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Everything You Always  
Wanted To Know About  
Alzheimer's But Were  
Afraid To Ask



Answers to the 101 Most Frequently Asked  
Questions About Alzheimer's

# **Everything You Always Wanted To Know About Alzheimer's But Were Afraid To Ask**

## **Answers to the 101 Most Frequently Asked Questions About Alzheimer's Disease**

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# **Everything You Always Wanted To Know About Alzheimer's But Were Afraid To Ask**

## **Answers to the 101 Most Frequently Asked Questions About Alzheimer's Disease**

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# TABLE OF CONTENTS

Answers to the 101 Most Frequently Asked Questions  
at The Alzheimer's Resource Center

Introduction

1. Dementia and Alzheimer's
2. Life expectancy for Alzheimer's patients
3. Having a loved one evaluated
4. Understanding what a loved one is feeling
5. Wandering
6. Hallucinations/delusions
7. Guilt
8. Why am I feeling so much anger?
9. Is Alzheimer's hereditary? What are the risk factors?
10. Do I tell my mom she has Alzheimer's disease? Inform the rest of the family?
11. Can a person with early Alzheimer's disease lose speech?
12. "Sundowning"
13. What is the best environment for early-stage Alzheimer's?
14. Down's Syndrome and Alzheimer's
15. Pick's Disease
16. How to deal with agitation
17. Understanding your loved one's agitation
18. Communication to minimize agitation
19. Non-verbal communication and its relationship to agitation
20. Pain management and agitation
21. Environment and agitation
22. Other advice on agitation
23. Confusion and unsteadiness
24. Are there ever positive personality changes?
25. Do you tell someone with Alzheimer's that someone close to them has died?
26. Alzheimer's and cancer treatment
27. Pain and pain treatment

28. Depression
29. Making your home safe
30. If your loved one falls
31. Insomnia
32. Haldol and other medication options
33. "I wish I were dead."
34. Support for the person with Alzheimer's
35. Interactions between medicine and alcohol
36. My mom is always looking for her children
37. Thinking the people on TV are real
38. When reading is no longer an option
39. Adjusting to new surroundings after a move
40. When your loved one decides to give up
41. When you can't get a loved one to shower
42. When you can't get a loved one to bathe
43. Hiring a caregiver
44. Coping with feelings of grief
45. Keeping your anger under control
46. How to orient a hired caregiver and not upset the routine
47. Activities to do at home with loved one with Alzheimer's
48. Keeping a journal
49. Art as therapy
50. Can pets have a calming effect?
51. How important is routine?
52. When your loved one becomes verbally abusive
53. When your loved one becomes uncooperative
54. Music and aggressive behavior
55. The blessings of being a caregiver
56. Good and bad days
57. Finding an in-home caregiver
58. Help for the "sandwich generation"
59. What do I tell the grandchildren?

60. How to communicate with your loved one
61. Incontinence
62. When the loved one doesn't like to be told what to do
63. When the loved one expects to be entertained
64. When other family members are not involved with caregiving
65. Keeping a sense of humor
66. Giving the primary caregiver a break
67. How will I know my loved one can no longer take her medication?
68. Choosing the right adult day center
69. Getting your loved one to attend an adult day center
70. When to start looking at nursing homes
71. When to consider nursing home placement
72. How to choose the right assisted living facility or nursing home
73. Could my loved one be happier in a nursing home?
74. Staying home as long as possible
75. Group homes
76. Dementia care units
77. Aggression and inpatient assessments
78. How to get the nursing home to decrease medication
79. When the person with Alzheimer's constantly loses or breaks items
80. How to start family council meetings at the nursing home
81. When a nursing home evicts a patient for nonpayment
82. Knowing when to move from adult daycare to a nursing home
83. How often should I visit the nursing home?
84. Wandering from the nursing home
85. Getting your loved one with Alzheimer's to eat more
86. Aspiration and feeding tubes
87. Family council meetings
88. Speech therapy
89. Medicaid and division of assets
90. When your loved one keeps asking to go home
91. How professional staff and residents' families can work together

92. Would I benefit from a support group?
93. Advance directives
94. Power of attorney vs. guardianship
95. Durable power of attorney
96. Hospice care: when and how
97. Legal and financial issues
98. How to set up affairs to avoid probate
99. Concerns with driving a car
100. Preventing Alzheimer's disease
101. Is it naive to hope for a cure?

# Introduction

If your loved one has recently been diagnosed with Alzheimer's disease, you likely have lots of questions, such as:

- What is Alzheimer's disease?
- What future needs will my loved one have?
- How do I deal with what lies ahead?

This book provides answers to the 101 most frequently asked questions at the Alzheimer's Resource Center and provides information on how to care for your loved one who has Alzheimer's.

As you accompany your loved one through the stages of the disease, you'll find that your role changes. In the early stages, you may have questions about whether your loved one can continue to drive. Or perhaps you are concerned about how to get your or their affairs in order.

As the dementia progresses, you may have questions about caregiving techniques, medical issues, and what the best living arrangement is.

Late stage Alzheimer's bring new questions as you try to contribute to your loved one's quality of life, even as that becomes more difficult to do.

In this book, you'll find answers to your questions about the following issues:

- Symptoms of Alzheimer's disease; depression and other medical issues
- Caregivers' emotions and family involvement
- Driving and other safety issues
- Practical tips for activities of daily living
- Advice about adult day centers, in-home care, assisted living facilities, hospice, and nursing homes
- Resources for additional information, assistance, and support groups
- Medicaid and how to cover the cost of your loved one's care

Know that even though life's challenges may be frustrating and frightening, you are not alone. Others have taken the journey. Their experience and advice will help you as you deal with caregiving, legal matters, and your own emotions. You may also rediscover your sense of humor and learn to appreciate the loving times and shared experiences with your loved one and other family members.

You did not ask for your loved one to have Alzheimer's disease, but perhaps you can begin to see the blessings as well as the sadness. As President Ronald Reagan's son, Ron, said after his father's death, "My dad may not always have known what was going on, but he could always feel the love."

## 1. What is dementia and how is it related to Alzheimer's disease?

The definition of dementia, according to the American Heritage Dictionary of the English Language, is “deterioration of intellectual faculties, such as memory, concentration, and judgment, resulting from an organic disease or a disorder of the brain. It is sometimes accompanied by emotional disturbance and personality changes.” Dementia is a syndrome or a group of symptoms that causes loss of intellectual function and usually progresses over time.

Alzheimer's disease is the leading cause of dementia and the one we hear about the most. Not all people with dementia have Alzheimer's. Different types of dementia exist. Other conditions, such as depression, will also cause dementia symptoms. Careful diagnosis of any dementia is essential in determining proper treatment and intervention.

Types of reversible dementia include Parkinson's Disease (PD), Vascular Dementia (stroke), Pick's Disease, AIDS, Multiple Sclerosis, Huntington's Disease, Wilson's Disease, Lewy Body Dementia, Creutzfeldt-Jakob Disease, Frontotemporal Dementia, and Wernicke-Korsakoff Syndrome (alcohol-related dementia).

Causes of reversible dementia can include depression, drug intoxication, alcohol and other poisons, nutritional deficiencies, brain disorders, diseases, a metabolic condition, organ dysfunction, traumatic brain injury, brain tumor, hydrocephalus, syphilis, encephalitis, and meningitis.

Alzheimer's is an irreversible dementia condition, but with the appropriate interventions, such as medication, irreversible dementias can be managed. Caregivers should seek out education, help, and support. Physicians' offices typically have resources available to get you started with this process.

If you would like further information on the different types of dementia, visit the following websites:

- The Mayo Clinic - [www.mayoclinic.com](http://www.mayoclinic.com)
- The National Institute of Neurological Disorders and Stroke - [www.ninds.nih.gov](http://www.ninds.nih.gov)
- The National Alzheimer's Association - [www.alz.org](http://www.alz.org). They have information on “related dementias.”
- Alzheimer's Disease Education and Referral Center (ADEAR) - [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)
- Web MD - [www.webmd.com/alzheimers/guide/alzheimers-dementia](http://www.webmd.com/alzheimers/guide/alzheimers-dementia)
- FamilyDoctor.org - <http://familydoctor.org/familydoctor/en/diseases-conditions/dementia.html>

## **2. How long can a person live with Alzheimer's disease?**

Each person with Alzheimer's progresses at a different rate, and not everyone experiences every symptom or stage. Some will plateau at a stage for quite some time, while other will progress very rapidly.

Alzheimer's disease does not cause death. However, the disease progresses to the point that many of the body's organs begin to shut down. If the patient becomes bedridden, he or she can develop an illness such as pneumonia and be unable to fight it off.

According to several resources, a person with Alzheimer's can survive from three to twenty years after the first symptoms begin, with an average of eight years.

A great resource for families and caregivers is the book, *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life* by Nancy L. Mace and Peter V. Rabins. This book can be purchased at your local bookstore or online.

### **3. Do I need to have my loved one evaluated? And by whom?**

Yes. When the first symptoms of dementia (more-than-mild forgetfulness or confusion) occur, a complete work-up and evaluation by a physician is mandatory. This exam will determine whether symptoms are due to such things as depression, poor nutrition, drug intoxication, alcohol abuse, or organ dysfunction. If your loved one has never been evaluated, a neurologist or geriatrician is your best bet. Those who have been diagnosed with Alzheimer's should see a geriatric psychiatrist for anxiety, depression, agitation, or any other behavioral issues.

Physician referral services can provide a list of these physicians. Some caregivers receive information and referrals at their support group meetings. It is comforting to see a physician that you know other caregivers have used and liked.

Everyone is different, so if you are not happy with the physician, look for another. Being comfortable with the doctor is important in order for you to ask any questions you need to ask at any time.

Early diagnosis of dementia can indicate treatment to help slow the progression of the disease with appropriate medication. A complete work-up includes: physical examination, medical history, neurological tests, laboratory tests, brain imaging, and function tests.

Once a diagnosis is made, inform the primary physician. Your loved one will continue to see a primary care physician for general checkups. The geriatrician, neurologist, or psychiatrist will be seen for issues directly related to dementia.

The best, most effective doctors in this field are also concerned about the health and well-being of the caregiver. Alzheimer's is a family illness. The doctor needs to be aware of the caregiver's stress level and be willing to offer support, suggestions, and encouragement to the caregiver. Making sure the caregiver is looked after is the greatest proactive intervention to promoting successful caregiving in the home.

#### 4. How can I better understand what my loved one is feeling/going through?

No one can truly empathize with any situation without having been there themselves. Even then, each person handles life differently. Perhaps the best way to try to understand how your loved one is feeling is to read what several people with Alzheimer's disease have written and published to educate those who want to know.

These books walk you through their personal journeys. It can be heart-wrenching to read about the devastating things they go through, but it is good for learning and understanding. Reading these books may bring out many of your own emotions, but it may also help you know how your loved one feels.

- *Living In The Labyrinth: A Personal Journey Through the Maze of Alzheimer's*  
by Diana Friel McGowin  
©1993, Dell Publishing/ Doubleday Dell Publishing Group
- *Show Me The Way To Go Home*  
by Larry Rose  
© 1996, Elder Books, Forest Knolls, California

You can find these books at your nearest Alzheimer's Association or at any bookstore or online book source.

## 5. I'm new to this disease; is wandering a big concern?

Wandering can be a concern, but it isn't a universal symptom of Alzheimer's. Each person with dementia is an individual who travels through this journey at his or her own pace. Unfortunately, you don't know if your loved one is a wanderer until he or she wanders for the first time.

Upon diagnosis of Alzheimer's disease, register your loved one in the "Safe Return" program with the Alzheimer's Association. This information can be located on their website at [www.alz.org](http://www.alz.org), or you can contact your local Alzheimer's Association. The national association will mail you information about the program and how to enroll. With the registration, you will choose the form of jewelry you would like your loved one to wear. The jewelry has the Alzheimer's Association logo on the front and your loved one's identification number on the back. Most choose the bracelet as it can be worn with or like a watch. Those who typically did not wear jewelry in the past will usually agree to wear a bracelet. To decrease your loved one's suspiciousness and possible resistance to the jewelry, you may want to order two bracelets and each of you wear one. This has been a successful approach for many caregivers and their loved ones.

It is always wise to think and plan ahead in any situation. You may want to join a support group and talk with other caregivers about devices or interventions that have worked for them. Browse through electronics stores and see what they have to offer. Visit the Alzheimer's Store at [www.alzstore.com](http://www.alzstore.com) to look at safety products. You can also hire agencies that will assess your home and environment to advise you on safety precautions.

At the first indication of wandering, take action. Put a baby monitor in the bedroom at night so you can hear when your loved one gets up. Install safety devices in your home. Inform your neighbors. Talk with your physician concerning treatment for this symptom.

If and when your loved one does wander, don't hesitate to call 911. Many police departments educate their officers about Alzheimer's disease and provide training in the best way to deal with situations such as wandering.

Another way to prepare yourself is to read the book *The 36 Hour Day* by Nancy Mace and Peter Rabins (see question #2 for more information). It will enlighten you on the stages of the disease and what you might encounter.

## 6. Are hallucinations or delusions a part of the disease, or are they the side effects of drugs?

*Hallucinations* are sensory experiences that cannot be verified by anyone other than the person experiencing them. Any sense may be involved, particularly seeing and hearing. *Delusions* are beliefs that are contrary to fact which remain fixed or persistent despite all evidence to the contrary. Both can result from either the disease process or drug side effects.

If you suspect that a medication might be causing these symptoms, talk with your physician. You can research this information yourself by talking with your pharmacist or by visiting the medication website. (Type in the name of the medication in your search engine, and you should find what you are looking for.) Even if you think the medication is causing the hallucinations or delusions, consult your physician before discontinuing use, as many medications can not be stopped abruptly; they need to be tapered off.

Hallucinations and delusions can also simply be symptoms of dementia. People who have Alzheimer's each experience the disease in a different way. Some have hallucinations, some have delusions. Some have both, some have neither.

The rule of thumb is if the hallucinations are friendly ones, meaning they don't upset or frighten your loved one, then the caregiver and those around the loved one need to just "go with the flow." Validation is important when dealing with hallucinations. When your loved one thinks he or she sees or hears someone who isn't really there, you can say, "What are your friends' names?" "Are they nice?"

If the hallucinations are not friendly, the situation becomes much more difficult. Your loved one may believe that someone is trying to kill them, break into the house, or cause harm in some other way. Validation also works in this situation, but it is more tricky. You may have to use what is called "therapeutic fibs"—meaning you may not be telling the whole truth, but it's for your loved one's own good. For instance, you may say you are afraid too, but you called 911 and police took the intruder away. This response may or may not put them at ease. If it does, it may be only for a short time. The hallucinations will start up again, and you will have to respond again. If unfriendly hallucinations continue, consult your physician.

## 7. How do I deal with the guilt?

The definition of guilt is “being responsible for the commission of an offense; remorseful awareness of having done something wrong; or self-reproach for supposed inadequacy or wrongdoing.” When we examine this word and what it means, we realize that we sometimes place guilt where it doesn’t belong.

If you are caring for a loved one and are feeling guilty, you need to put this feeling into perspective and “let it go.” Even if people in your life have worked at making you feel guilty, you need to rise above it. You don’t have control over many things in your life, but you do have control over how you respond. Guilt does nothing but tear you up inside and can make you less effective in all that you do.

If you reflect upon what you are doing as a caregiver, you will realize you are doing the best you can. Your best is good enough. Even if your loved one lives in a nursing home, you are in charge of certain parts of his or her life affairs. You are your loved one’s advocate.

Try to journal your feelings and then look at what you are doing and whether you have just cause to feel guilty. Most of the time, you will find there is no reason to feel guilty. Even if you have siblings or other family members trying to make you feel that way, don’t let them. You can’t control what they are doing, but you can control the fact that you are not going to let them get to you. You are the one who has stepped up to the plate and volunteered to be the primary caregiver. You did not ask for your loved one to have this disease, but you have chosen to help.

Give yourself a break and let go of the guilt.

**GUILT: Give Undeserved Illusions Little Thought.**

## 8. Why am I feeling so much anger about my father's having Alzheimer's?

Always keep in mind that when you are dealing with a situation like this, you are going through a grieving process. One of the stages of grief is anger, and it is very normal. The important thing to remember is not to let the anger get so bad that it affects your mental or physical health.

When grieving, you may experience several different stages. Everyone goes through the stages at a different pace, and some don't even experience all of the stages. Be patient with yourself and let yourself feel. Let yourself grieve.

The usual stages of grief are:

1. **Shock:** Disbelief that a loved one has been diagnosed with Alzheimer's disease.
2. **Denial:** He will snap out of it. He is just going through a stage of forgetfulness.
3. **Depression:** Feelings of loneliness and utter isolation.
4. **Physical symptoms of distress:** Symptoms of illness or fatigue.
5. **Anxiety:** Worrying about what the future will hold.
6. **Anger:** Anger at the disease, at your loved one, at the doctor, at God for allowing this to happen.
7. **Guilt:** Blaming ourselves for things we think we shouldn't have done, like yelling.
8. **Hesitancy to keep up normal activities:** Fear of how friends and other people will treat you and your loved one.
9. **Healing of memories:** Realization that the pain of memories is actually a healing process.
10. **Acceptance:** Accepting that your loved one has the disease and that you have to make the best of it because you can't change the facts.

Because the disease continues to progress, you may go through stages of grief each time your loved one goes through a new stage of the illness. Know that this is a common response. Let yourself grieve. Let yourself be angry. Journal your feelings; this can be a healthy way to express yourself. It allows you to get your feelings out without hurting anyone around you. Deal with your feelings—then you will be in a better emotional place to care for your loved one.

If you get down mentally, it will affect your physical health. Don't internalize your feelings or it will hurt you. Then who will be there for your loved one?

## **9. Is Alzheimer's disease hereditary? If so, what are the risk factors?**

The answer to this is still not definitive. What researchers are currently saying is that if you have a relative with Alzheimer's disease, you have a greater chance of developing the disease than someone who has no family history.

The presence of more than one family member with Alzheimer's does not necessarily indicate that your family has one of the strongly-inherited forms of Alzheimer's disease.

For more information on this topic, visit [www.alzheimer.ca](http://www.alzheimer.ca), the site for the Alzheimer Society of Canada. On this website is detailed information concerning genetic research and Alzheimer's disease.

As a suggestion to those of you who have a loved one with Alzheimer's, you need to deal with this in a constructive way. As hard as it may be, you don't want to ruin your quality of life by worrying about something that may or may not ever happen. Living in fear can be debilitating, and you need to free yourself of this. Try to journal your thoughts. Seek professional counseling. Don't try to deal with this alone; involve others in your family and join a support group. If a support group is not available, start one. Even if it is just going to coffee with other family members whose loved ones have Alzheimer's, it's a good start. You need to talk about it, especially with others who are experiencing it too, as they will understand.

## **10. Do I tell my mom she has Alzheimer's disease? How do I inform the rest of the family about the diagnosis and what to expect?**

This is yet another topic that has been debated for years. Do you tell a person she has Alzheimer's? Some professionals feel persons with Alzheimer's should be told, and others think they should not. Putting all the opinions aside, what is best for your loved one? If you tell her about the diagnosis will it put her into a tailspin and depression? Or will she take it with stride? Will knowing help her cope?

Chances are, if you don't tell her, someone will slip and it will be devastating. If she likes her doctor and has a good relationship with him, he is the best one to tell her in a matter-of-fact way. A family member should be with her when the doctor talks with her. After the doctor talks with her, you can call a family meeting and let everyone know. To have the diagnosis out in the open is freeing for everyone involved.

When you have the family meeting, you can all brainstorm on what the next step will be. Getting her financial and legal affairs in order is a very important first step. If there is tension within the family and you are having disagreements, this is not healthy for your mother. In that case, set a time when you can meet without her being present so you can hash it out without upsetting her. If you need a mediator, get one. You need to be adults now and do what is right for your mom.

Allow your mom and yourself to grieve. Alzheimer's is a devastating diagnosis. Take care of yourself and each other. Join a support group to talk with others in the same situation. There are early stage support groups for your mother; get her involved with them. She will be expressing and dealing with her feelings with others who have also been diagnosed with Alzheimer's disease. This is a great outlet for both of you. If you still are having a lot of difficulty coping, seek out a professional counselor.

Support each other the best you can. Work as a team. Let go of the things you can't control. Choose your battles. Keep a good sense of humor.

## **11. Can a person with early stage Alzheimer's disease lose speech?**

Keep in mind that each person with Alzheimer's is unique, developing symptoms differently and at different times and rates. Many symptoms of Alzheimer's disease are common, such as loss of memory, frustration with limitations, feelings of insecurity, and feelings of fear. Some never experience certain symptoms, while others seem to have all the symptoms ever reported.

Losing speech typically occurs in the mid to later stages of the disease, if at all. As the brain deteriorates, it begins to shut down certain functions of the body, and one of these functions is speech. It begins with losing words and not being able to complete sentences. Then it may move to talking gibberish—the person speaks full sentences, but the words make no sense. In some cases, the person may lose speech altogether.

One of the complications of a neurological disease like this is the possibility of mini strokes. Many individuals diagnosed with dementia experience these strokes. Others are first diagnosed with strokes and then develop dementia secondary to the strokes. If a stroke is severe, speech can be lost. Speech therapists can help these individuals work to regain their speech.

If a person with Alzheimer's loses their speech early on, it may be best to consult your physician. If you are not satisfied with the response of the doctor, seek another opinion. Also seek out a specialist such as a neurologist. Many times mini strokes are too small to detect with an MRI. Experienced doctors will make their determination or diagnosis by observation of symptoms and information from family.

Always talk with a physician concerning any medical situation. It is not typical for an individual with Alzheimer's disease to lose speech early on, but because it is a very individual disease, there are few definites.

## **12. What is “sundowning,” and can it affect my wife who has Alzheimer’s?**

“Sundowning” is a term that describes increased confusion as the day progresses. The actual cause of sundowning is unknown, but some factors that may precipitate the symptoms are fatigue, low lighting, and increased shadows. As these changes occur throughout the day, the person with Alzheimer’s becomes more confused. Sundowning is predictable, beginning at about the same time each day. Due to this predictability, measures can be taken to help both the person with Alzheimer’s and the caregiver.

To address the issue of fatigue, try to get your loved one to take a short nap in the afternoon after lunch, or carve out time in her daily schedule for her to have quiet time. This is time to relax and recoup so she can face the rest of the day. You can set the tone or atmosphere to encourage relaxation. She needs to be in a comfortable place such as a recliner or a bed. You can put on music that is relaxing to her; burn a fragrant candle or incense; plug in a diffuser; dim the lights or turn them off (you may want to warn her first so as not to startle her); turn on “white noise” such as a fan or water fountain; gently massage her hands and arms with warm lotion; and let her relax. This is also an opportunity for a volunteer from the church, a neighbor or friend, or another family member to be involved with her care. This is a time they can visit and give you a break.

Once the quiet time is over, make sure there is plenty of lighting throughout the rest of the day. Shadows and darkness are what tend to make her confused. Night lights throughout the house are one way of increasing lighting. If she is in an unfamiliar setting, such as a hospital room, or you are visiting somewhere, take things that are familiar to her so she can identify with them, e.g. pillows, throws, quilts, stuffed animals, or a radio.

As sundowning begins, try to keep her busy. If she is involved in something worthwhile to her, it will distract her from the lowering of the sun.

**13. My mother has early stage Alzheimer's. How do I know the best environment for her? She lives halfway across the country. Is it best to leave her there or move her close to me?**

If she is still lucid and can make—or at least be involved in—her own decisions, discuss this situation with her. You may want to go to where she lives and talk face to face. While you are there, you will have the perfect opportunity to assess her home situation and determine if you are comfortable with her living there alone. You can also determine if she could live alone with assistance from in-home care. At that point, you can contact a geriatric care manager to look after her in your absence. If this is not feasible or comfortable for you, you may want to look at facilities in her area. Talk with a social service agency in the area she lives to find these resources. Even if she goes to a facility, you can hire a geriatric care manager to visit her on a regular basis and report back to you. The manager would act as a liaison for you and also as an advocate for your mother to ensure she is getting proper care.

If you still are not comfortable with the situation, discuss moving her close to you. Decide whether she would live with you or in a facility near you. If she were to live with you, would she need supervision, or would she be safe alone while you work? If supervision is needed, contact a social service agency to get a list of resources in your area. In-home care is also an option. Adult daycare is another, if you have a center in your area. Daycare services include supervision, meals, activities, and socialization. Some provide nursing services. This option would mean she would leave your home and go to a center each day. This could be arranged through the center's transportation service, if offered, through specialized public transportation, or you could take her and pick her up on your trip to and from work.

When you talk with your mother, you will get an idea what environment is best for her. Think through your options; run them past a trusted friend. Then make a decision.

**14. My brother has Down's Syndrome and now Alzheimer's disease. How do I deal with his behavior changes? He looks the same, so I expect him to act as he always has.**

Those with Down's Syndrome are living longer and thus are experiencing the onset of dementia. Especially if your brother was high-functioning, this is difficult to accept. Those with Down Syndrome have typically lived at home with family into their adult years. The family is accustomed to their level of input as part of the family unit. When the dementia begins, their behavior begins to change. Part of that change is loss of memory and the ability to perform even the simplest of daily activities, including dressing, setting the table, exercising, and generally helping around the house. They begin to withdraw, not wanting to leave the house because of their feelings of insecurity and fear of unfamiliar happenings and surroundings.

A routine is crucial for maintaining their self esteem. Allowing them to help at appropriate levels will help increase feelings of self-worth. Provide a failure-free environment as much as possible. Let family members compensate for the duties the individual can no longer perform.

As his sibling, you have to let yourself grieve. You have lost the person you once knew and continue to lose him bit by bit. Give yourself time. Keep a journal of your feelings to help you deal with the shock, denial, anger, isolation, fear, and depression. Once you have allowed yourself to grieve through these stages, the final stage is acceptance. For your sake and the sake of your brother, you need to get to the point of acceptance. This isn't to say that once you reach acceptance, you won't continue to grieve at times.

Look at pictures of your brother, you, your family. Reminisce about the good times. We've been given the gift of memory to remind us of when times were good. This is can be a painful activity, but through the pain we can find healing.

Let your brother function at the level he can. Lower your expectations. If you are stuck in denial, you will push him to do things he is not capable of, and you will both become frustrated. Accept him right where he is. Let him assist you with certain activities that he will feel successful doing. Remember that these activities may be completely different from those he could previously do, or they can be the same types of activities but modified for his current level of functioning.

Just a note: A physical disability would remind you of your brother's new limitations. However, since Alzheimer's disease involves the brain and he looks the same on the outside, you may forget that he is functioning differently. You may expect him to be like he always was. Instead, go with the flow and let him be himself.

**15. I need information on Pick's disease. Where can I find it? Is there support for people with this disease?**

Finding information on Pick's disease can be difficult. According to the National Institute of Neurological Disorders and Stroke (NINDS), Pick's disease is a form of dementia characterized by a slowly progressive deterioration of social skills and changes in personality, along with impairment of intellect, memory, and language. Although the disease varies greatly in the way it affects individuals, there is a common core of symptoms which may be present at different stages of the disease. These symptoms include loss of memory, lack of spontaneity, difficulty thinking, emotional dullness, loss of moral judgment, and progressive dementia.

Although the disease usually affects individuals between the ages of 40 and 60, the age of onset may range from 20 to 80. Patients typically have atrophy of the frontal and temporal lobes of the brain. Some nerve cells have characteristic abnormalities when viewed under a microscope at autopsy, but the cause of the disease is unknown.

Currently there is no cure, but certain symptoms of Pick's disease can be treated. Along with the National Institute of Neurological Disorders and Stroke, the National Institute on Aging (NIA) conducts research relevant to Pick's disease. For more information, contact:

NINDS: [www.ninds.nih.gov](http://www.ninds.nih.gov)  
NIA: [www.nih.gov/nia](http://www.nih.gov/nia)

There is a wonderful online Pick's disease support group at [www.pdsg.org.uk](http://www.pdsg.org.uk). Contact the Alzheimer's Association or aging department closest to you to inquire about a support group for Pick's in your area. If there isn't one available, contact a social service agency to get one started. Support from others in a similar situation is priceless.

## 16. What are ways, other than medication, to deal with agitation?

Many times, understanding the meaning of a word can give us great insight into the issue at hand.

- “Extreme emotional disturbance.” (*The American Heritage Dictionary of the English Language*)
- “A stirring up or arousing; disturbance of tranquility; disturbance of mind that shows itself by physical excitement.” (*Webster’s Revised Unabridged Dictionary*)
- “A mental state of extreme emotional disturbance, the feeling of being agitated; not calm.” (*WorldNet 1.6*)

Many of us, at some time in our lives, have experienced agitation—the feeling of being so emotionally overwhelmed that it causes unrest. Fortunately, we can identify this feeling and cope with it—but for persons with Alzheimer’s, this can be difficult or impossible. Many times they cannot get in touch with or express their feelings. So when they experience agitation, it is difficult for caregivers to understand and help.

One area that won’t be discussed in depth here, but needs consideration, is medication. Sudden agitation or a change in severity could be related to medication—a new medication or a change in dosage. Journal things you notice and discuss them with your doctor. Don’t wait for the next appointment; call the doctor right away for assistance. Both over-the-counter and prescription medications can cause agitation. Of course, consult your physician before starting, stopping, or changing any medication.

## 17. How can I better understand my loved one's agitation?

Many professionals working with individuals with dementia believe that behind every behavior is a cause or reason. Malcolm Goldsmith of the *UK Journal of Dementia Care* said, ***“If we spent as much time trying to understand behavior as we spend trying to manage and control it, we might discover what lies behind it is a genuine attempt to communicate.”***

When a person with dementia displays agitation or other “symptoms,” we must try to determine what they are attempting to communicate.

The person with dementia is just that, a *person*... an individual with a disease. In spite of the disease, this person continues to feel and needs to be heard. If we think about what causes us to become agitated or angry, many times it is a result of not being heard. We need to have our feelings validated and be understood. For example, you tell a trusted friend about a situation that made you cry. Your friend responds, “Why should that make you cry?” This response causes feelings of not being heard or being validated. A better response from your friend would be, “I’m sorry you’re upset. Would you like to talk more about the situation?” Your friend may not agree with your feelings (what upsets you may not upset her), but she can still validate you.

Another example of validation is an upset child telling her parents that someone is picking on her at school. If the parent shrugs it off, then the child doesn’t feel heard, understood, or validated. But if the parent says, “That really upsets me, too. Let’s talk about it and see how we can make the situation better,” then this validates the child’s feelings. The end result is that she feels good about herself. The situation at school may not appear important to the parent, but it is important to the child. In order to determine if the issue needs to be addressed, we must listen.

It is very much the same for the person with dementia. He or she needs to feel heard and genuinely validated. His or her experience may not seem like a big deal to us, but it is to them. Many common daily activities become so difficult that the person feels inadequate, unsure, and even fearful. He or she needs to feel love and support to get through the frustrations of each day without agitation. Affirming statements such as, “Thank you for your help,” “You did a good job,” “I love you,” “You are in a safe place,” or “You are a wonderful person,” can help self esteem and make a person feel validated. Even though what was said may be forgotten, the good feeling will remain.

We need to validate feelings, affirm frequently, and genuinely listen.

## 18. How can I best communicate with my loved one to minimize agitation?

Good communication is an important part of any relationship. When caring for a person with dementia, however, communication becomes more and more difficult. Both expressing and processing information becomes impaired. This inability to express and process can be frustrating and manifest itself as agitation. Agitation can include anything from pacing to actually lashing out. As caregivers, we want to prevent this reaction as much as possible by communicating effectively.

The following tips will improve communication:

- Approach from the front to prevent startling.
- Maintain eye contact.
- Lower the tone of your voice; a high pitch may indicate that you are upset.
- Smile and be pleasant.
- Talk with a calm presence.
- Speak slowly, clearly, and directly.
- Identify yourself if necessary.
- Use short, simple sentences.
- Ask one question at a time.
- Eliminate background noise.
- Give plenty of time to respond.
- If he or she cannot find words, gently finish the sentence.
- Repeat information when needed—repetition is good.
- Frequently affirm/praise him or her, even for the smallest things, i.e. “Good job,” “Thank you,” “You’re the best!”
- Allow choices when possible—“Would you like coffee or milk?” “Should we pay the electric or phone bill first?”
- Validate feelings.
- Use touch. Touch the shoulder, knee, back, hand.
- Give hugs many times a day.
- Don’t argue—you’ll never win.
- Laugh together.
- If your words become heated, stop. Go back and try again later.
- Don’t talk down. Respect him or her as an adult.
- Don’t correct him or her.
- Don’t demand—ask nicely.
- Don’t take adverse behavior personally.
- Slow down! Hurrying increases frustration.

## 19. What if words don't seem like enough?

Non-verbal communication is important—both what we are communicating to our loved ones, and what they are communicating to us.

Our non-verbal communication is expressed through body language, facial expression, and tone of voice. At times, an Alzheimer's patient can look into your eyes and seem to read your soul, almost like a "sixth sense." They are sensitive and intuitive to people and things around them. They know when someone is being sincere. They know if they're not being included and if they're being talked down to.

We must also be aware of their body language and what it is telling us. Suddenly getting up from a chair and walking around may indicate the need to go to the bathroom or some kind of pain or discomfort. The possibility of pain is always part of the equation.

When it comes to calming our loved one's anxiety/agitation, sometimes no words are needed. Touch is an important part of human existence. A hug or gentle touch on the hand, arm, or shoulder will do. A simple embrace can change a person's entire disposition in an instant. Many times the caregiver may be feeling angry and won't want to give a hug, but the loved one still needs it. Embrace him or her. It may be stepping out of your comfort zone, but you will be amazed at the result. If your loved one is tense, a hug can release that tension instantly. It might possibly have the same effect on you. A massage or gentle back rub can also have a relaxing effect.

## 20. How can pain contribute to agitation?

Illness or pain almost always cause increased confusion/agitation. A sudden onset of increased confusion/agitation often means something is going on physically—dementia typically does not progress that rapidly. The cycle of pain gives us an idea of how pain affects our entire body. *Pain... Anxiety... Fatigue... Depression... Pain... Anxiety... Fatigue... Depression...* and so on. If the person with dementia is in this cycle and is unable to communicate it, we have to step in and figure it out.

There are many causes of pain, including infection, arthritis, joint and muscle problems, inflammation, and headaches. If your loved one has a history of any of these conditions, continued treatment as ordered by your physician is crucial. An ongoing assessment of overall health is important to determine the possibility of pain, such as urinary tract infection, headache, or other conditions that might cause discomfort or pain. Prior to the appointment, tell the physician what has been going on.

A simple sore on a foot or a bout with arthritis is enough to cause a change in behavior. Facial expressions and body language are important indicators of what is going on.

If your loved one takes medication, be aware of the possibility that some medications can cause agitation. Always consult your physician if you have questions or concerns. For the caregiver, care management is a constant guessing game of assessing and responding to needs.

Talk with other caregivers, whether in a support group or individually, to get support and help sort things out. Family and friends who genuinely care and try to understand are also good sources of support. Don't think you have to do this alone. Reach out for help, and receive it when given.

## 21. How can I structure my mother's environment to minimize agitation?

Environment plays a big role in human behavior. A person with dementia needs to feel safe in her environment to decrease feelings of fear and insecurity. Many environmental aspects cause increased confusion and agitation. A continual assessment of the overall environment can help prevent agitation. For example:

- Temperature: too hot or too cold
- Lighting: too bright or too dim
- Walkways/hallways: too cluttered
- Noise: too loud, too much
- People: whether comfortable with those who are around

Look for patterns associated with agitation: time of day, activities or events such as children visiting, bathing. When you notice the pattern, address that specific issue. Perhaps the children need to come in the morning when your loved one is rested. Maybe taking showers in the morning instead of at night is upsetting internal programming. These issues seem insignificant, but they can make a huge difference to your loved one.

Setting up an environment that is relaxing can help calm agitation. Whatever works for your loved one is what is best. Some examples of calming effects are:

- Burning fragrant candles or incense or using an electric infuser
- Playing a favorite kind of music or video
- Sitting in front of the fireplace
- White noise, such as a fan
- Getting fresh air outside
- Watching the birds from the porch
- Or anything else that will decrease agitation for your loved one.

## 22. Can you give me any other advice on preventing agitation?

Choose your battles wisely and know that just because a behavior is bothersome to us, does not mean it is an issue for the person with dementia. When feeling stressed about a behavior, ask yourself, “Is he in danger? Is this detrimental to his health? Or am I making a mountain out of a molehill?” For example, your loved one is putting on multiple layers of clothing. This isn’t how she dressed prior to having dementia; but you need to ask yourself the question, “Is it really hurting anyone?” If not, then... let it go. If you were to confront your loved one and make her change her clothes, it could result in agitation and possibly an angry outburst. Your goal is to prevent any stimuli that could bring on agitation.

As adults, we don’t like to be told what to do. The person with dementia is no different. So if you can “go with the flow” and address only the issues that are serious enough to address, your lives will be much less stressful.

Always remember that as human beings, people with dementia need to feel loved, needed, useful, and a part of their environment. We must provide this for them by showing them love, including them whenever possible, allowing them to help, and setting them up for success.

Use “behavior acceptance.” If we look at a behavior as part of the disease process and there is a reason behind it, we can respond more effectively.

Instead of saying, “Your clothes are dirty. Would you please change into something clean?” you could say, “Let’s go change our clothes so we can go to the store.” This is a directive, but less demanding. Because you are involving yourself, it is less threatening.

You can live by this: “We cannot control what comes our way, but we can control how we respond.” The person with dementia is unable to change, so we must. We can change our focus to “How can I best respond to this situation/behavior?” as opposed to looking at the person with dementia as being “the problem.”

*“Love cures people. Both the ones who give it, and the ones who receive it.”*

—Karl Menninger

## **23. Are confusion and unsteadiness a part of the disease progression, or are they caused by medication?**

Confusion and unsteadiness can be either a part of the disease progression or a side effect of medicine.

Alzheimer's disease is a neurological disorder that causes confusion and can affect ambulation. Due to the effect on the brain, the person with Alzheimer's can experience difficulty with perception which can affect the way a person walks. A shiny floor may appear wet; a black carpet strip may seem to be a threshold to be stepped over. This can cause unsteadiness.

The difficulty is that medication can also cause confusion and unsteadiness. As a family member, it is important for you to continually observe his behavior. If he has changed a medication or changed the dosage of a current medication, you need to watch for side effects. A sudden increase in confusion is likely due to the change in medication, because Alzheimer's typically does not progress that rapidly. To read about the side effects of medications, ask your pharmacist or visit the website of the specific medication, e.g., [www.namenda.com](http://www.namenda.com). These websites contain a lot of information.

Another possibility to be aware of is physical difficulties unrelated to the Alzheimer's or any medication. Sudden confusion and/or difficulty walking could be signs of pain or an infection. This requires taking the time to observe behavior and then do the detective work to figure out what is causing it. You will soon begin to do this without consciously thinking about it. But remember, when you have tried everything and nothing seems to be working, these symptoms might simply be a part of the disease's progress.

## **24. Has anyone experienced positive personality changes in their loved one with Alzheimer's?**

Actually, the answer is yes, but not necessarily in the way you would think. Many times, a positive change in personality comes out due to a personality disorder which was present before the onset of Alzheimer's, such as alcoholism, bipolar disorder, or schizophrenia. Some families of individuals affected by these disorders say their loved one was "blessed" with dementia or Alzheimer's disease. Before, the person was harsh and sometimes abusive. Now, the dementia has made him or her docile, loving, and happy.

These families joke about having a support group for people who are happy about dementia. One was a man who had been married to his wife for about 50 years. She had been an alcoholic most of their marriage, while raising their six children. As the disease progressed, she forgot to drink and she became more and more loving and docile. It's as if the dementia brought out the best in her that many around her had seldom seen in previous years. Her children would visit, and she would be loving to them. She also had a good sense of humor and laughed a lot. Her husband stated many times that these were some of the best years of their married lives. He was almost grateful for the dementia. He felt this disease had given them a second chance at a happy life together. She remained in their home with him as her primary caregiver until her death.

So, sometimes blessings come forth from tragedy.

## **25. Do you tell someone with Alzheimer's that someone close to them has died?**

This topic has been debated quite a bit. It really depends on the person. You know your loved one better than anyone. If you think he or she can handle it, then the answer is probably yes. You have to think about how it will affect them and whether telling them is of any benefit. Also consider how he or she handled stressful situations in the past.

If the person who dies is someone your loved one saw every day and will be missed, it may be beneficial to tell them. The difficult part of this is, due to the short-term memory loss, your loved one will more than likely forget and keep asking about the person. At that time you will have to decide again whether to keep retelling the news or use "therapeutic fibs." Therapeutic fibs are ways to protect the person with dementia. You can try telling your loved one about the deceased person and see how it goes. If he or she continues to ask, you can say that the person isn't here right now. Or you can say he or she isn't here, and you're not sure where the person is, but you know they are okay and in a safe place.

Whether to tell them about a death also depends on their stage of the disease. In the early to mid stages of dementia, you may feel obligated to tell your loved one about a death. In the later stages, telling probably wouldn't be beneficial. No matter what the stage, if the deceased person wasn't around your loved one on a regular basis, telling may not benefit your loved one.

The same decision applies if your loved one asks about his or her parents. Of course, many times the parents have been gone for many years. Because the person is drawing on long-term memory, he or she is thinking about them again. The best way to handle this is through validation. You can say, "I know your parents aren't here now and you miss them, but they are okay and they know where you are." Then you can reminisce.

**26. My mother has Alzheimer's and also recurring colon cancer. How aggressive should we be with cancer treatment?**

This is a very tough situation. The decision you make is individual to you and your family. A family meeting with the oncologist concerning the cancer would help all of you be on the same page. The doctor can answer specific questions you have concerning the cancer, prognosis, and treatment options. More than likely, you won't want to be too aggressive or invasive. Any type of operation or aggressive treatment will cause increased confusion. If surgery is necessary, be sure you understand the risks involved.

Your doctor can order hospice services. Hospice not only assists families dealing with a loved one with cancer, but also patients in the late stages of dementia or Alzheimer's disease. Hospice is a wonderful organization that provides support, education, and care. The goal of hospice is to keep your loved one out of the hospital and in her own home, to keep her comfortable and pain free, and to have the best quality of life possible. Hospice not only works with the patient, but they are also involved with family; they want to educate the family and support them in any way they can.

**27. Does pain cause Alzheimer's disease to worsen? Should we continue to treat conditions such as a UTI? What about in the later stages?**

Pain in itself does not cause dementia to worsen, but it can cause increased confusion, agitation, and depression. The possibility of pain needs continuing assessment.

The issue of pain is a difficult one when dealing with a person with dementia. Many times the loved one cannot express his needs, so he acts it out in other ways, such as wandering, agitation, grimacing, sleeping, or just shutting down. If your loved one exhibits a sudden change, such as increased confusion, it is possible that something is causing discomfort or pain. It could be anything from shoes that are too tight to an infection.

In regard to treatment, the simple answer is "pain is pain," whether Alzheimer's is involved or not. When working with cancer patients, for example, the goal is to keep the patient as comfortable as possible by eliminating pain. It should be no different with individuals who have Alzheimer's disease, no matter the stage. They need to be pain-free and comfortable. A UTI (urinary tract infection) can cause pain, with symptoms of inflammation, burning, and itching. Treatment is not invasive and will ease discomfort, increasing quality of life.

If a person with Alzheimer's has a history of arthritis or other pain-producing illness, continued treatment according to doctor's orders is advisable. This will aid in prevention of pain. Other types of pain such as headache, backache, sore throat, and foot pain also need assessment and treatment. Always seek a doctor's advice.

Pain can cause a person to become depressed. A good indication that your loved one may be experiencing pain is a sudden decrease in interest in things they once enjoyed. This is also a symptom of non-pain-related depression, so these issues can become a guessing game.

## **28. Should I be looking for symptoms of depression in my loved one?**

Typically those who are around someone with depression tend to notice it more than the person suffering from it. If you notice your loved one wanting to sleep a lot, losing interest in activities he or she once enjoyed, exhibiting a change in eating habits or weight (up or down), or just being in an overall “down” mood, you could be seeing signs of depression. Comments like “I’m no good anymore,” “I don’t want to do anything,” “I wish I were dead” should be taken seriously and attended to. If you detect symptoms of depression, it is crucial to have a physician examine your loved one.

If the physician has diagnosed dementia, the person still needs to be assessed for depression, because depression can accompany dementia.

Antidepressant medications can help alleviate symptoms within a few weeks. Other interventions that help with depression are good nutrition, an adequate amount of sleep (not too much, not too little), and exercise.

## **29. How can I make my home safe for my loved one with Alzheimer's?**

More than likely a person with Alzheimer's disease is going to walk, wander, or pace. Caregivers must allow this behavior by structuring the environment to be as safe as possible. A person with Alzheimer's has perception difficulties. Carpet with black trim may look like a "black hole" to be stepped over; a shiny tile floor may appear wet. Good lighting without a lot of glare will reduce misperception, thus reducing anxiety.

Removing clutter from around the home is very important. Items like foot stools, baskets on the floor, plants on the floor, or papers and magazines lying around increase confusion and can be unsafe. Remove obstacles.

There are many products that can help with increasing security and decreasing the caregiver's level of anxiety. Bells, alarms, and locks on the doors can aid in keeping track of the person with dementia. Baby monitors are also good for monitoring, especially during the night. If your loved one has trouble with falling out of bed, put the mattress on the floor or put an extra mattress next to the bed to help prevent injury.

Information on purchasing home safety devices can be found at [www.alzstore.com](http://www.alzstore.com). Other safety devices can be found at Radio Shack. Baby monitors can be found at most stores that carry baby products.

### **30. What should I do if my loved one falls?**

First, protect yourself. If you try to help on your own, you could seriously injure yourself and the whole situation will snowball.

If you must help by yourself, there are techniques such as a gait belt—a strong canvas belt designed specifically for assisting with ambulation. If your loved one starts to go down and you are close enough, you can grab the belt and lower her to the floor. This breaks the hard fall. But this only works if you are able to do it without injuring yourself. You can purchase a gait belt through a durable medical equipment company or get one through the home care agency you are working with.

If you can't get her up and you have no one close enough to help, call 911. Most emergency response teams have been trained on the issues of Alzheimer's disease. The EMTs understand situations such as wandering, falling, and choking. They are more than willing to come to the home to assist. They can also assess your loved one for injury and transport them to the hospital if needed. There have been numerous testimonies from caregivers who were desperate and called 911 for help. They report being treated with the utmost respect, concern, and care, so don't hesitate to call.

Medical alert devices worn on the wrist or around the neck can assist you in calling for help. You push the button, and soon, help arrives. These systems are sold through several different companies and can be researched on the internet.

### **31. What can I do if my loved one with Alzheimer's isn't sleeping at night?**

Insomnia can be a common issue with Alzheimer's, but not all individuals experience it. If your loved one does, here are some helpful tips:

- Limit caffeine and alcohol intake.
- Try to keep your loved one active as much as possible during the day. Try dancing, walking, working in the yard, etc.
- Discourage naps during the day.
- Plan relaxing activities close to bedtime, such as playing soothing music.
- Avoid upsetting activities around bedtime. For example, if bathing is upsetting, do it earlier in the day.
- Keep a bedtime routine but, as always, remain flexible.
- Ensure comfort with room temperature and comfortable clothing.
- Ask the doctor about medications that may be disturbing sleep.
- A light snack before bedtime can have a calming effect.
- Make sure your loved one goes to the bathroom before bedtime.
- Don't make bedtime too early.
- If the person falls asleep on the couch, let him or her sleep there.
- If putting on nightclothes upsets your loved one, let him or her sleep in regular clothes.
- Use a favorite blanket or pillow to aid in relaxation.
- Use night lights in the bedroom, hallways, and bathrooms.
- Keep your physician informed so he or she can intervene if needed.

**32. My mother takes Haldol. Can it increase confusion? Is there a better medication than Haldol for agitation with fewer side effects? If she should change medication, how long does it take Haldol to leave the system?**

Haldol was one of the first psychotropic drugs on the market. It was designed to subdue young and healthy, but violent, psychiatric patients. It has been a successful drug when used for the right purpose and at the right dosage.

Medications affect individuals differently. What works for one person doesn't work for another. It becomes a real guessing game. All medications have side effects, but some patients experience them more than others. Some medication will have the opposite effect than what it was prescribed to do. For example: a medication is prescribed for decreasing anxiety, but it increases anxiety. This can be fairly common, especially among older patients.

Typically, Haldol is prescribed for aggressive behaviors and hallucinations. Unfortunately, if taken for long periods of time, Haldol can cause many side effects. Ask the physician to try other medications and see how they work. Some individuals tolerate Haldol well. Haldol is a drug that builds up in the system, so depending on how long your mother has been on it, complete removal from her system may take a few weeks.

The best approach in your mother's situation is to discuss it in detail with her physician. Talk with him about what you are seeing and what your options are. What other medications on the market are used for the same purpose? There are many good medications that have been developed for the same symptoms.

If you are not completely satisfied with the response from her physician, seek another opinion. Neurologists and geriatric psychiatrists are usually informed of the newest and most effective medications. Geriatric patients are almost always started on the lowest dose available and then increased as needed.

Another option is to have your mother admitted to a gero-psychiatric unit. These are specialized units for observing behavior and monitoring and changing medication specifically for senior adult patients. The benefit is the 24-hour observation and monitoring over several days, which gives the doctors a more complete and accurate picture.

### **33. All day long my mom says, “I wish I was dead.” How do I deal with this?**

This could be your mother’s way of expressing her frustration about the disease, or it could be an indication that she is dealing with depression. She needs to be observed and monitored. If you think she has depression, consult your physician right away. He can evaluate her and if necessary, prescribe an antidepressant.

She needs reassurance about what is going on. Talk to her on a regular basis about how she is feeling. Try to get her in touch with feelings, such as anger, frustration, and fear.

Once again, validation is essential. You can say, “Mom, I know you are not feeling yourself these days, but you are so wonderful. That hasn’t changed.” Or, “Mom, please tell me what you are feeling that you would want to die.” Chances are, she will respond with answers that describe how inadequate she feels. Constantly reassure her that she is loved and needed, then take one step further and give her opportunities to help so she feels she is contributing to the family.

As human beings, we need to feel we are contributing. When individuals suffer from Alzheimer’s or any type of dementia they often feel they have nothing to offer. Those who love and care for them must set up their environment for success so they feel needed and useful. Provide them with opportunities to help with daily activities around the house. An example would be helping with laundry. Any activity needs to be modified to the level your loved one can understand. For example, in the early stages, she may be able to gather the clothes from around the house, sort according to color, run the washer and dryer, and fold and put clothes where they belong. In middle stages, she may be able to take clothes from the washer, put them into the dryer, and help fold. In later stages, she may only be able to fold. Folding towels, washcloths, and socks is a successful activity in mid to later stages. She can also try to match pairs of socks.

### **34. Is there support for the person with Alzheimer's disease?**

Yes, there is support for the person with Alzheimer's disease.

Start with a visit to [www.alzhope.com](http://www.alzhope.com). There, you'll be part of a loving community and can post questions to others caring for loved ones with Alzheimer's.

You can also visit the Alzheimer's Association website at [www.alz.org](http://www.alz.org). They have a list of the programs they offer, one being support for the individual diagnosed with Alzheimer's disease. From this website you can link to the association in your area and read about resources close to home.

One of the most common support systems is an early stage support group. They are sponsored by the Alzheimer's Association and have started to catch on around the nation. These support groups are designed to meet the support needs of the person who has been recently diagnosed. A skilled facilitator guides the group in discussions about such issues as the diagnosis and what it means, financial and legal concerns, family dynamics, and emotional issues. These groups are a place to express innermost feelings in a safe place with others who understand. They laugh, cry, eat, and problem-solve together. Groups typically meet once a month for an hour and a half. Someone from the association can assess individuals to determine if they are able to benefit from the meetings. While they are meeting, their family members have their own meeting in a separate area, typically in the same building.

Individual support can also be found through professional counseling, members of the clergy, or home health agencies.

For more information on support, you can also contact the Alzheimer's Disease Education & Referral Center (ADEAR) at (800) 438-4380 or [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers), or the National Institute on Aging/Alzheimer's Disease Information at [www.nia.nih.gov](http://www.nia.nih.gov) or (800) 222-2225.

**35. Is wine or alcohol okay for my father who has Alzheimer's disease? Can it interact with the medications he is taking?**

When discussing any issue such as medication or the health of your loved one, always contact his doctor first. If your father has several doctors, talk with the primary physician who sees him regularly and writes orders for medications.

If the doctor feels it is safe for your father to have alcohol, he will advise you of an appropriate amount. It is wise to follow the doctor's orders. Too much alcohol could cause an adverse reaction and cause your loved one to become violent, lethargic, or exhibit one of many other types of behaviors related to alcohol consumption.

Wine, on occasion, will be suggested by a physician for an individual with Alzheimer's disease to help with a difficult behavior. If the patient is too active, restless, anxious, or even agitated, wine can have a very calming effect. Some persons with Alzheimer's drink wine before going to bed to help them sleep.

**36. My mom is in stage 5 and is always looking for her children. Would a doll to hold be helpful to her?**

It is worth a try, as it has worked for many individuals with Alzheimer's. A basic human need is to nurture. There have been many with Alzheimer's disease who truly thought the doll was real. They carried it around everywhere they went and made sure it was cared for. This can be a beneficial intervention.

There can be a down side to the doll therapy, though. If the person with Alzheimer's believes the doll is a real baby, she may have a tendency to worry about it. There was a woman at an adult day center who was very, very busy, to say the least. She had been a volunteer most of her adult life in hospital-type facilities. She was a natural nurturer; she loved caring for people and things. The staff at her facility gave her a doll. At first it appeared it was the miracle answer to her "busyness." After several hours went by, she began to worry about the "baby" needing to be fed. She worried so much about it, she became agitated. The staff had to cleverly get the doll from her, saying they were babysitting, and got it out of her sight. Once she couldn't see the baby any more, she began to calm down. The doll was put away for several months and then given back to her. At that point, she was able to carry the doll around and not be stressed about it.

Offer your mother a lot of validation and reassurance. This will be an ongoing process. Tell her that her children are doing fine and they are safe. She is probably thinking about when they were young, and she's worried about them. Getting her redirected in other types of activities will also help keep her mind busy and off her children.

Stuffed animals also work well because the person with Alzheimer's has the need to touch, love, and give affection.

**37. My mom, who lives in a nursing home, thinks that people on TV are real. Once she refused to play bingo until she asked the newscaster if he wanted to play. She loves the music shows, but thinks they are live concerts. Should I eliminate her TV altogether?**

This behavior is a common symptom of Alzheimer's disease. Think it over: is it causing any real harm?

The rule of thumb is that if thinking TV personalities are real becomes distressing, the situation becomes something to deal with. But as long as the characters on the TV are friendly and not threatening to her, let it be. You can never have too many friends!

If the people on TV become threatening, then you will have to limit how much TV she watches. Talk with the staff at the nursing home and let them know what you are observing. Let them know you would like to limit her TV. Other residents will be watching TV, but your mother could be redirected to another activity such as bingo. If she has a TV in her room that is causing some of the difficulty, you could just remove it. Chances are she isn't getting much but distress from it anyway.

If the TV is taken from her room, talk with the staff to make sure she is taken out to one of the facility TVs to see her favorite music programs, if appropriate. If there is a VCR, you can buy or rent music videos so she can view them at any time.

**38. My mom used to love to read but now that is changing. Any suggestions on what she can do if books are no longer an option?**

If books have become too long and she is losing interest, try giving her short stories or magazines.

Ask her to do such things as read recipes to you when you are in the kitchen. She's not only reading, but she is helping you. Comprehension really isn't an issue, because she isn't actually doing the cooking.

You can go to your local library and check out books on tape. There are all types of books, magazines, and newspapers on audio cassette tapes and CDs. In some areas, you can also check out a tape player and keep it at your home for as long as it continues to benefit your mother. The tape player is designed to be user friendly for individuals who are blind or have other disabilities. Headsets are also available so she can listen anywhere and any time without disturbing others. Check out books that are upbeat, inspirational, or funny. Pay attention to the volume. If it is too loud, it can cause your mother to become over-stimulated which can lead to anxiety, agitation, or even wandering.

Many libraries have reading programs. She could ride the bus or have a friend or family member take her to listen to the programs. Senior centers also have similar programs.

She could attend an adult day care center and join in the activities there. If she can still read but doesn't comprehend, she could read to the other clients and feel she is helping them. This would help her self-worth. Many times, centers have reading times so she could listen to a live person read.

You could find a volunteer such as a neighborhood girl or boy, a neighbor, church member, civic organization, or family member to come over and read to her. This would be a great service project for a student. Many people are willing to help; they just need to be approached.

Reading together can be quality time you could spend with your mother. If you are unable to do this, don't feel guilty; find someone to do it for her. But if you are looking for something to do with your mother that would benefit both of you, read to her. Even if she doesn't completely comprehend what is being read, she is experiencing an activity she has always enjoyed, and that feels good to her.

### **39. I moved my father from New York to Washington state where I live. Any suggestions on how to help him adjust to new surroundings?**

Allow your father time to adjust. Adjustment could take a week or it could take months.

He needs to be able to express his feelings and concerns. He needs to have his feelings validated and his concerns answered. He will be dealing with feelings of grief. He not only has lost his wife, his job, and now his long-time home, but he is also losing a part of himself every day.

Many times trying to reason with a person with Alzheimer's is a dead end street. Trying to explain in detail why you had to move him may cause him increased confusion and more unrest. When he inquires about the situation you can respond, "I know this move has been difficult for you, Dad, but I love you and wanted you close to me."

To help with his adjustment, there are a few things you can do:

- Make a picture album of good memories that he can review; including pictures of family, friends, house, favorite vacations and accomplishments. He can look at these pictures several times a day, especially when he is feeling sad or stressed. This should have a calming effect on him.
- Put personal items that he can identify with in his room.
- Introduce him to neighbors and friends.
- If he can still write, give him a journal and encourage him to write down his feelings at least once a day. (This may take one-on-one attention from you to get him started.)
- Find a support group he can attend. You can locate one by contacting your local Alzheimer's Association.
- Have him talk with someone other than you—a friend, clergy member, or professional counselor.

Your father will need time and attention. He will need continual reassurance and affirmation. Reassure him that he is in a safe place, that you love him, and that you have made and will continue to make decisions based on his best interests and needs. Affirm him frequently by telling him how well he is doing. Thank him for the times he helps. Include him in decision-making as much as possible and allow him input at a level he can handle.

You may be surprised. He may adjust with little difficulty.

**40. What is the best way to support my mom if she has decided to give up and is calling it quits? How do I accept her wishes? Do we get the doctor involved? Do we call in hospice?**

This is a good question, as this sometimes happens with individuals who suffer from Alzheimer's. At some point toward the end of the journey, she may decide she is ready to die. If she is verbal, she may express it. If she is non-verbal, you will likely sense it. This disease process has been a tough battle, and she is tired. As hard as it is for the family, you have to let go and allow your mom the peace she is seeking. Death is a part of life.

For her, death is a good thing. For those left behind, it is difficult. No matter how long this disease has gone on or how long you think you have prepared yourself for this final goodbye, it is never easy. You have lost a lot of your mother along the way, but this is so final. Let yourself grieve. Talk with friends, family, clergy, or a professional counselor. Continue to talk with your mom. Reminisce about her life and your life together. Sharing thoughts and feelings can be a healing process.

If you have sensed that your loved one is ready to die, contact her doctor and discuss the situation. At that point the doctor may order hospice services. Hospice is a wonderful organization and will not only help and support your mother, but also support you and your family. Their goal is for your mother to be pain free, comfortable, and peaceful. Their goal for you is to support you in your time of grief and offer assistance with your mother to lighten your load, allowing you time to rest and recoup. Hospice assists the whole family in the grieving process.

#### **41. I can no longer get Mom into the shower. What are my options? How do I keep her clean?**

Individuals with a dementia typically do not like to bathe. Such reluctance usually stems from fear.

Take note of these suggestions:

- Make sure the lighting in the bathroom is adequate for her to see. If she can't see well, her fear will increase.
- Let the shower run for a while to warm up the bathroom. No one likes taking off clothes in a cold room and then getting into the shower, especially someone who is confused.
- Use a shower chair so she can sit and feel steadier. These can be purchased at a medical equipment company or pharmacy.
- Use a hand-held shower head. This takes the water down to her level and is less threatening. She may become frightened if the water comes directly at her face.
- Play soft, soothing music.
- Use a fragrant soap, a type of soap she always preferred.
- Allow as much privacy as possible. See if she can still bathe herself with you gently coaching her.
- If you have a bathtub, try having her soak. This will clean areas that are difficult to get to in a shower.
- Talk with your doctor about having a home health agency representatives come to assess your bathroom and make suggestions and recommendations that could make both of your lives much easier.
- Sponge baths are always an option in between baths. Bed baths are done regularly in hospitals and nursing homes. There are many useful products on the market now that assist with this, like dry shampoo.

Keep in mind how she has always bathed, and try to adhere to that schedule, routine, or ritual. Did she bathe in the morning or evening? Did she shower or take a bath? Did she bathe three times a week or every day?

Many caregivers hire a bath aide to deal with this issue. You can hire on your own or go through an home care agency. Sometimes the individual with dementia will respond better to someone outside the family; it can be uncomfortable or even embarrassing be bathed by a family member.

**42. I can't get my loved one to take a tub bath—and he always loved to take tub baths. Any suggestions?**

As Alzheimer's progresses, hygiene can be a concern. Frequently, the reluctance of an Alzheimer's patient to get into a bathtub has to do with safety.

There is frequently fear of falling, and that may make him reluctant to climb into the bath. There may also be a fear that the water is too hot or too cold, and that also can be troubling, so the first step is to get the water temperature right; then, reassure him about his safety.

Alzheimer's patients frequently have difficulty with spatial relationships. In other words, it may be difficult for the patient to see where the water begins and the bathtub ends. It can be confusing due to the appearance of the water in the tub; so add a few drops of food coloring to the water, or some bubble bath, so that your loved one can distinguish where the water begins. Alternatively, you might get a very brightly colored bath mat and put that on the bottom of the tub. Your father needs something to be able to distinguish where the tub begins and ends and where the water begins.

Frequently, if you try one of these tips, you'll find that your loved one, who once so enjoyed taking baths, will again be able to enjoy that activity.

**43. I'm bringing my mom home to live with me. I plan to hire someone to come in to help. How do I know what training a caregiver needs for my situation?**

This will depend on the level of care she requires. A home health/private duty agency can assist you through this process. For instance, if you just need assistance with the duties around the home, i.e., cooking and cleaning, a *housekeeper* would be your choice. If your mother is still in the early stages of the disease and fairly independent, but you don't want to leave her alone, a *sitter* would be appropriate. (Request an individual who has experience with dementia.) When your mother starts requiring more assistance such as dressing, bathing and toileting, then you will need a *certified nurse aid*. Only if your mother requires skilled services would a *nurse* become involved. This usually occurs following a hospital stay.

Using a home care agency will provide you the guidance and assistance you need in this situation. The agency does the hiring, background checks, training, payroll and benefits, and dismissal. It's probably worth paying a little more to have that support.

Hiring an assistant on your own is also a possibility. This will typically cost you less financially but will cost you a lot more time.

Another option is an adult day care center. Your mother would go to the center and have all the levels of care mentioned above in one place. Not only would she have supervision, meals, and assistance provided, she would have socialization and activities. This is a win-win situation. You can get a break or go to work, and she gets quality care.

Keep in mind when you are dealing with anyone caring for your loved one, go with your gut feeling. If you are not 100% comfortable with the person, then you need to reconsider the situation and make changes.

#### **44. How do I cope with the ongoing feelings of grief about losing a little of my loved one each day?**

Grief is a natural and normal process. Remember you are a unique individual who will cope and deal with this in your own way. If you know others who are dealing with a similar situation, try not to compare yourself to them. Some grieve quickly; others grieve for a long time. The goal for everyone is to reach a stage of acceptance.

Try writing in a journal. Grieving brings about many emotions which need to be expressed, including shock, anger, depression, loneliness, fear, anxiety, and resentment. Writing down your feelings will let you express yourself in a safe place. Escaping to this “safe place” is much easier than attending a support group, going to a counselor, or talking with a friend. It is an immediate release and a healthy avenue of coping.

Along with journaling, attending a support group is extremely helpful and advisable. Attend with an open mind, so when others are expressing their feelings, you don't become overwhelmed. Each person in attendance is dealing with a similar, but also unique, situation. Not only are you receiving help, you are helping others. Doing something for others makes us feel good about ourselves, which helps relieve feelings like depression.

If you have close friends you can confide in, talk with them frequently. Many times we feel we are a burden to others, but as the saying goes, “That’s what friends are for.” If the tables were turned, you would do the same. Even if you have many friends, there will most likely be just a few you come to rely on.

Talk with a clergy member you know and trust. Many members of the clergy are also trained in counseling, and there are typically others in the church who can counsel you if the pastor can't.

Don't hesitate to see a professional counselor trained in treating grief. Some facilitate grief support groups. If grief is an overriding issue for you, you may want to attend a grief support group instead of a general caregiver group.

Talk with your family. Many families are close and can rely on each other. Others are not so close, but are there for each other during the tough times. Some families are not there at all. That is when you need to turn to the other sources listed above.

#### **45. I screamed at my mother today and I feel terrible. How do I deal with my anger?**

This is a very difficult subject. Anger is a common emotion when caring for a loved one. The person you once knew as being independent is now having difficulty with things as simple as getting dressed. She can't understand much of what is being said to her and she has forgotten many valuable memories. Why wouldn't you be angry? Each day, and sometimes each moment, you are losing a little part of this person you have known and loved all your life. You are grieving. Anger is a part of grief.

If the yelling occurs only occasionally, you may have to accept the fact that at times you are going to get frustrated enough to yell. When this happens, you need to work on letting go of the guilt. You are human. Give yourself a break. It doesn't feel good to yell, but it happens.

Speaking of breaks, you also need breaks from your mother. Take your mother to an adult day center. This allows you a break and gives her something productive to do. Hire someone to come into the home, and then leave for a while. Work on letting go. Take advantage of family, friends, neighbors, or church volunteers who may offer to help by giving you a break.

Join a support group and/or seek a professional counselor. Individuals who attend a support group are experiencing similar issues. They can give you tools for coping. A professional counselor can assist you with dealing with anger.

If you cannot get your anger under control and the yelling becomes more frequent, you may need to look into other options for your mother's care. Keep in mind that quality time with her is more important than quantity time. If the time you have together is nothing but stress and strain, it may be time to consider a nursing home, group home, or assisted living situation. At that point, when you do visit her, you can enjoy the time together. Sometimes placement in a facility is a healthier choice for everyone involved.

Let go of any guilt you feel about placing her in a facility. You can still be involved in managing her care through coordination with the facility. You can then enjoy your time together. Take her out for lunch, to the park, or to your home. Have fun with her.

#### **46. If we hire someone to come to my mother's home, how do we orient them so as not to upset Mom's routine?**

When you have the candidates narrowed down to two or three, as part of the interviewing process, bring the candidates into your mother's home and observe how each interacts with her. That will tell you a lot and most likely will quickly narrow down your choices. Look for a kind and attentive person. You can teach the other things, such as when medication is needed, the daily routine, tips on how best to deal with your mother when trying to bathe, dress, or feed her, etc.—but if good rapport isn't there, it's hard to force it after the fact.

Involve your mother as much as possible. Even if your mother is in the later stages of Alzheimer's, she can tell you in her own way how she feels about each candidate. She may wrinkle up her nose after a candidate leaves. She may do a thumbs up or down, or she may resist all together and not want to give an opinion. Observe her body language when the candidates are around. How does she respond to each one?

Once you have hired the person, bring her in one day before she actually starts work. Allow her plenty of time with your mother so they can start to bond. Tell your mother what is happening, that this person is coming to spend time with her and help her. Let the hired caregiver know your mother's background, her likes and dislikes with both food and activities, and how best to deal with her in unusual circumstances. The better she knows your mother, the better she can care for her.

You may want to start her for just a few hours on the first day. This will assure your mother that her world hasn't been turned upside down. Then she can start full time.

Keep a good working relationship with the hired caregiver and encourage her to call you with good and bad information pertaining to your mother.

Throughout this relationship, let your mother express her feelings about how things are going. You will know by observation if she is unwilling or unable to tell you. You can then make a decision whether to continue with the current caregiver or move on to another one or another situation.

## 47. What kind of activities can I do with my husband at home?

There are many things you can do to keep your loved one busy at home. Anything you do can be an “activity.” Involve your husband any way you can. It doesn’t take much to make him feel helpful and useful. An activity can be something as simple as grocery shopping together and letting him push the cart or place items in the cart. He can help put the groceries in the car. When you get home, he can hold a bag of groceries while you unlock the door. These simple steps will help him feel a part of your life together.

The following is a list of activities you can do at home. Modify as needed according to your loved one’s functioning or cognitive level. Some can be done alone and others need a partner. As time goes on, he will need increased assistance. Remember how important is to have a routine or schedule.

- **Word games:** A large print word search can work well, but there are many types of word games readily available at any bookstore or magazine stand. You can also take a word and see how many other words he can make out of it.
- **Video Respite:** These are videos specifically designed for individuals with Alzheimer’s. These ten interactive videotapes will typically keep the person’s attention for the duration (between 20 and 53 minutes). To receive information or order, call Innovative Caregiving Resources, P.O. Box 17332, Salt Lake City, UT 84117; phone (801) 272-9446, website [www.videorespite.com](http://www.videorespite.com).
- **Write his life story with him:** Organize pictures and narratives to help him remember his life. Include special events, awards, accomplishments, ceremonies, and family. Organize this information in a durable book your loved one can carry with him and look through frequently.
- **Play music:** Calming music is a good way to relax. Choose upbeat music you can dance to, and it becomes good exercise. Music also enhances memory.
- **Relaxation:** Each day after lunch, have a relaxation time. Play calming music, burn candles or incense, or plug in a diffuser for aroma therapy. Keep in mind to use scents your loved one responds to positively. Warm some lotion and gently massage his hands and arms. This would also be a good bedtime ritual.
- **Exercise:** Go for walks, join a gym (this will benefit both of you), use an exercise video or audio tape, bat a balloon back and forth to each other, play games such as horseshoes or croquet, putt on a portable putting green. Use your imagination.
- **Play games:** Play cards (you may have to keep it simple), board games, or checkers.
- **Read enjoyable material:** It could be spiritual, funny, or inspirational. You can read together or you can read to your loved one.

**48. As the primary caregiver, should I journal about the disease process, my thoughts, my feelings?**

Most definitely. Journaling is recommended for everyone, but especially for individuals who are dealing with something as stressful and emotional as caregiving.

To journal is to put your feelings down on paper, just between you and the pages. If you worry that someone will read it, keep it in a secure place. Just make sure it isn't such a secure place that you forget to write in it!

Put journaling into your schedule or routine. It doesn't have to be done daily, but should be done on a regular basis. It's like exercise for your brain and emotions. You don't have to journal for a long time—just long enough to get things out and off your chest. Journal your thoughts and feelings. Deal with your guilt, anger, fear, resentment, and any other emotion you feel. You can “write to the disease.” Tell it how much you hate it and what it is doing to your loved one and to your lives. You can voice your resentment over the fact that you have worked all your lives to enjoy retirement, and now this. If you are feeling these things, you need to deal with them, and journaling is a healthy way of doing that.

You can also journal about your loved one. You can journal various patterns such as eating, sleeping, behavior, and toileting. This information will help you when talking with the doctor. It will also let you look back at how you handled certain situations.

Journaling also helps you sort out your thoughts. When you are feeling overwhelmed, it helps put things into perspective. Journaling, however, should not be your only outlet. Be sure to talk with friends and family and join a support group. You need human contact and socialization to refill your tank.

**49. I've heard art is very therapeutic even if the individual never was an artist. Is this true?**

Art is one of the common alternative therapies used with individuals with dementia. It is another avenue for them to express themselves in a non-verbal manner. It is another form of journaling their thoughts and feelings but in pictures, not words.

When participating in an art activity, the caregiver should remember to savor the moment. The project is not about what the end product will be or look like but about the process of getting there. If the individual with Alzheimer's is enjoying the moment while painting, you have reached the goal and served the purpose. Don't be surprised if your loved one finishes a painting only to look at it later and fail to recognize it.

The Alzheimer's Association has a successful program called "Memories in the Making." Volunteer artists go to facilities and work with small groups of individuals with Alzheimer's using watercolors. To see someone pick up a brush and begin to paint when she hasn't even spoken for months is beyond expression. Materials for the project are purchased by the facility through the Alzheimer's Association.

This activity can also be incorporated in the home setting. Look for an artist in your community who would be interested in volunteering. The artist could recommend or purchase the materials needed for the project. Many times persons with Alzheimer's will resist this new activity. They need encouragement and praise throughout the project. Even though the end product is not the goal, you will be amazed at the results.

## 50. Do animals have a calming effect on a person with Alzheimer's?

Dogs, or pets in general, can be very therapeutic. Many nursing homes have incorporated pets into the environment. Any type of therapeutic programming or intervention affects each individual in its own way. Some respond well, some do not. One resident on an Alzheimer's unit liked animals, but because she had lived on a farm, animals never came into their house. When the dogs came for a visit, a staff member would have to take her for a walk away from the unit. The unit was her home, and it upset her to see dogs in the house.

Some people fear animals, especially dogs. Dogs are trained as therapy dogs are taught to "behave" when they are with older persons. This keeps them from becoming too rambunctious and hurting one of the residents by knocking them down. The dogs also learn to sit next to the residents so they can pet them. Usually they are docile dogs and lie around a lot, giving the facility a home-like feel. Some are specially bred to be allergen-free.

If your loved one has had pets most of his life, then chances are he will have a positive response to having one in your home now. Some caregivers have purchased a dog for the specific purpose of having something for their loved one to do. A pet creates another whole world of activities. Your loved one can feed and water the pet, brush it, and take it for walks. This gives your loved one a sense of responsibility and a feeling of giving. People need to feel needed, and this activity serves that purpose.

If you currently have a pet, especially a dog, you will most likely notice a change in the animal along with the change in your loved one. Dogs have a tendency to sense something is different and become very protective. The dog will stay close to the person with Alzheimer's as if to guard and protect. Even if your loved one didn't care for the dog before and it was primarily your dog, that doesn't matter. The dog will be loyal to both of you, but especially to the person with Alzheimer's.

Other pets are also therapeutic. Fish are fun to watch. Cats are fun to have to curl up on your lap and pet. Birds sing and are fun to watch, too. Many individuals with Alzheimer's like to sit outside and watch wild birds. Filling bird feeders is another activity your loved one can do to help out around the house.

Pets can be a wonderful addition to the life of a person with Alzheimer's disease by offering them "unconditional love."

## **51. How important is routine to the person with Alzheimer's disease?**

Routine is extremely important. As the person with Alzheimer's progresses into the disease and begins to lose more and more memory, a routine is comforting and familiar. If your loved one is still living at home, make everything you do part of the routine or schedule, if possible. You need to develop a routine for both your sakes.

Rituals are also very important (for example, a bedtime ritual). If your loved one always checked the doors to make sure they were locked going to bed, continue this ritual. If he ate a bowl of ice cream before bed, continue this. You want him to feel at home, and routines and rituals help with that. If he is restless before bed or having a difficult time falling asleep, let him get up and do the ritual.

The routine for the day can consist of eating at certain times, taking medication at a certain time, going to check the mail at the same time every day, bathing on certain days, going to the hairdresser or barber on certain days, and anything else you want to add. Even drinking water at scheduled times each day is advisable—it adds to the routine while at the same time encouraging hydration. Making time in your schedule to sit down and relax is also important. You both need this so you can regroup.

Other examples of activities that can be included in your daily schedule are going for a walk, feeding the dog, folding towels, taking out trash, reading the newspaper, drinking coffee, going for a drive, or getting a special treat.

Try to have fun with this, but avoid becoming rigid. Remain flexible so if the activity you had planned isn't working for your loved one, you don't argue. Just go with the flow and move on to the next thing. If the previous activity needs to be completed, such as dressing, go back later and try again.

**52. My father is verbally abusive to my mom and me. I don't have to live with him, so I can deal with him for short periods, but Mom is with him every day, all day long. What can we do?**

Abuse of any kind is difficult to deal with, even if the abuser has Alzheimer's disease and you know he can't control it.

First of all, you have to work at not taking it personally. If this is an extension of his previous personality, you know it's just the way he is. If this is a personality change, it will be a shock. You will have to mourn the fact that he has changed dramatically, and get to the point of acceptance.

Give your mother a break. Whether it means hiring someone to come in, taking him to an adult day center, or having family members take turns, she needs a break. Chances are he will act differently with non-family members. If he does verbally abuse staff you have brought in or at the adult day center, it becomes a bigger problem. At that point, you may want to get his doctor involved. Let the doctor know what is going on and see if he has any suggestions. He may want to try something for anxiety or depression. Many times individuals with Alzheimer's are acting out because of an underlying problem such as anxiety, depression, or even pain.

Another way also to deal with this situation is with humor. You can't control how he is acting, so you have to control how you respond. At one adult day care center, when patients would say harsh things or become verbally abusive, the staff referred to it as "terms of endearment."

Validating your father's feelings may help decrease his frustration. Many times individuals with Alzheimer's are so frustrated that they act out through this type of behavior. He has lost much of his independence and now he has both of you telling him what to do. Be sure when you are trying to get him to do something or avoid something, that you ask in a non-threatening way. If he resists, stop and go back later. Give him time to calm down, and then try again. Also try not to talk down to him. He is still an adult with a life history of success and independence. He will sense it if he is being treated differently.

Finally, join a support group. Many times others in the group will have experienced the same behavior with their loved ones. Group members may be able to counsel you on how they coped or dealt with it. Journal your feelings and frustrations about his behavior. Dealing with your feelings will help you deal with his behavior more effectively.

**53. My mom refused to get dressed this morning. She would eat only chocolate pudding for breakfast, which she spilled down the front of her and then would not let me clean her up. I called the nurse aide we've used for seven years to come over and help, and Mom completely cooperated for her. What's her secret?**

First of all, she has a different relationship with your mother than you do—they are not relatives. Many times our loved ones are much harder on us and more cooperative for those who are not family. With family members, your mother probably feels she can be herself and still be loved unconditionally. Or if you never had a good relationship with her, this behavior is just more of the same. Most of the time, our loved ones are on their best behavior for someone outside the family. This includes doctors, home assistants, and even strangers.

Sometimes the loved one and the caregiver have spent too much time together. She might just need a change, someone different. Both of you may need a break from each other.

Try not to take it personally. Your mother loves you, but remember—she has dementia. With dementia, almost all inhibition is eliminated. Somehow, however, she can maintain her manners with someone she is not as familiar with as you. It's a mystery.

As a caregiver, try to let things go. If she wants to eat only chocolate pudding, what is that hurting? Pudding may not be the most nutritious breakfast, but it's not going to hurt her. Step back and think about these situations, consider the ramifications of each one carefully, and then learn to choose your battles wisely. If she doesn't want to get cleaned up, go away for a while and try again. Chances are she will cooperate the second time.

## 54. Does music help aggressive behavior?

Music is said to be “the universal language” and can contribute to many areas of therapeutic intervention. Most individuals with Alzheimer’s respond well to music. Their responses may depend on the type of music. There is a stereotype that this population will only like “old music”—music from their era. But any music from the time they were born to the present is “from their era.” One downfall we have when working with individuals with Alzheimer’s, or the older population in general, is that we tend to limit their possibilities.

If your loved one is agitated and you try playing music they once enjoyed but it’s not helping, try a different kind of music. Some music, even classical, can be very “busy” and will tend to over-stimulate persons with dementia and cause more anxiety or agitation. If they feel over-stimulated and become extremely agitated, they may become aggressive and lash out as a response. They can’t always tell you how they are feeling, so they act out instead.

“White noise” is often calming to a person with Alzheimer’s. White noise machines can be purchased, but another example of this is the noise a fan makes. Just running a fan may help them relax. Another example is a fountain. You may try one of these types of noise to help calm your loved one. There are CDs or cassette tapes that you can purchase with calming noises such as the ocean, birds, or wind. Once again, the birds can be over-stimulating, so if you notice your loved one becoming increasingly agitated, turn it off. Sometimes those with Alzheimer’s need complete silence—so when all else has failed, try quiet!

## 55. How do I look at the blessings of being a caregiver?

Although this is a devastating disease, there are different ways you can look at it—as a burden or a blessing. So much of life we cannot control. We can't control what others think of us or how they run their lives, or whether we get a disease. What we *can* control are our own reactions. As difficult as it is, as a caregiver you must arrive at the place of acceptance. This place will not be reached, though, until you have allowed yourself to grieve.

Grieving is a personal journey. Some move through the stages fairly rapidly and others get stuck in certain stages, maybe never moving on to the next stage. Grieving consists of emotions:

**Shock.** You first hear the diagnosis, and you can't think, speak or react.

**Emotional release.** You cry, yell, and maybe even throw things.

**Depression.** You feel loneliness and isolation.

**Physical symptoms of distress.** You begin to feel ill or extremely fatigued.

**Anxiety.** You worry about what the future will hold.

**Hostility or anger.** You have feelings of anger toward your loved one, family, the doctor, and even God. The anger at God can then cause feelings of guilt.

**Guilt.** You feel you aren't doing an adequate job of caregiving, or you feel guilty about your thoughts or feelings.

**Hesitancy to keep up normal activities.** You fear how others will react or treat your loved one.

**Healing of memories.** You come to the slow realization that painful memories are healing memories. This is the time to embrace fully what is going on in this situation and that life must change if it is going to continue. Draw on the good memories to get you through the tough times.

**Acceptance.** You get to the point of accepting this new chapter in your life. If you can accept what is happening, it will lessen your stress considerably.

Due to the continual changes caused by Alzheimer's disease, you will continue to grieve. Even though you have reached the acceptance stage, you may cycle through all of the stages again, or just a few at different times. That is completely normal. It doesn't mean you have slipped or gone backwards. Give yourself a break. Don't be so hard on yourself. Let yourself feel.

Once you have reached the acceptance stage, you can begin to see the blessings. Some say Alzheimer's disease is our second chance in life. All the inhibitions are gone and patients become blatantly truthful, which can be very funny.

Just remember that you did not ask for your loved one to have dementia, nor did you ask to care for him. This situation has been "given" to you. When something is given, it is a gift. Your loved one is a gift to you.

**56. Is it common for a person with Alzheimer's to have good and bad days, days when they are more lucid than others?**

Yes. Like anyone, individuals with Alzheimer's have good and bad days. There will be days that it appears nothing is wrong, and then there will be days when you have no doubt it is Alzheimer's.

On their good days, they are lucid and things are “clicking” almost like they used to. They recognize people and remember things they couldn't before. They appear to be feeling good and are upbeat about life. These are times to savor. Look at these lucid times as a blessing. During these times, as a caregiver, you will need to be in touch with your own feelings. These moments are so good that you question whether the diagnosis is accurate. It gives a sense of false hope. Just know that these times are a blessing, but they will pass.

Caregivers often experience a grieving process. When we grieve, we tend to fantasize, thinking this is just a bad dream and that things will one day be the way they were. We deny that this is really happening. We hope our loved ones will “snap out of it” any day now. Lucid days or moments validate our fantasy, but then reality hits us squarely in the eyes.

Let yourself grieve, but on these good days, enjoy each moment. You may be blessed with a number of these good days or just a few moments—but either way, enjoy! Just keep in mind “quality vs. quantity.” If the quality time is limited, at least you had those moments. Continue to look at those times as a blessing. On the bad days, look back at these moments of blessing to help you through.

## **57. If I want to get an in-home caregiver, how do I go about finding and hiring one?**

You can get a list of private duty agencies that provide in-home care through your Area Agency on Aging, Department on Aging, Social and Rehabilitation Services, or Alzheimer's Association. These agencies have sitters, homemakers, and aides who each perform specific duties. If a nurse or skilled care is what you need, a home care agency provides that. Typically the doctor must be involved with setting up skilled services, including physical therapy, occupational therapy, nursing, etc., so your doctor should have information about these agencies.

Alternatively, you can hire an individual on your own. There are lists of health care providers that work independent of an agency. The Alzheimer's Association keeps a list of these individuals, but of course cannot recommend one over the other. What they can tell you is feedback they have received from other caregivers and their satisfaction level with certain care providers.

When hiring on your own, treat this as an employer/employee relationship. Use an application form. Generic applications can be purchased from most office supply stores. Ask for a copy of identification such as a drivers license, Social Security card, and/or their certificate for nurse aide certification, and ask for a resume—and references.

Interview several individuals. Schedule a time when they can come to your home and spend time with your loved one. Notice how comfortable your loved one is and how the two interact. Include your loved one in the process. Individuals with dementia have something of a sixth sense. Let them help you make the decision on who to hire.

Depending on your needs, you may want to hire a certified nurse aide. They are trained to help with dressing, bathing, feeding, and setting up medications. They typically have experience in working with individuals with Alzheimer's. Also check for CPR certification, and get a copy of it.

Once you have hired someone, keep a file of identification, certificates, and background check results. Orient your employee to your house and loved one, especially any special needs your loved one has. Explain daily routines and suggest things your loved one enjoys. Nurse aides can also cook and clean, but if that is all you need, a homemaker is more affordable. They can also sit with your loved one, but can't do any direct care.

Also, understand that in some states, paying an individual to care for your loved one, with proper care contracts in place, can cause Medicaid eligibility issues. Consult an elder law attorney in your area for assistance.

A caregiver support group is a great place to get information and referrals to both agencies and individuals members have used for their loved ones.

## 58. Is there help for the “sandwich generation”?

The term “sandwich generation” refers to families that are not only raising their children but are also caring for a parent or grandparent, while perhaps also holding a job. This adds a complicated dimension to the family unit. The grandparent can become harsh or abrupt with the children. The children may feel the grandparent is “in their space.” Trying to balance caring for a parent, children, and a spouse can be extremely difficult for the primary caregiver. A support group is highly recommended to aid with coping strategies. Also, look into a specific support group for children of individuals with Alzheimer’s disease.

There can be some battles, but with help, this type of “blended family” can work. There are a number of very helpful publications available at the American Health Assistance Foundation. You can contact AHAF at:

American Health Assistance Foundation  
22512 Gateway Center Drive  
Clarksburg, MD 20871  
(800) 437-2423  
[www.ahaf.org](http://www.ahaf.org)

The national Alzheimer’s Association also has many resources. They are located at [www.alz.org](http://www.alz.org) or they can be reached at 1-800-272-3900. Their contact center is available 24 hours a day.

## 59. What do I tell my grandchildren about the disease?

Depending on their age, children handle these issues differently and have different reactions and ways of coping. Variation in personalities will also play a role.

No matter what their ages, be honest with them at a level they can comprehend. Keep in mind that having someone you know and love with dementia causes grief. The grief process kicks in because a part of the person you love is changing or diminishing each day. Let your grandchildren talk about their feelings openly. If you are not comfortable telling them or talking with them, ask someone they trust to talk with them. Professional help may also be necessary with a licensed counselor and or a support group may be necessary. The family of the person with dementia is experiencing anticipatory grief, anticipating loss, change, and eventually death.

The national chapter of the Alzheimer's Association has excellent information for children and youth on their website. See [www.alz.org/living\\_with\\_alzheimers\\_just\\_for\\_kids\\_and\\_teens.asp](http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp)

There are some fine books available on this subject which are written at different developmental levels from young children to adolescents. You can find them at [www.alz.org](http://www.alz.org) or at any good bookstore or online book source.

Publications are also available from:

American Health Assistance Foundation  
22512 Gateway Center Drive  
Clarksburg, MD 20871  
(800) 437-2423  
[www.ahaf.org/alzheimers/resources/helpfulreading.html](http://www.ahaf.org/alzheimers/resources/helpfulreading.html)

## 60. How do I best communicate with my loved one who has Alzheimer's?

Good communication can decrease or even prevent many behavior problems. The number one tip to remember is to treat your loved one as an individual with a disease, not a diseased individual. He has an entire history of life that stays with him throughout this journey. He will continue to have many of the same characteristics he had before. If he was laid back before, he may be more so now. If he had high energy/anxiety, he may be tightly wound now as well.

All people need to have their feelings validated. A person with Alzheimer's is no different. In fact, because of memory loss and insecurity issues, he or she may need it even more. An example: Your father who has Alzheimer's is angry with your husband most of the time. They have had a great relationship in the past, but now your father blames him for everything. As difficult as it is, keep in mind that it's the *dementia* talking, not your father. You can say, "I don't blame you for being angry" and then move on. What he is feeling is real to him, even if it is not accurate. You will probably have to coach your husband as well. Let him know that this action isn't against him personally; it is the nature of the illness and "this too shall pass."

Individuals with Alzheimer's respond well to affirmation. When they do anything, no matter how insignificant it may be to you, praise them with "good job" or "thank you."

Other tips:

- When beginning a conversation, identify yourself. If your loved one says "I know who you are," laugh or say something humorous.
- Slow down when you speak and use short simple sentences.
- Ask one question at a time. Give adequate time for response. Yes/no questions are best.
- When speaking, maintain eye contact.
- Lower the tone of your voice; a high pitch may be interpreted as anger.
- Eliminate distracting noise. Turn off the TV or radio, or go to another room to talk.
- Smile and be pleasant.
- Use touch to get attention (hand on shoulder, hand on knee, hand on hand).
- When your loved one is upset and you can't communicate, try a hug. Soon anger will be forgotten and you can try again.
- Be aware of their body language. A sudden sit-to-stand change in position may indicate the need to go to the bathroom or some other kind of discomfort. Be aware of your body language too—try not to appear tense.
- Don't argue.
- Don't order the person around or be condescending.
- Don't talk about your loved one as if he isn't there; you never know just how aware he might be.

## **61. My mother is becoming incontinent; what should I be doing?**

Incontinence can be one of the more difficult aspects in dealing with Alzheimer's. It typically doesn't start until the mid to later stages of the disease. This condition can be temporary or it can become a permanent condition.

Talk with your physician. Have the physician check for secondary health problems that could be causing the incontinence, like a urinary tract or bladder infection.

Once health-related possibilities are ruled out, you can probably assume this condition will be permanent. Talk with her physician about incontinence products. This way, if she has an accident, she won't embarrass herself by wetting her clothes. Even if she begins to wear a brief, you can continue to take her to the bathroom regularly. If she wets her brief, change it as soon as possible. Clean her skin with a wet washcloth or baby wipe and dry it.

It is important to monitor the appearance and condition of her skin. If it is red and or irritated, it needs to be watched closely. If she develops sores, seek immediate attention from her physician or visiting nurse. If she sits for long periods of time, changing positions frequently will take pressure off of the affected area. Get her up for a walk around the room or house, have her change chairs, or lay her down for short periods. This will reposition her weight so it isn't always on the same area of her buttocks or lower back.

The physician may write an order for an evaluation from a home health agency to make a home visit. A nurse will assess the overall situation and make suggestions and recommendations accordingly. These recommendations can help make caring for her more successful and less stressful. Either way, you are not alone in this endeavor—there is help.

## **62. My husband doesn't like me telling him what to do; how can I make him feel better about this?**

Always aim to treat him as an equal, as an adult. Include him any way you possibly can, even if it means asking him a question related to the task at hand. For example, if you are sitting down together to pay bills, you can ask him which one to pay first, the light bill or the phone bill. He can stuff the envelopes and put the return address sticker and stamp on the envelope. You can go together to the post office or to put the mail in the mailbox. Let him stay involved at a level that is comfortable for both of you.

Talk with him. Let him answer, whether it's accurate or not. Just nod and don't argue.

Use a sense of humor. Laugh together when things don't go quite the way you had planned. Choose your battles. If you are telling him to take off a layer of clothing and it agitates him, don't worry about it. It's not how he would have dressed in the past, but at the same time it's not hurting anyone. Treat him like an adult—with respect and dignity. Frequently validate his feelings of frustration and loss. He needs to know you care.

Read books that will help you empathize. Think about how you would want to be treated if you were him. Try to put yourself in his place. You wake up one morning and the most simple things you could do yesterday, you can't do today. Things like not knowing where you are in your own home, remembering to go to the bathroom, how to get dressed, how to set the table, how to take the dishes to the sink after meals.. Treat him as a person with a disease, not as a "diseased person."

This situation is difficult for both of you. Your loved one was independent and now needs help with things that once came easy and naturally.

Give yourselves a break. This is a very difficult situation, to say the least. When things get really tough, step back, take a deep breath, and move forward. Take each moment one at a time, each day one at a time.

### 63. Dad expects me to entertain him during the day; how can I keep him busy?

It is common for a person with Alzheimer's to become very attached or even a shadow to the primary caregiver. That doesn't mean *you* have to provide the stimulation. Try these ideas:

- Play a musical video with a fast pace.
- Let him walk as much as possible.
- Pulling weeds or batting a balloon ball will also provide exercise.
- Exercise videos that have simple directions are available from senior supply companies.
- Let him help at a level he can. For example, he can hold the grocery sack while you unlock the door to the house.
- Let him set the table while you make lunch. If he doesn't set it just right, it's okay!
- Have him clip coupons or shred old documents.
- He can get the mail from the mailbox and open the junk mail.
- Have him feed the dog.
- Bake cookies. He can help stir and put them on cookie sheets while you deal with the oven.
- Ask a friend to visit to help keep your loved one entertained and to give you a break. The friend can walk with him, read to him, bat a ball with him.
- Get talking book audiotapes from the library. Many people with Alzheimer's like to be read to if they can no longer read. You may need to try several different topics before you find one that works. Usually humor speaks to anyone.

See also the publication *Alzheimer's Activities: Hundreds of Activities for Men and Women with Alzheimer's Disease and Related Disorders* by B.J. Fitzray, Windsor, CA: Rayve Productions, 2001. This and other helpful publications are available online at [www.ahaf.org](http://www.ahaf.org). Check out the Alzheimer's Association website as well, at [www.alz.org](http://www.alz.org).

## **64. If the rest of my family isn't involved in caregiving, how do I deal with that?**

If you have tried to involve family and they are not willing, you must let it go! You have enough to handle; you don't need the burden of others' actions, too. You cannot control how another person, responds, acts, or reacts, so you have to "Let go and let God."

Many family members of a person with dementia are intimidated by the illness. Others deal with it through denial. At the same time, you have chosen to deal with it, and you're doing all the work. The fact that they have chosen to be uninvolved is their problem. You have to move on and take care of yourself.

If solo caregiving is getting to you, seek help. You can see an individual counselor, talk with a trusted friend, or join a support group. A support group is a good, safe place where you can express your feelings. Almost always there will be someone in the group who can relate to your situation.

If you need more support, you could adopt someone new to be a part of your family—a church member, a friend, an acquaintance—and ask for help.

We all deal with situations/stress differently. The only thing you can do is keep your family in the loop as much as possible. You can give or send them information pertaining to Alzheimer's and then... "let it go." They are adults. They must decide for themselves what to do with the information they have received.

## 65. How do I keep a sense of humor while caregiving?

Laughing increases endorphin activity in the brain and makes you feel better. If you think you've lost your sense of humor forever, you're wrong. Like your body, your sense of humor needs exercise. There are several ways to do this. Determine what makes you laugh. Give yourself permission to let go and have fun... laugh!... a lot!

- Keep a humor file. This can contain internet jokes, cartoons, or anything that makes you laugh. When you've had a particularly stressful day, pull out this file.
- Check out or purchase comedy videos that you and your loved one can watch together. Laugh together—it's extremely healthy.
- Have a friend over and talk about old times. You can also include your loved one in the conversation.
- Listen to humor on the radio.
- When you or your loved one does something funny, laugh. Laughing at ourselves is great medicine.
- Go to comedies at the movie theater/dinner theater. Include your loved one for as long as you can.
- Surround yourself with healthy, happy people who don't take themselves or life too seriously.
- Take time out to read a humorous book, or read the "funnies" out of the newspaper.
- Post funny pictures/cartoons/jokes around the house. Put them in places where you spend a lot of time.
- Journal funny things that happened throughout the day, such as something you or your loved one did or said. You can go back later and reread them and laugh again.

## 66. As the primary caregiver, how can I get a break?

This is a family disease, meaning it affects everyone. Primary caregivers endure much stress. The first step in getting help is asking for help.

If you have family or friends willing to help out, please take advantage of their generosity. But many family caregivers don't have this type of support. There are numerous home- and community-based services that can help you get a break. Look for the following services in your area:

- **Private duty home care:** Many agencies provide this service in the community. A list of providers can be obtained in the phone book, from the local Alzheimer's Association, Area Agency on Aging, or any case management and referral source. This can include services such as bathing, sitting, taking to appointments, shopping, meal preparation, and other day-to-day essentials.
- **Adult Day Services:** The clients actually go to these centers for socialization, stimulation, and supervision while the caregiver gets a break. Look for a center that has experience caring for Alzheimer's patients.
- **Overnight respite:** Many assisted living and nursing home facilities offer short-term stays. Most facilities provide this according to space available.
- **Hired caregivers:** Another option is to hire an independent in-home caregiver. You may be able to obtain names of experienced caregivers from places such as your church, Alzheimer's Association, or Area Agency on Aging. Because no agency is responsible for these caregivers, treat this process as if you were hiring any employee. Check references, do a background check, meet, and talk with the prospective caregiver once and see how he or she interacts with your loved one. You can even ask your loved one for input about the person. People with dementia are often perceptive and intuitive.

Again... if you have family or friends who are willing to help, use them!

## **67. How will I know when my mother can no longer swallow her medication?**

As people with Alzheimer's continue to progress, they typically begin to have difficulty swallowing. This situation is due to the brain failing to signal the throat to swallow. This is a real concern for those caring for them, as caregivers need to be on alert to intervene if needed.

If your mother is in the mid to later stages of the disease, you need to observe her when she takes her medication. You should also observe her when she is eating. See if your mother chews and chews and chews, but never swallows. See if she pockets food or medication in her cheeks and holds it there for quite some time.

If this becomes an issue, there are some things you can do. Talk with your physician about the medication she is taking. If there are prescriptions that can be eliminated, start there. Then you only have to deal with the medication that is really needed for her quality of life. Vitamins are good, but you may discuss with the doctor whether to continue them, or perhaps to try a liquid form. The liquid form presents another problem as it may have a bad taste and she may refuse it. If this is the case, weigh whether the vitamins are necessary.

For the medication she does need to take, ask the physician if pills can be crushed. (Some medications lose their effectiveness when crushed.) If it can be crushed, you can put it in applesauce, yogurt, or pudding.

Keep in contact with her physician so if the situation continues to worsen, you can make a decision whether to continue the medication or not. You need to consider whether it is really benefiting her or whether making her take it is causing more discomfort than good.

## 68. How do I choose the right adult day center for my loved one?

Choosing an adult day center is much like shopping for a nursing facility. Researching available options *before* they're needed is beneficial to both you and your loved one. You can find a listing of day centers from your local Area Agency on Aging or ARC. Be sure to ask if the staff is equipped and trained to meet the needs of individuals with Alzheimer's disease; those day centers should be the first you visit.

Make an unannounced visit and ask for a tour of the entire facility. While you are there, notice whether the participants of the program appear to be happy and content. Are they involved in activity, or are they just sitting around with the TV on? (Television in itself is not a bad thing, but it should be incorporated as a specific activity; for example *The Lawrence Welk Show* as the afternoon activity; while some listen and sing, others dance to the music.) Are the participants involved with each other, conversing and interacting? Do the staff encourage the participants to be as independent as possible?

Find out what the requirements are for admission. Typically a history and physical from the physician is required with a current (within the last year) TB test or chest x-ray. Ask if the facility will do the TB test for you and if there is a cost. Make sure they go over the admissions packet with you. Ask about their policies and procedures, especially concerning fees, how they are billed (in advance or after the fact), and how they handle an absence. Each facility has its own policies on these issues. Again, if you have additional questions, call back later for clarification. Some centers will sit down with you and help you fill out the papers if you let them know you need assistance.

If the center exists in a state that requires a license, make sure the license is current. Ask to see results of their state inspection, which should be posted or available upon request. Find out if any deficiencies have been corrected.

Ask about the staff to client ratio. For Alzheimer's patients, the ratio should be *at least* one staff member for every eight patients. Meet the director and the staff. See how they interact with the participants and if they are attentive to you and your needs. Ask specific questions like, "How long has the facility been open?" "Is the staff specifically trained to work with Alzheimer's patients?" "How many participants is the facility licensed for?" "How do you handle participants who wander?" Be sure to ask any question that's on your mind. If you forget to ask any questions, you can call back later.

Other questions to ask:

- What are the philosophy, mission and goals of the center, management company, and/or board of directors?
- What is the rate of turnover?
- What are the emergency procedures?
- How are meals prepared? Are foods offered for special needs diets?
- What are the credentials of the direct staff? Certified Nurse Aide?

- What does a typical day consist of?
- Is there a secure outdoor area sufficient for walking and spending time outside? (An outdoor area is vital in providing a quality environment for an individual with Alzheimer's disease.)
- What are the hours of operation?
- Is there a charge for late pick-up?
- How often does the participant have to attend, and for how long?
- How involved can I be as a family member?
- Is transportation provided, and if not, are there community resources to help with this?
- Do you have a social worker on staff? Someone experienced to assist with resources, financial assistance, discharge planning, counseling, etc.?

## 69. If I decide to use an adult day center, how do I get my loved one to agree to attend?

Often Alzheimer's patients are reluctant to leave familiar surroundings and go to other places. An adult day center offers respite for the caregiver, as well as stimulation and a safe environment for the Alzheimer's patient. Sometimes calling the center by a "participant-friendly" name can help the patient feel more secure. You might try calling it the "club." Some caregivers also refer to the center as "work," "school," or "volunteering." You know your loved one better than anyone, so use techniques that may have worked in the past, such as "Please do this for me" or "This is your time to spend with your friends."

Some caregivers even suggest just getting in the car and arriving at the center. If there are questions along the way, tell them positive things like, "We're going someplace fun" or "It's your day to go to your club." Many times the person with Alzheimer's won't remember the center upon arrival, but then he or she usually recognizes it as "a safe place with friendly people." If there is resistance on arrival, you can have the center staff help you assist your loved one into the center. Make your good-bye *short* and then leave! If staff members are properly trained, their greetings should be inviting and loving.

Be sure to get to know the staff so they feel comfortable asking you questions that will help them care for your loved one as best they can. You can call throughout the day to check how your loved one is doing. In fact, the staff should encourage you to call and be involved.

The key to success is developing a consistent schedule. There will be times your loved one will be absent from the center, but minimizing days missed is wise in order to stay in the routine. Once participants get in the new habit and are familiar with it, they usually adjust well. Many times loved ones are not very happy to be at the center at first, until they are engaged in activities and make friends. Most people enjoy socialization with others who have similar interests or situations, and this environment offers this. Many reach the point where they look forward to going and ask about it on days they don't attend.

Another way to overcome objections from your loved one is to have someone other than the primary caregiver take him or her to the center. This person can be a neighbor, friend, church member, family member, or a community transportation service. This takes the perception of "bad guy" off the caregiver and puts the label of "hero" on them when they pick up the loved one at the end of the day. When your loved one returns home, try to put a positive edge on the day. If the center has an activity calendar and menu, you can go over it with your loved one and ask them how he or she felt about the day. Even if your loved one can't remember details, you can talk about how it felt to be there. Good or bad, validate the feelings and try to stay focused on the positives. Consistently reassure your loved one that you will always return to bring them home. Reassurance is crucial for filling the void and easing the feelings of insecurity.

Caregivers have shared over the years that even if the staff reports that a participant had a good day at the center, once he or she heads home, some complain and don't ever want to go back. This is where "difficult devotion" kicks in—the adult version of "tough love." If you as the caregiver truly feel this

is what is best for your loved one, you should continue to take them to the center. Sometimes it takes positive encouragement along with persistence to get the loved one to the point of adjustment and acceptance. Keep in mind that if they attend only part time, it will take longer to adjust than with daily attendance.

Go with your gut. If the center feels good to you, it is probably a good place. If your loved one continues to complain and your gut is telling you something different, sit down with the social worker or director of the center and discuss it. If you still don't feel comfortable, look for another center. Once you start at a center, you are usually not locked into staying. If the staff person you talk with is genuinely interested in you and your loved one, they may help you locate a more comfortable environment.

Some individuals with dementia become over-stimulated just by being with other people, even if it is a healthy environment. In this case, the option of staying home with assistance may be a better answer.

## **70. When should I start looking at nursing homes?**

As difficult as it can be, you should start looking at nursing homes as soon as you are comfortable. Planning ahead will help avoid a crisis situation later. You may not ever need a nursing home, but proceed in a proactive manner just in case. Making decisions in a crisis situation is difficult on everyone—planning ahead is better.

You can obtain a list of nursing homes from your local elder law firm, Alzheimer's Association, Area Agency on Aging, Department on Aging, or your state's facility regulatory department. They likely have lists of facilities that offer dementia care or have a dementia unit. When looking at facilities, take someone with you who is somewhat removed from the situation and who can be objective. He or she may notice things you don't.

Be sure to ask the facility if they offer respite care for short term stays. This will allow you an option should you go out of town, get sick, or just need a break. If you, the primary caregiver, have an unexpected situation such as hospitalization, you will have made arrangements for your loved one to be cared for. If and when respite care is needed, and you have planned ahead, you will have lowered the stress level for you and your family.

## 71. When is it time for nursing home placement?

The foremost desire of most Alzheimer's patients and their caregivers is to keep their loved one at home for as long as possible, primarily to keep the patient out of a nursing home. Each caregiver and/or family has different thresholds of what he or she can deal with in the home.

An example for some is the issue of incontinence. A caregiver may feel that once the loved one can no longer go to the bathroom on their own, they might have to place their loved one in a nursing home. Other issues caregivers worry about are feeding, wandering, difficult behavior such as anger or violence, caregiver health issues, and their loved one being unable to recognize family members.

Many caregivers reach their presumed threshold to find that it really isn't as bad as they had expected. This is especially true if they have taken the appropriate steps for help. Being prepared and seeking preventative interventions can increase tolerance at home and delay or even avoid placement.

Deciding whether to keep the patient at home or try placement in a nursing home is a very personal choice. Most families and/or family caregivers wish to keep their loved one at home for as long as possible. But keeping them at home isn't always the best choice for all parties involved. Those around the caregiver may see the effects of the disease on the *caregiver* and express their concerns. It's wise to at least listen and be open to what they have observed. Many caregivers are too close to the situation to see the negative effects it is having on them.

There are numerous senior services in place to assist with the hard decisions facing the Alzheimer's patient and his or her family. Seek out options soon after diagnosis. This will help you to plan and be proactive, rather than making an important decision in a crisis situation.

## **72. How do I choose the right assisted living facility or nursing home for my loved one?**

You can narrow your choices by location and whether they offer specialty care for Alzheimer's patients.

Get a list of facilities from the Alzheimer's Resource Center, Area Agency on Aging, Alzheimer's Association, or Yellow Pages. Look at the facilities *prior* to needing one, so you can make a rational decision when not in crisis. Look at several facilities and take notes so you can make comparisons. Take someone you trust with you who can be objective. He or she may notice things you don't see. Make two or three visits at different times of the day. Be aware of the atmosphere—is it warm and inviting? How is the staff interacting with the residents? Are they treating them with respect? Do they respond to their needs in a reasonable amount of time? Are they friendly? Is the facility kept clean and maintained inside and out? Are there odors? Are there outdoor areas secure for the residents use? Is the administrative staff available? Do they have an open-door policy?

Ask if you can have at least three names and phone numbers of families who currently have a resident in that facility you can talk to. Ask these families what they like and dislike about the facility. Talk with people in that community about the reputation of the facility. You can request to look at the most recent state survey to see if they had deficiencies and what they were. Most facilities have this ready and available.

When your loved one is placed in a facility, your involvement does not cease. As a family member, you can stay as involved as you want. Studies have shown that the number one reason for choosing a nursing home is close proximity to home. This makes visiting convenient for the family and allows for frequent drop-in visits to check on things.

It is common for Alzheimer's-specific facilities to have a waiting list. Go ahead and put your loved one's name on the list, as it can be months before a space becomes available. If you receive a call from the facility with an opening and you are not ready to make the move, usually you may pass at that time and have the name put further down the list. They will call again!

### **73. Could my loved one actually be happier in a nursing home than at home?**

Believe it or not, yes. Many people do quite well in nursing homes. The nursing home decreases feelings of intimidation caused by decreasing abilities, by associating with others who are similar. You can look at the nursing home like a college dorm. Each resident has his or her own space or room, while having access to common areas. These common areas, such as the dining room, become places of good social interaction. As human beings, we are very social creatures. Even individuals who were not as social throughout their lives usually enjoy socialization at this point.

A good nursing home normally offers daily activities. There is usually enough variety in the activities to meet the needs of almost everyone. There are group activities, such as bingo, and other activities that are geared more to the individual, such as reading or putting jigsaw puzzles together. If a favorite activity is not offered, most facilities are willing to provide it, as long as they are aware of the need or request. Residents are monitored all day, every day, and a nurse is available if needed. Medication is monitored regularly and administered daily. The facility doctor or medical director is available by phone to answer questions or write orders on an as-needed basis.

Once your loved one enters a nursing home, he or she can still leave for short trips or overnight stays with family or friends. If he or she is unhappy, a transfer to another facility or a return home with help is possible.

Being in a nursing home may increase feelings of independence. You may ask, "How could that be?" A nursing home is a safe place with care 24/7, good hot meals, socializing with others, and activities available every day. Residents who felt they were a burden to their families find that living in a nursing home eases that feeling.

#### **74. How can I help my mom stay at home and manage her own medications for as long as possible?**

There are several different ways to handle this situation. It is extremely important that she take her medication as prescribed, or there can be both physical and mental problems. How this is handled will depend on how much medication she takes, how many times a day she takes it, and her ability to manage it.

If she is capable of taking them on her own and just needs reminders, you can purchase several different kinds of medication minders at a drug store, medical supplies store, or discount store. You can fill the minder at the beginning of the week or have a nurse go in and fill it. This will work only if your mother remembers what time to take the medication. If she doesn't remember, you or the nurse can stop by and check on her. There are also minders with alarms that will remind her when to take the medication. Depending on her functioning level and/or level of confusion, you will have to decide which of these works best for her. Someone can also phone her and remind her to take the medication at the proper times. If none of these systems works, you will need to hire someone to go in on a daily basis to assist her.

You can also enroll her in an adult day center and have them remind her while she is there. If the center has a nurse and your mother gets to the point of needing the medication administered, the nurse is licensed to do that. You are required to take the medication to the center in the original prescription bottle with the doctor's order on the label. This continuum of care will help your mother stay in her home longer.

## **75. Are group homes with four or five people appropriate for those with Alzheimer's disease?**

Different states call these homes different names. In some states, they are called boarding-care homes. Some states have licensure for these small homes and some do not. Call your state's facility licensing department and ask if the small homes are licensed and if a list of them is available. Look specifically for ones designed to meet the needs of people with dementia. Typically, the staff is trained in dealing with the specific issues of dementia care, and the facility is set up for safety. If there isn't a home close to you that specializes, then think twice about whether this type of facility is appropriate.

You also need to find out if it is a facility where your loved one can live out the rest of his or her life. If your loved one runs out of money, does the home accept Medicaid? If the person needs a wheelchair, or becomes incontinent or bedridden, can he or she stay?

In regard to dementia care, the smaller homes are ideal. They are not institutionalized, so they feel more like home. With only four or five residents, the home can be easier to manage—but the facility manager still has to hire the appropriate people and have an appropriate staff-to-resident ratio. The small homes usually require the staff to be versatile—doing the cooking and cleaning and assisting with toileting and bathing while carefully watching the residents.

The key to these homes is to include the residents in the daily schedule and routine. Some of the activities may need to be modified for the level of functioning, but residents can assist with things like preparing the meals, setting the table, dusting, folding towels and other laundry, sweeping the floor, watering plants, feeding animals, raking the yard, and helping with the trash. Allowing residents to help makes the environment feel more like a family as everyone helps each other.

Another aspect is that your loved one will make friends with the other residents. This allows them a community of their own.

## **76. How beneficial is a dementia care unit for my father with Alzheimer's?**

If the dementia unit is developed and staffed correctly, it can be very beneficial.

The idea of the dementia care unit is to provide specialized care. This includes staff training specifically for dementia, smaller units and spaces to ease feelings of being overwhelmed, a quieter environment to prevent over-stimulation, and a locked unit safe for wandering and pacing. Wandering and pacing are symptoms that most Alzheimer's patients experience. Instead of trying to stop them from this behavior, dementia units let them continue it in a safe environment.

If your father lived in an open facility, he might experience more confusion, due to the fact that most facilities are very large. They have high ceilings, wide open spaces, a lot of people coming and going, and a lot of noise from phones and call lights. In the special care unit, these things are typically diminished or nonexistent. The dementia unit is arranged to provide a higher level of care while decreasing stimulation. Many units have done away with the overhead intercoms, as this causes confusion or agitation for some residents.

The standard for Alzheimer's care in most facilities is that the special care unit has its own activities director. Many times the direct care staff are also trained to participate in activities with the residents. These are geared specifically to the needs of residents with dementia.

For further information on facilities in your area that have dementia care units or Alzheimer's units, contact your state's Department on Aging. They can either provide you with a list of units or direct you to the appropriate department.

If there are several units in your area, visit at least three. Take someone with you who is objective or somewhat removed from the situation. Meet the staff and observe how they interact with the residents. Look at the cleanliness of the overall facility. Ask to see their most recent state survey; they are required to have this available. If the facility has deficiencies, what are they and how were they corrected? (It's not unusual to have a few deficiencies, but the most important thing is what they were and how they were handled.)

When making a decision about a facility, listen to your gut feeling, which is often a very accurate way to gauge. Talk with the person who visited with you and make a list of pros and cons. Then you can make a rational decision that you can live with.

**77. The nursing home may evict my father due to aggression. They changed his medications and were unsuccessful, and now they want him to have an inpatient assessment. Chances are they won't take him back. Should I have him assessed?**

Typically, aggression stems from extreme agitation. If the agitation is under control, the aggression will more than likely decrease or stop altogether. If you are not convinced staff members have handled this as best they can, you can meet with the director of nursing and the plan of care team to discuss his situation. If you still are not satisfied and want to pursue it further, contact your state's long-term care ombudsman program. Ombudsmen are trained volunteers who advocate for nursing home residents and mediate between the facility and the resident's family to try to work out a problem.

If you are confident the facility staff members have done all they can, he needs to be assessed. The aggression is hard not only on those around him, but is also hard on him. To be agitated all the time is no quality of life.

There are good assessment programs throughout the nation. You can visit the Alzheimer's Association website at [www.alz.org](http://www.alz.org) and look for the nearest program in your area. The positive aspect about an inpatient assessment is the 24-hour-a-day observation. Assessment can lead to additions, deletions, or changes to his medication and observation of effects of these changes. It could be that his medication is causing him to be agitated. (Some drugs can have the opposite effect of what was intended when they were prescribed.) Be sure to keep his primary care physician updated on what is happening.

When he is being assessed, you can meet with the hospital social workers or discharge coordinators to help you find the right facility. They cannot make recommendations to any one facility, but they can steer you in the right direction.

Environment plays a huge role in how comfortable a person is. If your father is not comfortable in that environment, a move might be the best thing for him. Even though moving a person with Alzheimer's causes a lot of additional confusion and possibly setbacks, chances are he will recover. He needs an environment that feels accepting and loving to him. It is usually the staff that creates that atmosphere, not the building. So if you find yourself looking for another nursing home, make sure you meet the staff and observe how they interact with the residents. If your father did not previously live on an Alzheimer's unit, look for one. The staff members on these units are specifically trained to deal with the symptoms/issues that accompany Alzheimer's.

**78. I can see my mother's medication affecting her in a negative way. How do I get the nursing home to adjust it?**

I would document what you have observed since she started on this medication. Then make an appointment with the director of nursing and discuss it with her. You can also call the doctor that ordered the medication and talk with him about what you are seeing. In some cases, it takes some time for a medication to work to its maximum potential, and this could be a transition period.

If you are feeling some resistance from the nursing home staff, you can talk with the administrator of the nursing home. You can also request to attend the next care planning meeting for your mother. Family members are to be informed and invited to the meetings according to regulation. If you are still not satisfied, you have to make a decision.

You can call the long-term care ombudsman in your state. Ombudsmen are volunteers who have been trained to advocate for and on behalf of the residents of nursing homes. They can try to mediate between you and the facility to work out this situation so she can stay. In order for her to stay, you have to feel confident that she is in an environment that is safe and appropriate for her. If you are not at that comfort level after these discussions, you may have to move her to another facility.

This decision is a difficult one because moving is very hard on persons with Alzheimer's. You have to weigh the pros and cons. The bottom line is if you are not comfortable with the place your mother is living and you are worrying, *your* quality of life suffers; you also need to think about how this situation is affecting you.

If all else fails, and if you are your mother's power of attorney for health care, you can request a change of medication. But be sure you have talked with her physician to be sure this is what is best for her.

**79. My dad is living in a nursing home. How do I deal with his constantly losing his glasses and wallet? What about missing or broken dentures—do we continue to replace them?**

Talk with the person in charge of his unit and see if there is a reason as to why those items keep getting lost, and proceed from there. Each time an item is lost or broken, the family needs to reassess if these items are really making a difference in the person's life. Are these items adding to their quality of life or are they in fact taking away from the quality of life because they are worried about their being missing?

Replacing the wallet probably isn't as difficult an issue as with more expensive items. Sometimes the wallet acts as a security blanket and does add to the quality of life. You can purchase an inexpensive wallet. You may want to purchase several to have on hand for replacement.

Replacing glasses and dentures is different. If he still enjoys reading and he can only do it with his glasses, then replace them. You could purchase a less expensive frame, or the inexpensive reading glasses sold in drug stores might suffice.

Dentures obviously play a huge role in proper nutrition. If they are broken, fixing them should be more reasonable than replacing them. If they have been lost, chances are they will be lost again. He may be taking them out because they cause him discomfort. If he has lost a significant amount of weight, the dentures could be loose, moving around in his mouth and causing sores on the gums. If you suspect this may be happening, consult with his dentist. Many times dentists have techniques to make dentures more comfortable.

**80. My husband lives in a nursing home. I understand many nursing homes have a family council that meets regularly to deal with issues of the nursing home—but this one doesn't have one. How can I can get one started?**

Family councils are very beneficial if they are set up and facilitated properly. The goal of the meetings is to talk about issues of the home with the staff in a non-threatening, constructive atmosphere. It is not a place to constantly complain or to degrade the facility or staff. At meetings you can share ideas, concerns, and possible solutions. And you can bond with the staff and develop working relationships with them.

Talk with the administrator of the facility about your desire to create this council. You might not face much resistance, as these councils are common practice. Decide together how to proceed, where to meet (what room is available), what day and time to meet, who should facilitate the meeting, and how you will inform staff and family members of the meetings. When you have your first meeting, talk with the other families about the best time to meet, and you can decide as a group.

Your meetings can be formal, with minutes, or less formal. The structure isn't as important as how information is shared.

Another function of the family council is to arrange facility activities that include residents and their families. These activities are usually picnics held at the facility. These functions help encourage the feeling of a family unit for residents, staff, and families.

**81. I'm looking for a nursing home for my mom, who has Alzheimer's. What is your advice about nursing homes that kick a person out when they run out of money?**

This is a very good question and one that you need to ponder before making your final decision on a specific facility. Some nursing homes and assisted living facilities do not have certification to accept Medicaid once a resident runs out of money. Those who do accept Medicaid may have a long waiting list for their Medicaid beds. Therefore, you need to consider carefully where you place your loved one if money is going to be an issue down the road.

If you know the monthly cost of the nursing home and you feel your mother may outlive her money, you can choose one a facility that accepts Medicaid to cover the cost of her care, once she is eligible. Most families of individuals with Alzheimer's disease do not want to move them again once they have adjusted. Changing environments is stressful on a person who has a dementia.

## **82. How will I know it's time to move my father from adult day care services to a nursing home? Is assisted living appropriate?**

The simplest answer to this question is: when you can no longer care for him at home.

Because adult day care is only a day service, it works only if you can continue to provide care in the evening and on weekends. Some adult day care centers provide some evening and weekend services, but many times it is not enough. One solution to this dilemma is to “package” your services by hiring a home care agency *in addition to* the time he spends at the center. Using a home care agency to help in the evenings and on weekends can reduce caregiver strain and help keep your father in the home longer.

If you are feeling overwhelmed and the quality of life at home has diminished, it is time to consider a nursing home or assisted living facility. Keep in mind that if your time with your father is so strained that neither of you have good quality of life, then it isn't fair for either of you. Spending a lot of time together doesn't make quality time. If he were to go to a facility, your time together would be limited, but you could focus on doing enjoyable things together during your visits, in a more stress-free environment.

An assisted living facility can be appropriate if the staff is equipped to handle individuals with Alzheimer's disease, but many are not. Some will take Alzheimer's patients until they become incontinent or to another point when they need skilled care. Whether you use assisted living or not depends on the facility, its limitations, and whether you are willing to move him again if it becomes necessary.

This is a decision only you, the primary caregiver, can make. Every caregiver has a threshold and limitations. If you know you have reached your limit, make the most appropriate and effective decision for everyone involved. Know that you have done your best, and your best is good enough. Let go of any guilt. Guilt will only destroy you.

### 83. How often should I visit the nursing home?

The facility staff may ask you not to visit at all for the first few days, to allow time for your loved one to adjust to the new environment and routine and minimize confusion. This may seem like a harsh approach, but it is done in your loved one's best interests.

In regards to *your* adjustment (because this a big one for you too), talk with your support system, other caregivers, a clergyman, or a counselor. Also keep in close contact with the staff on your loved one's unit. Having a good rapport with the staff will make things much more pleasant. Don't look at the staff as the enemy. Talk with them and get to know them. This will keep you in contact with your loved one in an indirect way. If it is a good facility, the staff will know how to handle this adjustment period for you and your loved one. If at any time you are uncomfortable with the situation, by all means, go to the facility. Stay involved with your loved one's care at a level that won't cause you stress.

After this adjustment period, it is not suggested that you visit every day. If you do, try not to stay for long periods of time. Remember "quality time vs. quantity time." Develop a schedule that works for you and allows you time to do other things. Spending too much time at the facility can add to your stress, eventually affecting your health.

Some family members visit at mealtime so they can help with feeding. In most facilities, you may eat with your loved one if you make reservations in advance with the facility kitchen. Some facilities have separate rooms where family can eat together away from the other residents. Many facilities will help you celebrate birthdays, anniversaries, and other special occasions.

An individual plan of care is developed for each resident by a team of staff representatives from each department of the facility. The resident and family are invited to attend these care planning meetings. The meetings discuss the resident's diagnosis, strengths, weaknesses, goals, and interventions. This is a good opportunity to be involved in your loved one's care. You can make suggestions and express concerns in a neutral environment. These meetings are usually held every 30 to 90 days, depending on the level of care.

Many facilities have family council meetings, usually on a monthly basis. This is a time for families to come together with the staff and discuss upcoming events, any changes that will be affecting the facility, and other issues.

There are effective ways of being involved without physically being at the facility. If you want to be there more, that is your choice. Some family members enjoy "hanging out at the nursing home," making friends with the residents.

**84. My father wandered from the nursing home where he lives. Could it be that he is inappropriately placed?**

This depends. If he is at high risk for wandering and the facility is not equipped to deal with this, he may be inappropriately placed. If this was a one-time incident and the staff says they can handle it from now on, try to keep him there. Moving a person with Alzheimer's disease is often traumatic. Unfortunately, you can't determine if a person is going to wander until the first time he does. The facility may have been caught off guard and now will be more alert to the possibility. The nursing home may have a "wander guard" system in place, but until your father wandered, the staff didn't think to tell you about it.

Talk with the activity director of the facility and see if he participates in any of the activities. If not, ask the director to get him involved in a group or individual activity. This will keep his mind stimulated and his body active and keep his mind off wandering. Exercise is a great activity that uses up excess energy.

You can also talk with the staff about hiring someone to come in and spend time one-on-one with him. This is called private duty or sitting services. There is no guarantee that he won't wander, though, due to the nature of the disease.

If he continues to try to leave the facility and the staff are unable to prevent it, you may need to look at your other options. If you are in a small town, there may not be other nursing home options.

Does your father seem extremely agitated or anxious? If so, talk with his doctor about something for this. Feeling agitated is very uncomfortable for the person experiencing it, and can be treated with proper medical intervention. It may be that no matter where he is, he will be agitated enough to wander, so be sure to keep his physician informed of the situation.

## 85. How can I get my loved one to eat more?

One of the great struggles that Alzheimer's caregivers often face is how to get their loved one to eat more. Oftentimes, as the disease progresses, Alzheimer's patients lose their appetite. Getting them to eat can be a constant struggle.

A recent study in *Clinical Nutrition* magazine showed that it may be beneficial to have Alzheimer's patients' food served on brightly-colored plates and to have their drinks served in brightly-colored glasses. It's a little-understood fact of Alzheimer's that often, as the disease progresses, the ability to process all types of information is lost. It might seem very easy for you or me to distinguish objects and to see the food on our plates, but for the Alzheimer's patient, this can be a challenge. A study showed that, for Alzheimer's patients in nursing homes, when the food was served on bright red plates with red cutlery and when the liquids were served in bright red cups, the patients ate about 24% more food and drank about 84% more liquid than when the same meals were served on white plates and the drinks served in plain glasses.

So if you're having trouble getting your loved one to eat or drink, try serving them on bright red plates with plastic red utensils and putting their beverages in a red cup to help them eat and drink more.

**86. My dad is in the later stages of Alzheimer's. Food pockets in his throat cause aspiration or coughing and food backup. Should we consider a feeding tube?**

This decision is difficult because of the negative information you hear about feeding tubes. Feeding tubes serve several purposes, including the issue your father is experiencing. If your dad has an advance directive, review this document concerning his wishes about a feeding tube. This may help in making your decision.

Talk with your dad's physician in detail. Other options may be available, such as speech therapy. Speech therapists work with patients on swallowing techniques, but the patient has to be aware enough to comprehend the instructions. Review all of the options before making a decision.

Also discuss with the physician the types of feeding tubes. Several are available, and all options need to be discussed in detail. Some procedures are more invasive than others. Obviously, a less invasive procedure would cause less stress on your dad. Discuss the risks of the feeding tube and the risks if you choose not to use a feeding tube.

If you feel any uneasiness after talking this over with the physician, don't hesitate to get a second opinion. Even if this is a physician your dad has trusted for years, you need to be at peace with your decision. A second opinion never hurts.

**87. We are starting a family council at my mom's nursing home, and I will be president. We plan to start by having representatives from each department give a brief description of their responsibilities and then open up for questions. Any ideas on what to do after that?**

Having the staff from each department there is a good place to start. The more you communicate, the fewer problems you should have. Hearing from the department heads will give you a clearer picture of their responsibilities and the reason they do things the way they do. Sometimes we question why something is being done a certain way. Many times it is simply because of state, federal, or health department regulations. Once you are aware of this, it makes more sense, thus making it easier to deal with.

Once you have met the staff of each department, work on the relationship between staff and the residents' families. You can invite other staff members to attend your meetings. Keep in mind that the staff on the floor, such as nurses and nurse aides, are very important. They are the ones doing the hands-on work with your loved one. It's important to get their input, too.

As a group, you can develop a method for effective communication if a complaint or concern arises. Then when a problem does arise, it should be less threatening for everyone to resolve it. You may also want to develop a way to compliment staff for a job well done such as a comment box or a personal note.

Arrange times for staff, residents, and their families to spend relaxed time together. Treat this as family. Plan for a picnic or other types of get-togethers.

Keep in mind that you don't want this council to become a gossip and complaint session. Also, no one wants to waste valuable time. The meetings need to be structured and effective. You can call other facilities and ask how they run their family council meetings and adopt their ideas for your group.

**88. My mom's doctor ordered speech therapy in the nursing home. She has been to two sessions and she says it is a waste of time. Is speech therapy really helpful? I can't see putting her through the stress if it's not doing her any good.**

It would be advisable to talk to your mother's doctor about the benefits and also sit down with the speech therapist to discuss in detail what therapy is doing for your mother. Therapists typically have a care plan which consists of a goal and steps to meet that goal. The attending doctor is also involved with that process, because he or she is the one who wrote the order for skilled services.

Speech therapy does a lot more than the general public realizes. These therapists not only assist individuals with speech difficulties but also with swallowing issues. As the disease progresses, swallowing can become difficult and sometimes life-threatening. If your mother can't swallow, she might choke and die. Speech therapists assess this serious situation and respond as needed. Many times they conduct a swallowing test on the person with dementia through X-rays. Test results are used to create a plan of action. A person with dementia probably wouldn't understand this.

Ask your mom's doctor to explain to her the seriousness of the situation. That way, when your mother complains about going to speech therapy, you can back up the doctor, because you have become more educated and knowledgeable about the reason for speech therapy.

## **89. My father is applying for Medicaid to pay for a nursing home. What is “division of assets”?**

“Division of assets” is the term commonly used for the Spousal Impoverishment provisions of the Medicare Catastrophic Act of 1988. It applies only to married couples. The intent of the law was to change the eligibility requirement for Medicaid in situations where one spouse needs nursing home care while the other spouse remains in the community. The law, in effect, recognizes that it makes little sense to impoverish both spouses when only one needs to qualify for Medicaid assistance for nursing home care.

As a result of this recognition, division of assets was born. Basically, in a division of assets, the couple gathers all of their non-exempt (countable) assets together in a review. Depending upon the rules of your state, exempt assets are usually the home, household and personal belongings, one vehicle, burial plots and irrevocable funeral plans, cash value of life insurance (as long as the total cash surrender value does not exceed \$1500), and cash (the amount varies from state to state).

The non-exempt assets are then divided in two, with the community (at-home) spouse allowed to keep one-half of the assets, up to a maximum of about \$110,000. The other half of the countable assets must be “spent down” until a certain amount remains. This amount varies from state to state. The amount of countable assets which the at-home spouse gets to keep is called the Community Spousal Resource Allowance (CSRA).

Each state also establishes a monthly income floor for the at-home spouse. This is called the Minimum Monthly Maintenance Needs Allowance (MMMNA). This permits the community spouse to keep a minimum monthly income ranging from about \$1,750 to as much as about \$2,650.

If the community spouse does not have income of at least \$1,750, he or she is allowed to take the income of the nursing home spouse in an amount large enough to reach the MMMNA. The nursing home spouse’s remaining income (minus a personal needs allowance) goes to the nursing home. This often helps avoid the necessity for the at-home spouse to dip into savings each month, which would result in gradual impoverishment.

Seek advice from someone who knows Medicaid law. You can find an elder law attorney in your area by visiting [www.NAELA.org](http://www.NAELA.org), the website for the National Academy of Elder Law Attorneys.

## 90. Mom keeps asking to go home. What do I tell her?

The best way to answer this question is to think about the word “home” and what it signifies. To most people, home is a place we feel loved, accepted, and safe. Depending on where she is in her memory, she may be thinking about her childhood home with her parents and siblings, her home when she was first married and her children were young, or any time before, after, or in between. She may be living in the same home she has lived in for 25 years and still ask to go home.

When a loved one begins to ask about home, a caregiver may drive her past a previous or childhood home. Many times, she will not recognize the house because a house and a home are two different things. This is why it is best to help her feel safe and secure wherever she is.

Due to the nature of this disease, your mom is probably feeling insecure, fearful, and unlovable. This is *not* your fault. She is losing a part of herself bit by bit, day by day, and she is frightened. Fear produces many emotions, including insecurity, anger, anxiety, and low self-esteem. What she needs is to feel safe. If she doesn't feel good about herself, she doesn't feel she could possibly be loved by anyone. She may feel she is a burden.

The most important thing to remember is to validate her feelings. Instead of telling her she is home, tell her she is in a safe place and that she is loved very much. For example, you can say, “Mom, you are staying with Bob and me for awhile. We love you, and we're happy you're here.” Reminiscing about her childhood and reviewing her life and life accomplishments will also make her feel good about herself and decrease the negative feelings.

Because she has short-term memory loss, she will continue to ask about home. Repeat many times a day that she is safe and loved. Giving her hugs throughout the day will say much more than words. A hug is a gesture that produces feelings of love, acceptance, and security.

## **91. How do you get the professional staff of a nursing home or assisted living facility and residents' families to work together, rather than "them vs. us"?**

This tip will be addressed to both the family members and the staff.

First to the families: When you first admit your loved one to a nursing home, get to know the staff. Express to the staff that you care about their well being and that you would like an open relationship to discuss issues concerning your mother's care. Let them know pertinent information about your mother and her life—her likes, dislikes, rituals, moods, and how to approach her in different situations. The more they know about your mother, her background and personality, the better they can care for her. Compliment the staff when you see them doing something you like. Be involved with the facility as much as possible. Attend social events and family council meetings if they are available.

One man took a picture of his wife and the staff on her unit. He had the picture blown up to an 8 x 10 and put the name of each caregiver underneath their picture. He then placed the picture on her closet door. This serves two purposes, to help his wife recognize the people in the picture and to help the staff feel included. It made the staff feel important and that the family really care about them. This small gesture bridged a lot of gaps.

To the staff: Don't be intimidated by the families of the residents. Without you, there would be no care for their loved one. You are the front line worker. They have entrusted the care of their loved one into your hands. That is quite a compliment and an honor. Show an interest not only with the resident but also the family. Introduce yourself and tell them a little about you, your life, your interests. You may want to let them know how long you have been a caregiver and why you chose this line of work. When the family enters the unit, greet them and give them information concerning their loved one, both good and bad. If their loved one does something good during the day, call them and let them know. These are the little blessings.

Unfortunately, there is still a stigma concerning nursing home care and the people who work there. Everyone needs to work together to overcome these negatives so the residents will have a positive experience in their new home.

## 92. **Would I benefit from a support group?**

A support group is not for everyone, but for most Alzheimer's families, it is a godsend. There are many types of support groups, and you need to find one you feel comfortable with. Each group usually has a specific focus, such as caregiving, adult children, spouses, etc. For the best benefit, look for a group that meets at least twice a month.

A group that discusses caregiving issues in general is also a good choice. Most issues with caregiving are similar, no matter what the disease. Issues include guilt, fatigue, anger, frustration, finances, physical challenges like incontinence, and so on. The purpose of a support group is to provide a secure and confidential way of expressing your feelings and concerns. Caregiving is a difficult job and no one really asks for it. Sharing with others who understand your situation is comforting, affirming, and validating. If you are experiencing a difficult problem or situation with your loved one, you can take it to the group and let them help you solve it. Chances are, someone in the group has experienced a similar problem and has a practical solution.

The person with Alzheimer's needs to talk about his or her feelings and experiences with the disease, too. A support group for those dealing with the disease can assist in diffusing anger and frustration. Such groups talk openly about the disease, what to expect and how to plan—so the participant must be aware of the diagnosis. Support groups for persons with Alzheimer's are a fairly new concept, so are not as readily available. Currently, they are mostly located in larger metropolitan areas.

If you live in an area that does not offer support groups, there are groups online. One such group is The Alzheimer List, sponsored by the Alzheimer's Research Center in St. Louis at <http://alzheimer.wustl.edu/adrc2/alzheimerlist>.

### 93. What is an advance directive?

An advance directive allows you to communicate your health care preferences when you lose the capacity to make or communicate your own decisions. Advance directives can include power of attorney for health care decisions, living wills, and informal directives people make in letters, conversations, and conduct. An advance directive must be signed while a person still has the mental capacity to sign legal documents.

A Supreme Court decision (*Cruzan et ux. v. Director, Missouri Department of Health*) recognizes that all people have a constitutional right to refuse any medical treatment, including ventilators and feeding tubes. Further, state laws authorize you to name a person to make health care decisions for you when you cannot. Advance directives are documents intended to ensure that your wishes are known and followed. They allow you to state in advance your wishes regarding the use of life-prolonging procedures. The documents will be more helpful and informative if you discuss your wishes with your family, friends, and health care providers as part of your advance care planning.

The Power of Attorney for Health Care Decisions is the most-often used health care directive. It allows you to appoint a person to make health care decisions for you when you are incapacitated and to state your wishes about such issues as life support and organ donation. This document goes into effect only when you cannot make or communicate decisions for yourself.

Once your advance directive is completed, give copies to appropriate individuals such as physicians, family, friends, clergy, and attorney. Discuss the details of your advance directive with these individuals. Ask your physician to make it a part of your permanent medical record. Whenever you are hospitalized, take a copy with you.

Your advance directive is valid in any state, but because of state-to-state differences, it is a good idea to have advance directives drawn up, witnessed, and notarized in the state where you live.

Unless you revoke your advance directive, it stays in effect until your death.

#### **94. What is a durable power of attorney for property/financial decisions? Do I need a lawyer to draft it?**

A durable general power of attorney for property/financial decisions is a legal document wherein one person (the principal) authorizes another (the agent) to act on the principal's behalf regarding financial decisions. It allows a person to plan for care and control of property in the event he or she becomes incapacitated.

Powers of attorney are the single most important documents to put in place so that a family member or trusted friend will have the legal authority to carry out your wishes if you can no longer speak or act for yourself. Without a power of attorney, if something happens to you that results in your inability to make decisions, your family may later face court proceedings and court supervised guardianship and/or conservatorship.

You do not need a lawyer to draft the powers of attorney—but without the proper, specific wording, your agent may not be able to deal with some of the issues that are important to you.

Some people purchase a “form document” power of attorney from an office supply store or download one from the internet. While these documents legally authorize persons to act on another's behalf, there are certain things this type of power of attorney document may not address. In fact, the law provides that your agent cannot handle certain matters unless specific wording in the document empowers him or her to do so. Such matters include the power to make gifts on your behalf and the power to remove and /or add assets to a trust. Also, laws vary from state to state and a form document might not address that issue.

These powers can be critical in Alzheimer's planning. That's why it's so important to do the documents now, while your loved one still has the capacity to do them. Later on, as the disease progresses, it may be too late, causing great problems for the family.

## 95. What is the difference between a power of attorney and guardianship?

A *power of attorney* is a legal document where one person (the principal) authorizes another person (the agent) to act on his or her behalf, either for health care decisions or for financial decisions.

*Guardianship* is a legal relationship whereby a *court* gives a person (the guardian) the power to make personal decisions for another (the ward). A family member or friend initiates the proceedings by filing a petition in the circuit court in the county where the individual resides. A medical examination by a licensed physician is necessary to establish the individual's condition. A court of law then determines whether the individual is unable to meet the essential requirements for his or her health and safety. If so, the court appoints a guardian to make personal decisions for the individual. Unless limited by the court, the guardian has the same rights, powers and duties over his ward as parents have over their minor children. The guardian is required to report to the court annually.

A *conservatorship* is a legal relationship whereby a court gives a person (the conservator) the power to make financial decisions for another (the protectee). The court proceedings are very similar to those of a guardianship, except the court of law determines whether an individual lacks the capacity to manage his or her *financial* affairs. If so, the court appoints a conservator to make financial decisions for the individual. Often the court appoints the same person to act as both guardian and conservator for the individual. Like the guardian, the conservator is required to report to the court annually.

Powers of attorney for health care and property/financial decisions are relatively low cost and private way to decide which family member or trusted friend will have the legal authority to carry out your wishes if you can no longer speak or act for yourself. If you do not have power of attorney, or if your powers of attorney are not drafted properly and something happens that results in your inability to make decisions, your loved ones may later face court proceedings and court-supervised guardianship and/or conservatorship. A court proceeding is not only costly, but the person appointed as your guardian/conservator may not be the person whom you would have chosen yourself.

## **96. What exactly does hospice do? When and how do you call in hospice?**

Hospice is an organization that serves individuals with a terminal illness and their families. Hospice provides a holistic approach to pain and symptom management through physical, emotional, and spiritual care and support. The main focus is to maintain dignity and quality of life. The care provided is not meant to cure the person. It is palliative care which is aimed at relieving or reducing discomfort.

When the primary care physician determines that the patient has six months or less to live, the physician can call in hospice. Whether your loved one is at home or in a long term care facility, hospice will go there. Some facilities have their own hospice programs, so if your loved one lives in a facility, check with staff about their services.

Once hospice is called in, the current plan of care for your loved one usually stops. For example, treatments like radiation would stop, and palliative care would take over. The hospice team then develops a new plan of care for your loved one. Your physician coordinates care with hospice.

The hospice team generally consists of a chaplain, certified nursing assistants, a medical director, registered nurse, and social worker. Some hospice agencies provide bereavement care to the family for several months following death.

Hospice is a wonderful service and is highly recommend for the care of your loved one when that time comes.

## **97. What should I do about legal and financial issues?**

Call an elder law attorney right away, especially if your loved one has no documents in place. These attorneys are well versed on the multitude of issues you will be dealing with. They can inform you of all your options—in many cases, options you might not have been aware of.

An elder law attorney can prepare health care and financial powers of attorney so that these matters are handled according to the wishes of your loved one. This attorney can also prepare wills or trusts and advise you on care options and Medicaid planning.

You can call your state bar association and ask for an attorney who specializes in elder law. You can also find an elder law attorney in your area by visiting [www.NAELA.org](http://www.NAELA.org), the website for the National Academy of Elder Law Attorneys, and clicking on “Locate an Elder Law Attorney.”

Either way, you need to have your loved one’s financial affairs in order as soon as possible, while he or she still has decision-making capacity. Having financial affairs in order makes dealing with other issues a little more bearable.

## 98. I am caring for my husband who has Alzheimer's. How do I set up our financial affairs so that when we die we can avoid probate?

When an individual who has written a will dies, and he or she owns property solely in his or her name, a formal court procedure (“probate”) is usually required to confirm to whom the property will pass. If the person dies intestate (without a will), the property also goes through probate court and will pass to the individual’s heirs at law. The intestacy laws of your state will determine who the individual’s heirs are and what they receive.

However, it is possible to legally pass property to another person without going through probate. The following are examples of some probate avoidance devices. (Keep in mind that although it is often beneficial to avoid probate, because it can be costly and time consuming, these devices have pitfalls; probate is sometimes the best option.)

**Joint Tenancy** – Adding another person to your assets as a joint owner of “joint tenant with rights to survivorship” will allow your property to pass to the other individual upon your death without the need for a probate proceeding. The obvious pitfall is that while you are alive, the other owner has access to 100% of that asset, and the asset is subject to any claims of the co-owner and/or creditor of the co-owner.

**Beneficiary Designations** – You can add a Transfer on Death (TOD) beneficiary to your motor vehicle; Pay on Death (POD) beneficiaries on bank accounts; and Beneficiary Deeds to real estate (this will vary depending on the state in which you reside). Unlike joint tenancy, adding beneficiary designations to your property allows you to name an individual to inherit your property at your death without giving him or her any current ownership. The property will pass to the individual of your choice without going through a probate proceeding. One of the problems associated with beneficiary designations is that often times, the estate is not divided equally among the family as was intended by the individual.

**Revocable Living Trust** – Revocable trusts are documents wherein an individual (the “grantor” or “trustmaker”) names an individual (usually himself/herself) or a bank as “trustee.” The grantor then transfers property into the trust, and the trustee manages the property and distributes the property according to the terms of the trust. Unlike the addition of joint tenants or beneficiaries on your accounts, which may lead to conflict among family members, a revocable living trust allows you to specify how you wish your property to pass upon your death. A revocable living trust also avoids some of the adverse tax consequences associated with joint titling and beneficiary designations, while accomplishing the same goal of avoiding probate.

Other considerations:

**Last Will and Testament:** It is *very* important to understand that if you have listed beneficiaries on your assets, the assets will be distributed to those beneficiaries upon your death. They *will not* be distributed according to your Last Will and Testament, if those beneficiary designations conflict.

***Incompetency:*** What happens if an individual is incompetent? If her or she has a well-drafted power of attorney for property/financial decisions in place that specifically states that the appointed agent can create a trust or add/change a beneficiary on the individual's account, then the agent may do so. Keep in mind, the agent named in the power of attorney has a fiduciary duty to act in the principal's best interest, which includes following their testamentary wishes.

***Spousal Elective Share:*** If you are married, before titling/adding beneficiaries to your assets, you need to take into account your husband's or wife's spousal elective share (the amount they are entitled to inherit from you by state law). The spousal elective share is different in each state. Additionally, if you or your spouse is applying for/receiving Medicaid, the state may consider the applicant's/recipient's failure to receive the spousal elective share as a transfer of assets, which will disqualify your spouse for benefits.

This information is general. Before taking action to avoid probate, you should consult an elder law attorney in your state who can examine your specific situation and advise you accordingly.

## **99. I'm very concerned about Dad's driving; how do I get him to stop?**

If he trusts his physician, the doctor can usually have more success than the primary caregiver. If the physician is honest with him and explains that he has a medical condition that interferes with safe driving, this states fact and it helps with his understanding of how serious the situation is. This scenario is good for the caregiver, as it takes the responsibility off the caregiver and puts it on the medical condition, with the physician being the messenger.

Talk with other caregivers about how they handled this situation, but remember that each loved one is an individual. What worked for one may not for another. The ideas others share can be modified to fit your situation.

The Alzheimer's Association has information about driving, as do the other organizations mentioned in this guide. You can also purchase items that can be installed on the engine of the car to disable it, from sources such as [www.alzstore.com](http://www.alzstore.com).

## **100. Are there prevention measures for Alzheimer's disease at this time?**

Just like any other disease, prevention of Alzheimer's is all about taking care of yourself. You need to exercise both your body and your brain. This means you need to stay active no matter what. For your body, go for daily walks, join a gym, play tennis, or ride a bike. For your brain, read books, work word puzzles, take up a new hobby, volunteer.

Make sure you remain physically healthy. An annual physical by your doctor is a good idea. You need to keep your blood pressure under control—so if you have an issue with this, please follow your doctor's orders and plan of treatment. Have your blood checked to measure cholesterol and blood sugar levels. Keep your weight under control.

If you suspect you may have depression, see your doctor. When depression is not treated it doesn't go away on its own, and in many cases it continues to worsen. When depression becomes severe, it has dementia-like symptoms. Depression is manageable if you see your doctor and follow the plan of treatment.

## **101. Is it naive to hope for a cure for Alzheimer's disease?**

Not at all. Hope is a positive way of coping with negative happenings in our lives. Reasonable hope is healthy. To hope for a cure in the not-so-distant future is an attainable reality. If researchers find that Alzheimer's disease is hereditary, this information will help future generations. You can hope for a cure in the near future so you or your children are spared, but be cautious of false hope—for instance, that a cure might happen in the next few months and it would cure your loved one who already has Alzheimer's disease.

Researchers have made great strides in Alzheimer's research. They have uncovered many possible causes of the disease. Their research will continue with the help of organizations like the Alzheimer's Association and other generous donors.

The information available has allowed for the development of medications. These medications do not stop the disease's progress, but are geared toward slowing down the progress. Earlier and more thorough diagnosing also aids in the effectiveness of treatment. These are exciting and beneficial advancements. With hope, continued research will lead to a cure.

We can always hope!