on Aging  
1801 Main Street  
P.O. Box 8206  
Columbia, SC 29202-8206  
phone: 800-868-9095  
fax: 803-898-4513

Oregon State LTC Ombudsman  
Office of the LTC Ombudsman  
3855 Wolverine, N.E., Suite 6  
Salem, OR 97305-1251  
phone: 503-378-6533  
fax: 503-373-0852

South Dakota State LTC  
Ombudsman  
Office of Adult Services and Aging  
700 Governors Drive  
Pierre, SD 57501-2291  
phone: 605-773-3656  
fax: 605-773-6834

Pennsylvania State LTC  
Ombudsman  
Department of Aging  
555 Walnut Street, 5th Floor  
P.O. Box 1089  
Harrisburg, PA 17101  
phone: 717-783-7247  
fax: 717-783-3382

Tennessee State LTC Ombudsman  
Commission on Aging  
Andrew Jackson Building  
500 Deaderick Street, 9th Floor  
Nashville, TN 37243-0860  
phone: 615-741-2056  
fax: 615-741-3309

Puerto Rico State LTC  
Ombudsman  
Governor's Office for Elder Affairs  
Call Box 50063

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Texas State LTC Ombudsman  
Department on Aging  
4900 North Lamar Boulevard,  
4th Floor  
P.O. Box 12786  
Austin, TX 78751-2316  
phone: 800-372-4464  
fax: 512-424-6890

Utah State LTC Ombudsman  
Division of Aging and Adult  
Services  
Department of Social Services  
120 North, 200 West, Room 401  
Salt Lake City, UT 84103  
phone: 801-538-3924  
fax: 801-538-4395

Vermont State LTC Ombudsman  
Vermont Legal Aid, Inc.  
264 North Winooski  
P.O. Box 1367  
Burlington, VT 05402  
phone: 802-863-5620  
fax: 802-863-7152

Virginia State LTC Ombudsman  
Virginia Association of Area  
Agencies on Aging  
530 East Main Street, Suite 428  
Richmond, VA 23219  
phone: 800-552-3402  
fax: 804-644-5640

Washington State LTC  
Ombudsman  
South King County Multi-Service  
Center

1200 South 336th Street  
P.O. Box 23699  
Federal Way, WA 98093  
phone: 253-838-6810  
fax: 253-874-7831

West Virginia State LTC  
Ombudsman  
Commission on Aging  
1900 Kanawha Boulevard East  
Bldg. #10 Hall, Grove  
Charleston, WV 25309  
phone: 304-558-3317  
fax: 304-558-0004

Wisconsin State LTC Ombudsman  
Board on Aging and Long Term  
Care  
214 North Hamilton Street  
Madison, WI 53703-2118  
phone: 800-815-0015  
fax: 608-261-6570

Wyoming State LTC Ombudsman  
Wyoming Senior Citizens, Inc.  
756 Gilchrist  
P.O. Box 94  
Wheatland, WY 82201  
phone: 307-322-5553  
fax: 307-322-3283

## APPENDIX 2

# Accessing Care in Canada

Although the provinces and territories of Canada are struggling to make their systems accessible, it can still be extremely frustrating to try to find information regarding residential care. To access the system in your province, you can ask your physician, call a social worker or discharge planner in a hospital, or look up the health department in the blue pages of your phone book. You might call information and ask for a number using terms like *long-term care*, *continuing care*, *health authority*, *home care*, or something similar. When you obtain a phone number, you may have to ask if they are the ones who deal with nursing homes. If they are not, they will usually be able to give you the number of the agency that does. You can also phone the local Alzheimer's Association chapter and they will be able to tell you where to begin.

Each province and territory has a different system of providing residential care, but many aspects of care are common in different forms to all areas of the country. Care systems are evolving continuously but tend to be headed in the same direction—a single-point entry system. A single-point entry system means that all services, whether in one's own home or in a residential facility, are coordinated and offered through the same or affiliated agencies. They all at least work closely together. If you need care, you call one agency and they follow you throughout the time you are in the system, from the time you may need only homemaker services or adult day care up to and through the time you would need placement in a nursing home. Ideally, you are assigned one case manager as you go through the system.

At the point of entry, there will be an intake worker who will take some basic information and pass it on to an assessor, who will do an in-depth assessment. This may start over the phone, but usually someone will come to your home. The assessor examines the subject's cognitive



## APPENDIX 2

ability (thinking, memory, judgment, etc.), physical functioning, and ability to manage in the home. He or she will usually talk to family, physicians, and others who are involved. The resulting assessments usually help establish a care level that corresponds to the type of care someone is eligible to receive and the amount of support he or she needs. For instance, level one might mean someone is eligible for only home care, while level three might indicate a nursing home. The level system is different in each province, and the levels have different meanings.

Governments prefer to help people stay in their own homes for as long as possible with home support because it is cheaper than residential care. If you and the assessing agency feel you cannot manage at home any longer, they will put your name on at least a couple of nursing home wait lists that you request, provided that the facility is able to provide the care that you need.

Waiting list rules differ from province to province. Usually you are allowed to put your name on two or three appropriate lists. In some provinces, if your name comes up and you are not ready, you are allowed to be skipped or go to the bottom of the list. In some provinces, you can turn down one or two offers of a bed, but you must accept the third time a bed is offered or your name will go off the list or become inactive. In some provinces under some circumstances, if a bed is offered and you turn it down, your name goes off all waiting lists and you must reapply later.

The eligibility criteria for waiting lists also vary from province to province. Whereas in one province you may qualify for nursing home care, in another you may not, even with the same conditions. You can always appeal that decision by talking with the case manager or the agency administrator.

Policy regarding waiting lists and admission to a nursing home varies by province. In some provinces, admission priority is based more or less strictly on the date when your name was placed on a list. In other provinces, priority for admission is based on comparing different candidates' needs and risk at home, as well as the date on the list.

Most provinces have exceptions to waiting list admission policy. For instance, if there is a community emergency, then someone might be placed immediately even if he or she is not on a waiting list. Or, if a husband is in care and his wife needs care, she may be placed immediately or higher up on the waiting list, so that the two of them can be together. Also, it may happen that someone has been on a waiting list in one area of the province for a year and then decides that she wishes to live in an-

## ACCESSING CARE IN CANADA

other part of the province. She can “take” her waiting list date with her to another facility’s list, and this would put her higher on the new list than people who have a more recent wait list date.

If there is an emergency or you are in hospital, the system may require that you move to the first appropriate facility that has a bed available and wait there for the place of your choosing. They do this because care in the hospital can cost more than five times the amount of care in a nursing home.

If you live in one part of a province and wish to have care in another part (for instance, if you wish to live closer to a son or daughter), you call the agency *in your area* that is responsible for residential care. They will do the assessment and send it to the region where you wish to live. If you live in one province but wish to receive care in another, call the agency in the region where you *wish* to live. They will explain the process necessary. Some provinces allow you to apply for care from outside the province, so you are eligible to receive care as soon as you arrive. In others, there is a residency requirement, so you need to live in the province before you can apply for care. That can mean that you may have to live in the province for up to a year before you are even eligible to go on a wait list. Residency requirement lengths vary among the provinces. Currently the provinces are trying to work out reciprocal agreements to make this system easier. Sometimes exceptions will be made to the policies.

Most provinces have several types of residential care, including assisted living and group homes. In some provinces, as your care needs increase, you may have to move to another facility that can provide that level of care. This means that there can be several moves once you start in the residential care system. Not all provinces will subsidize residency in all the types of care, even though they may license and monitor them. For instance, many provinces at present do not subsidize assisted living.

Almost all provinces have a system of for-profit facilities that coexist with the nonprofits and government-owned ones. Some of these are outside the public system and are not funded; others do have government-funded beds. The funded beds may be all or only a percentage of the total. The levels of care available through private homes vary from congregate living to assisted living up to nursing home or hospital-like care. Even when nursing homes are not subsidized, they are licensed by the governments and must meet certain standards.

All provinces have adult day care centers. These are programs that someone can attend from one to five days per week, depending on need

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and space available. Adult day care centers can be extremely helpful in giving caregivers a break and maintaining someone in the community through the provision of social stimulation, good meals, and monitoring of health status. Some of the centers are open weekends and evenings.

All provinces have a respite bed system. This means that for up to four weeks a year someone may live in a facility to give the caregivers a rest. This is an excellent way to begin to help your relative become accustomed to care and “try it out.” If you would like to use the respite system, you may have to book the bed far in advance, especially in the summer.

Costs in most provinces are based on income. The ability to pay is usually determined by a financial assessment. Some provinces include assets in estimated ability to pay; some take only income into account. They all have a minimum daily fee for someone who is on a fixed-income pension. This minimum fee is always less than a person’s total monthly income, although it might not leave much left over. This means that every Canadian has the funds to pay for residential care. Most provinces have a maximum top rate irrespective of income and assets. This means that whether you are worth \$5 million or your yearly income is \$100,000, the top ceiling rate is the same as for someone who is worth one-tenth of that. A couple of provinces require that a majority of personal resources be exhausted before they will begin to subsidize. This means they will require you to “spend down” your resources until they have gone below a certain level. If they find that you have given away your resources in order to qualify for the subsidy, they will pursue payment from those to whom you distributed your wealth.

The following is a list of questions you should ask the agency in your area:

1. Who handles the waiting list?
2. What are the eligibility requirements to be put on a list for a nursing home?
3. What are the rules of waiting lists, and what are the exceptions to those rules?
4. How do the wait lists actually function?
5. What happens if I turn down a bed that is offered to me?
6. Once I am in a home, under what conditions or circumstances would I have to move to another?
7. What services are available to me while I am waiting for a space in a nursing home?

## ACCESSING CARE IN CANADA

8. Do you fund assisted living, group homes, or other alternatives to nursing homes?
9. What are the costs, and how are they determined?
10. To whom do I talk if I have a complaint about the home or the placement system?
11. What services are provided in nursing homes?

Make sure you understand the terminology that the system uses (e.g., *nursing home*, *personal care home*, etc.), so that you obtain the care you need and you get what you think you are getting.

## APPENDIX 3

# Nursing Home Residents' Rights under U.S. Law

Nursing home residents and their families have a number of rights that are enshrined in and protected by U.S. federal law. The law requires nursing homes to promote and protect the rights of each resident and places a strong emphasis on individual dignity, choice, and self-determination. Nursing homes must meet residents' rights requirements to participate in Medicare or Medicaid.

The Nursing Home Reform Act requires each nursing home to care for its residents in such a manner and environment as will promote the maintenance or enhancement of the quality of life of each resident. Each nursing home is required to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that is initially prepared with participation to the extent practicable of the resident, the resident's family, or a legal representative. This means that a resident should not decline as a direct result of the nursing facility's care.

The Nursing Home Reform Act also grants nursing home residents these specific rights:

The right to be fully informed, including:

- The right to be informed of all services available as well as the charge for each service;
- The right to have a copy of the nursing home's rules and regulations, including a written copy of their rights;
- The right to be informed of the address and telephone number of the state ombudsperson, state licensure office, and other advocacy groups;
- The right to see the state survey reports of the nursing home and the home's plan of correction;

## NURSING HOME RESIDENTS' RIGHTS UNDER U.S. LAW

- The right to be notified in advance of any plans to change their room or roommate;
- The right to daily communication in their language;
- The right to assistance if they have a sensory impairment.

The right to participate in their own care, including:

- The right to receive adequate or appropriate care;
- The right to be informed of any changes in their medical condition;
- The right to participate in planning their treatment, care, and discharge;
- The right to refuse medication and treatment;
- The right to refuse chemical and physical restraints;
- The right to review their medical record.

The right to make independent choices, including:

- The right to make independent personal decisions, such as what to wear and how to spend free time;
- The right to reasonable accommodation of their needs and preferences by the nursing home;
- The right to choose their own physician;
- The right to participate in community activities, both inside and outside the nursing home;
- The right to organize and participate in a resident council.

The right to privacy and confidentiality, including:

- The right to private and unrestricted communication with any person of their choice;
- The right to privacy in treatment and in the care of their personal needs;
- The right to confidentiality regarding their medical, personal, or financial affairs.

The right to dignity, respect, and freedom, including:

- The right to be treated with the fullest measure of consideration, respect, and dignity;
- The right to be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints;
- The right to self-determination.

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The right to security of possessions, including:

- The right to manage their own financial affairs;
- The right to file a complaint with the state survey and certification agency for abuse, neglect, or misappropriation of their property if the nursing home is handling their financial affairs;
- The right to be free from charge for services covered by Medicaid or Medicare.

Rights during transfers and discharges, including:

- The right to remain in the nursing facility unless a transfer or discharge is (1) necessary to meet the resident's welfare; (2) appropriate because the resident's health has improved and the resident no longer requires nursing home care; (3) needed to protect the health and safety of other residents or staff; (4) required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request;
- The right to receive notice of transfer or discharge. A thirty-day notice is required. The notice must include the reason for transfer or discharge, the effective date, the location to which the resident is transferred or discharged, a statement of the right to appeal, and the name, address, and telephone number of the state long-term care ombudsperson;
- The right to a safe transfer or discharge through sufficient preparation by the nursing home.

The right to complain, including:

- The right to present grievances to the staff of the nursing home, or to any other person, without fear of reprisal;
- The right to prompt efforts by the nursing home to resolve grievances.

The right to visits, including:

- The right to immediate access by a resident's personal physician and representatives from the health department and ombudsperson programs;
- The right to immediate access by their relatives and for others subject to reasonable restriction with the resident's permission;
- The right to reasonable visits by organizations or individuals providing health, social, legal, or other services.

## **NURSING HOME RESIDENTS' RIGHTS UNDER U.S. LAW**

*Source:* Information from National Citizens' Coalition for Nursing Home Reform. If you would like to learn more, NCCNHR has several publications that may be of interest. To order, visit the Web site at [www.nccnhr.org](http://www.nccnhr.org) or call 202-332-2275.



## APPENDIX 4

# Questionnaires

### 1. GUIDE TO VIEWING NURSING HOMES

STAFF	Home A	Home B	Home C
Nurses <i>Number per resident</i>			
<i>Training</i>			
Nurse's aides <i>Number per resident</i>			
<i>Training</i>			
Director of Care <i>Qualifications</i>			
Recreation workers <i>Number per resident</i>			
<i>Training</i>			
Recreation director <i>Training</i>			
Social worker <i>How often?</i>			
<i>Training</i>			
Physical Therapist <i>On site?</i>			

## QUESTIONNAIRES

STAFF (cont.)	Home A	Home B	Home C
Occupational therapist <i>On site?</i>			
Other rehabilitation staff			
Registered dietitian <i>On site?</i>			
House physician			
Access to geriatric physician			
Access to mental/ geriatric mental health worker			
Pharmacist available			
PROGRAM	Home A	Home B	Home C
Pastoral care			
Art therapy			
Music therapy			
Other			
Recreation programs <i>Number</i>			
<i>Variety</i>			
<i>Evenings?</i>			
<i>Weekends?</i>			
Care conferences <i>How often?</i>			

# APPENDIX 4

<b>PROGRAM (cont.)</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Educational programs for staff			
Accredited			
Survey results			
Lifestyle programs/opportunities			
Independent living			
Assisted living			
Nursing home			
Acute care			
Dementia unit			
Limitations on care or acuity levels			
<b>DINING</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Dining room cleanliness			
Dining room atmosphere			
Dining hours appropriate			
Appearance of food			
Variety of menu			
Choices/alternatives available			
Meals served in rooms			
Family can join residents			

## QUESTIONNAIRES

<b>LAUNDRY</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Laundry done on premises			
How often?			
Can family do laundry?			
<b>FACILITY</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Cleanliness			
Lighting			
Smell			
Access to outdoor space			
Access to shops/ shopping			
Equipped for wheelchairs			
Bedsore incidents in past year			
Handrails			
Rails / grab bars in bathrooms			
Single rooms			
Double rooms			
Appearance of rooms			
Size of rooms / room space			
Storage in rooms			
Lighting in rooms			

# APPENDIX 4

<b>FACILITY (cont.)</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
View from rooms			
Can bring in own furniture			
Can bring in television			
Cable ready			
Can have telephone in room			
Call bell by bedside			
Call bell by toilet			
Distance of rooms from dining/activity			
Floors/elevators			
<b>CHARACTERISTICS</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Atmosphere			
Visiting hours			
Management seems flexible			
Residents appear well dressed			
Residents appear clean			
Residents appear happy/content			
Staff appear helpful, interested			
Staff appear to have good relations			

## QUESTIONNAIRES

<b>CHARACTERISTICS</b>			
<b>(cont.)</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Staff turnover			
Management is open to family input			
<b>POLICY</b>	<b>Home A</b>	<b>Home B</b>	<b>Home C</b>
Residents council			
Family council			
Copy of admission agreement			
Copy of recreation schedule sample			
Copy of menu			
Policy on theft			
Policy on abuse			
Policy on restraints			
Policy on roommates			
Policy on room changes			
Pets allowed/available?			
Plants allowed/available?			
Visitors can take residents out			

APPENDIX 4

HOW DOES IT FEEL TO YOU? Notes:
Home A
Home B
Home C

## QUESTIONNAIRES

### 2. DAILY SCHEDULE

What time do you wake up?

---

What time do you have breakfast?

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What do you have for breakfast?

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What is your morning hygiene routine?

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What do you do in the morning?

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What time do you have lunch?

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What do you have for lunch?

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What do you do in the afternoon?

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---

---

What time do you have dinner?

---

What do you have for dinner?

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---

---



## APPENDIX 4

What do you do after dinner?

What is your evening hygiene routine?

What time do you go to bed?

How often do you get up at night?

Weekly activities (such as bridge club, dinner with your family, meetings, church)?

Special needs/equipment, etc.?

## QUESTIONNAIRES

### 3. SOCIAL HISTORY

Use a separate sheet of paper to record the responses.

1. Where were you born?
2. Describe your family. What was your father like? Your mother? How many brothers and sisters?
3. What were relationships like in your family? Between your parents? Between you and your parents? Between you and your siblings?
4. What was your childhood like? What kind of child were you? Did you have pets?
5. Describe your schooling.
6. Describe your young adulthood. What were your friendship and dating circles like? Your activities and interests?
7. Describe your work life and history.
8. Were you married or in a long-term relationship? Describe the relationship. What was your spouse/partner like? What kinds of things did you do together? Describe some of the ups and downs that the two of you had.
9. Did you have children? What was your family life like? What were you like as a parent?
10. Have you had any particular life crises? How did you handle them?
11. What were your retirement years like?
12. Describe your usage of alcohol and other substances.
13. Have you ever had any psychiatric treatment, or was there any psychiatric illness in your family? Any chronic family illnesses?
14. What did your parents die of? Siblings? Ages of death?
15. What has brought you to the point where you need to go into a nursing home?
16. Describe your personality. What are you like? How do other people see you? What are some of your strengths and weaknesses?

#### **APPENDIX 4**

17. How do you react to stress and frustration? Are you easily angered or frustrated? What kinds of things bother you?

18. When are you happy or content?

19. What do you want people to know about you?

20. What is important to you that will mean you are getting good care?

21. Do you have any regrets about your life?

22. How would you evaluate your life?

# Resources

## Books and Pamphlets

These are just some of the books that I have found useful. If you have access to the Internet, I would recommend that you go to [amazon.com](http://amazon.com) or a similar bookstore site and see what they carry on grief and loss, nursing homes, and caregivers. There are thousands of books on these subjects.

Abraham, Janet L. *A Physician's Guide to Pain and Symptom Management in Cancer Patients*. Baltimore: Johns Hopkins University Press, 2000. A thorough and compassionate manual, with a separate bibliography for patients and their families.

Advocates for Care Reform. *Alone in a Crowd: Social Isolation of Seniors in Care Facilities*. Peanut Butter Publishing, 1998. Description of life in a nursing home by the people who live in nursing homes. This is the result of a broad survey done by the Advocates for Care Reform in Vancouver, Canada.

Amarnick, Claude. *Don't Put Me in a Nursing Home*. Deerfield Beach, Fla.: Garrett Publishing, 1996. A guide to the different options and ways to keep an aging relative at home and not burn out.

Astor, Bart. *The Baby Boomer's Guide to Caring for Aging Parents*. New York: Macmillan/Spectrum, 1998.

Blaivas, Jerry G. *Conquering Bladder and Prostate Problems: The Authoritative Guide for Men and Women*. New York: Plenum Books, 1998.

Boss, Pauline. *Ambiguous Loss: Learning to Live with Unresolved Grief*. Cambridge, Mass.: Harvard University Press, 1999.

Bradshaw, John. *Healing the Shame that Binds*. Deerfield Park, Fla.: Health Communications, Inc., 1988. An in-depth look at the issues of shame that run our lives.

## RESOURCES

- Bridges, Barbara J. *Therapeutic Caregiving: A Practical Guide for Caregivers of Persons with Alzheimer's and Other Dementia-Causing Diseases*. Mill Creek, Wash.: BJB Publishing, 1995. An excellent guide with practical advice for the caregiver who is caring for someone at home.
- Bua, Robert N. *The Inside Guide to America's Nursing Homes: Rankings and Ratings for Every Nursing Home in the U.S.* New York: Warner Books, 1997. An excellent guide.
- Buckman, Robert. *I Don't Know What to Say: How to Help and Support Someone Who Is Dying*. New York: Vintage Books, 1992.
- Burger, Sarah Greene. "Avoiding Drugs Used as Chemical Restraints." Washington, D.C.: National Citizens' Coalition for Nursing Home Reform, 1994.
- . "Avoiding Physical Restraint Use: New Standards in Care." Washington, D.C.: National Citizens' Coalition for Nursing Home Reform, 1993.
- . *Nursing Homes: Getting Good Care There*. San Luis Obispo: American Source Books, 1996. This is an excellent in-depth guide to care planning in nursing homes.
- Burgio, Kathryn L., K. Lynette Pearce, and Angelo J. Lucco. *Staying Dry: A Practical Guide to Bladder Control*. Baltimore: Johns Hopkins University Press, 1989.
- Byock, Ira. *Dying Well: The Prospect for Growth at the End of Life*. New York: Riverhead Books, 1998. A compassionate guide for families on how to deal with someone who is terminally ill.
- Caplan, Louis R., Mark L. Dyker, and J. Donald Easton. *American Heart Association Family Guide to Stroke, Treatment, Recovery, and Prevention*. New York: Times Books, 1996.
- Carlson, Richard. *Don't Sweat the Small Stuff—And It's All Small Stuff: Simple Ways to Keep the Little Things from Taking Over Your Life*. New York: Hyperion Books, 1997. A bestseller, this wonderful little book has some very succinct and simple advice on coping and putting events in perspective.
- Caruso, Ellen M. *Keeping Them Healthy, Keeping Them Home: How to Care for Your Loved Ones at Home*. Los Angeles: Health Information Press, 1998.
- Colgrove, Melba, Harold H. Bloomfield, and Peter A. McWilliams. *How to Survive the Loss of a Love: 58 Things to Do When There Is Nothing to Be Done*. Los Angeles: Prelude Press, 1991.
- Furman, Joan, and David McNabb. *The Dying Time: Practical Wisdom for the Dying and Their Caregivers*. New York: Bell Tower, 1997.

## RESOURCES

- Heart and Stroke Foundation of Canada. *Canadian Family Guide to Stroke*. Toronto: Random House of Canada, 1996.
- Hegland, Kenney F. *Fifty and Beyond: The Law You and Your Parents Will Need to Know*. Durham, N.C.: Carolina Academic Press, 1999. Written by lawyers for the general public, this book covers a range of topics in elder law, including nursing home admission, durable power of attorney, making decisions for an incapacitated relative.
- Hughes, Mary L. *Nursing Home Experience: A Family Guide to Making It Better*. New York: Crossroads Publishing, 1995. A practical guide to managing some of the difficulties in a nursing home.
- Kraatz, Eileen. *A Spy in the Nursing Home: Inside Tips and Tactics for Choosing the Right One in Five Days*. Los Angeles: Health Information Press, 1999.
- Kranz, Marian R. *The Nursing Home Choice: How to Choose the Ideal Nursing Home*. Boston: Branden Publishing, 1998.
- Kubler-Ross, Elisabeth. *On Death and Dying*. New York: Scribner Classics, 1997.
- Kushner, Harold S. *When Bad Things Happen to Good People*. Avon Books, 1997. How to cope with the senselessness of tragedy in life.
- Levy, Naomi. *To Begin Again: The Journey toward Comfort, Strength, and Faith in Difficult Times*. New York: Ballantine, 1999.
- Loverde, Joy. *The Complete Eldercare Planner: Where to Start, Questions to Ask, and How to Find Help*. New York: Hyperion Books, 1997.
- Mace, Nancy L., and Peter V. Rabins. *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life*. 3rd edition. Baltimore: Johns Hopkins University Press, 1999. The classic book in the field for caring for someone with dementia. It has a section on nursing homes.
- Myers, Edward. *When Parents Die: A Guide for Adults*. New York: Penguin Books, 1997.
- Quinn, Mary Joy, and Susan K. Tomita. *Elder Abuse and Neglect: Causes, Diagnoses, and Intervention Strategies*. New York: Springer Publishing, 1997.
- Salerno, Evelyn, and Joyce S. Willens. *Pain Management Handbook: An Interdisciplinary Approach*. St. Louis: Mosby, 1996. Written for professionals; an excellent and comprehensive guide to all aspects of pain management.
- Sankar, Andrea. *Dying at Home: A Family Guide for Caregiving* (rev. and updated ed.). Baltimore: Johns Hopkins University Press, 2000.

## RESOURCES

Thomas, William H. *Life Worth Living: How Someone You Love Can Still Enjoy Life in a Nursing Home—The Eden Alternative in Action*. Acton, Mass.: Vander Wyk and Burnham, 1996. An inspiring guide to what a nursing home can be.

Weenolsen, Patricia, and Bernie S. Siegel. *The Art of Dying: How to Leave This World with Dignity and Grace, at Peace with Yourself and Your Loved Ones*. New York: St. Martin's Press, 1997.

### Organizations and Web Sites

There are numerous organizations and Web sites for caregivers, including an organization for almost every disability and disease. Most have both U.S. and Canadian counterparts. If you wish to call the U.S. resources from Canada and the 800 number is valid only for the United States, try dialing 880.

It is essential for you to have an understanding of the disease that you are facing. Because people at these organizations are specialists in their areas, they have the most up-to-date information on treatments, research, medications, and so on. They know more than many professionals because they are able to focus on their areas of interest. They can be excellent resources to help you choose a nursing home. If there is not a local chapter near where you live, you can call the national office. In addition, most of them have Web sites.

It is well worth your time to go online and look at the Web sites below or just go to search engines and search for “nursing homes,” “eldercare,” “seniors,” “long-term care,” “long-term care insurance,” “death and dying,” etc. No matter where you live, there are people on the Web who can be there for you. This is one of the best examples of the positive power of the Internet.

AARP, 601 E Street, N.W., Washington, DC 20049. 800-424-3410. [www.aarp.org](http://www.aarp.org); e-mail: [member@aarp.org](mailto:member@aarp.org). Advice and information on a range of topics affecting seniors, including long-term care insurance.

Administration on Aging, Department of Health and Human Services, 330 Independence Avenue, S.W., Washington, DC 20201. 202-401-4541. [www.aoa.dhhs.gov](http://www.aoa.dhhs.gov). They have a very complete listing of resources on aging. Their directory is well worth a look.

Agenet Information Referral Network, [www.agenet.com](http://www.agenet.com). A comprehensive Web site of resources and information on geriatrics and aging.

## RESOURCES

- Among other services, they provide a medication assessment, a resource directory, and a housing directory.
- Aging with Dignity, P.O. Box 1661, Tallahassee, FL 32302-1661. 850-681-2010. [www.agingwithdignity.org](http://www.agingwithdignity.org); e-mail: [fivewishes@aol.com](mailto:fivewishes@aol.com). You can download Aging with Dignity's Five Wishes, a guide for health care proxy decision making. It is legally recognized in thirty-four states. Aging with Dignity is also an advocacy group for elderly persons and their caregivers.
- Alzheimer's Association, 919 North Michigan Avenue, Suite 1000, Chicago, IL 60611-1676. 800-272-3900. [www.alz.org](http://www.alz.org); e-mail: [info@alz.org](mailto:info@alz.org).
- Alzheimer Society Canada, 20 Eglinton Avenue W., Suite 600, Toronto, Ontario, M4R 1K8. 800-616-8816. [www.alzheimer.ca](http://www.alzheimer.ca); e-mail: [info@alzheimer.ca](mailto:info@alzheimer.ca).
- American Association of Homes and Services for the Aging, 901 E Street, N.W., Suite 500, Washington, DC 20004-2037. 202-783-2242. fax 202-783-2245. [www.aahsa.com](http://www.aahsa.com).
- American Diabetes Association, 1701 North Beauregard Street, Alexandria, VA 22311. 800-342-2383. [www.diabetes.org](http://www.diabetes.org); e-mail: [customer.service@diabetes.org](mailto:customer.service@diabetes.org).
- American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231. 800-AHA-USA1. [www.americanheart.org](http://www.americanheart.org).
- American Parkinson Disease Association, 1250 Hyland Boulevard, Suite 4B, Staten Island, NY 10305. 800-223-2732.
- Arthritis Foundation, 1330 West Peachtree Street, Atlanta, GA 30309. 404-872-4100, 800-283-7800. [www.arthritis.org](http://www.arthritis.org).
- Arthritis Society of Canada, 393 University Avenue, Toronto, Ontario, M5G 1E6. 800-321-1433, 800-323-1400. [www.arthritis.ca](http://www.arthritis.ca); e-mail: [info@arthritis.ca](mailto:info@arthritis.ca).
- Assisted Living Facilities Association of America, 10300 Eaton Place, Fairfax, VA 22030. 703-691-8100. fax 703-691-8106. [www.alfa.org](http://www.alfa.org).
- Association for Protection of the Elderly, 528A Columbia Avenue, Suite 127, Lexington, SC 29072. 800-569-7345. fax: 803-356-6212. e-mail: [ape@apeape.org](mailto:ape@apeape.org).
- Canadian Association of Retired Persons, 27 Queen Street East, Suite 1304, Toronto, Ontario, M5C 2M6. 800-363-9736. fax 416-363-8747. [www.fiftyplus.net](http://www.fiftyplus.net).
- Canadian Diabetes Association, 15 Toronto Street, Suite 800, Toronto, Ontario, M5C 2E3. 800-BANTING or 416-363-3373. [www.diabetes.ca](http://www.diabetes.ca); e-mail: [info@diabetes.ca](mailto:info@diabetes.ca).



## RESOURCES

- Caregiver Network, 561 Avenue Road, Suite 206, Toronto, Ontario, M4V 2J8. 416-323-1090. [www.caregiver.on.ca](http://www.caregiver.on.ca); e-mail: [karen@caregiver.on.ca](mailto:karen@caregiver.on.ca). A Canadian Web site for caregivers.
- Caregivers.com. A general site for caregivers, associated with Agenet. They have a number of resources, including a directory of geriatricians and geriatric care managers in your area and links to other information sites.
- CareGuide, Inc., 739 Bryant Street, San Francisco, CA 94107. 415-474-1278. [www.careguide.com](http://www.careguide.com). A private company that provides care management services. Their Web site is especially helpful.
- Children of Aging Parents, 1609 Woodbourne Road, Levittown, PA 19057. 215-945-6900. An organization dedicated to caregivers. They have lots of great pamphlets on issues pertinent to caregiving.
- Diamond Geriatrics, Inc., 31 West 11th Avenue, Vancouver, BC, V5Y 1S6. 604-708-1596. [www.diamondgeriatrics.com](http://www.diamondgeriatrics.com). The author's care management and consulting company.
- Eldercare Online. [www.ec-online.net](http://www.ec-online.net). A very comprehensive Web site that offers information of interest to caregivers. Also has information about issues related to nursing homes and finding a good one.
- Heart and Stroke Foundation of Canada, 222 Queen Street, Suite 1402, Ottawa, Ontario, K1P 5V9. 613-241-4361.
- Medicare. 800-MEDICARE. [www.medicare.gov](http://www.medicare.gov). Medicare has a very effective toll-free line, and their Web site is quite useful. They have a section called "Nursing Home Compare," which gives a complete, comparative listing of all nursing homes in the United States that receive federal or Medicaid funding.
- Multiple Sclerosis Society of Canada, 250 Bloor Street East, Suite 1000, Toronto, Ontario, M4W 3P9. 800-361-2985. [www.mssoc.ca](http://www.mssoc.ca); e-mail: [info@mssoc.ca](mailto:info@mssoc.ca).
- National Academy of Elder Care Lawyers, 1604 North Country Club Road, Tucson, AZ 85716-3102. 520-881-4005. [www.naela.org](http://www.naela.org); e-mail: [info@naela.com](mailto:info@naela.com).
- National Association of Professional Geriatric Care Managers, 1604 North Country Club Road, Tucson, AZ 85716-3102. 520-881-8008. fax 520-325-7925. [www.caremanager.org](http://www.caremanager.org).
- National Center for Home Equity Conversion, 360 N. Robert #403, Saint Paul, MN 55101. 651-222-6775. fax 651-222-6797. [www.reverse.org](http://www.reverse.org). The Web site explains all you want to know about reverse mortgages.
- National Citizens' Coalition for Nursing Home Reform, 1424 16th Street,

## RESOURCES

- N.W., #202, Washington, DC 20036. 202-332-2275. [www.nccnhr.org](http://www.nccnhr.org); e-mail: [nccnhr@nccnhr.org](mailto:nccnhr@nccnhr.org); The NCCNHR is an advocacy group. They put out a number of excellent booklets, including "Avoiding Drugs Used as Chemical Restraints" and "Avoiding Physical Restraint Use."
- National Family Caregivers Association, 10604 Concorde Street, Suite 501, Kensington, MD 20895-2504. 800-896-3650. [www.nfcacares.org](http://www.nfcacares.org); e-mail: [info@nfcacares.org](mailto:info@nfcacares.org).
- National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017. 800-Fight-MS. [www.nmss.org](http://www.nmss.org); e-mail: [info@nmss.org](mailto:info@nmss.org).
- National Parkinson Foundation, Bob Hope Parkinson Research Center, 1501 N.W. 9th Avenue, Bob Hope Road, Miami, FL 33136-1494. 800-327-4545. [www.parkinson.org](http://www.parkinson.org); e-mail: [mailbox@npf.med.miami.edu](mailto:mailbox@npf.med.miami.edu).
- Parkinson Foundation of Canada, 4211 Yonge Street, Suite 316, Toronto, Ontario, M2P 2A9. 800-565-3000. [www.parkinson.ca](http://www.parkinson.ca); e-mail: [alicia.pace@parkinson.ca](mailto:alicia.pace@parkinson.ca).
- Partnership for Caring: America's Voices for the Dying, 1035 30th Street, N.W., Washington, DC 20007. 800-989-WILL (9455). [www.choices.org](http://www.choices.org). Founded in 1967, this group advocates and trains for end-of-life issues. Also has state-specific advance directives which can be downloaded for free or mailed for \$5.00.
- Senior Housing Net. [www.seniorhousing.net](http://www.seniorhousing.net). This site explains senior housing and has a comprehensive guide by state to all kinds of housing for seniors.
- Senior Sites. [www.seniorsites.com](http://www.seniorsites.com). Use this site to search by county and state for nonprofit nursing homes and other residential care alternatives.
- The Truth about Nursing Homes. [www.jeffdanger.com](http://www.jeffdanger.com). An excellent site that takes a hard-hitting view of nursing homes, from someone who has worked there.
- Web of Care. [www.webofcare.com](http://www.webofcare.com). A comprehensive site for caregivers which deals with many different issues and diseases.

### Information Resources on Payment

- AARP. 800-424-3410. [www.aarp.org](http://www.aarp.org). They have several excellent booklets describing Medicare and Medicare options such as Medigap (the supplemental insurance) and Medicare HMOs. The booklets are clearly written, with comparative information.
- The Complete Guide to Long-Term Care Insurance*, by Robert W. Davis. 600 Wet Ray Road, Suite D-4, Chandler, AZ 85225. 800-587-3279.

## RESOURCES

Health Care Financing Administration (HCFA), Room 314 G, Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201. 800-MEDICARE. [www.hcfa.gov](http://www.hcfa.gov). HCFA is the U.S. government agency responsible for overseeing Medicare and Medicaid. Each state also has an Information Counseling and Assistance office to help beneficiaries with questions about HCFA, Medicare, and Medicaid.

Health Insurance Association of America, 555 13th Street, N.W., Suite 600 East, Washington, DC 20004. 202-824-1600. [www.hiaa.org](http://www.hiaa.org). This is a lobbying group for insurance companies. They can provide you with information on long-term care and other types of insurance.

Medicaid. For Medicaid eligibility and benefits, you need to contact your state office. For general information, you can contact HCFA (see above).

Medicare. 800-MEDICARE. [www.medicare.gov](http://www.medicare.gov). (See above under “Organizations and Web Sites”).

National Center for Home Equity Conversion, 360 N. Robert #403, Saint Paul, MN 55101. 651-222-6775. fax: 651-222-6797. [www.reverse.org](http://www.reverse.org). Information on reverse mortgages.

National Senior Citizens Law Center, 1101 14th Street, N.W., Suite 400, Washington, DC 20005. 202-289-6976. fax: 202-289-7224. [www.nslc.org](http://www.nslc.org). Legal information, articles, and advocacy on issues affecting lower-income senior citizens.

Social Security Administration. 800-772-1213. Handles enrollment for Medicare.

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