

Later Stage Alzheimer's Disease



**A Caregiver's
Guide**

alzheimer's  association®

Massachusetts/New Hampshire Chapter

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Caregivers should consult with their physician/health care provider before initiating a new care strategy.

Introduction

Alzheimer's disease affects not only the person diagnosed with it, but it also has an impact on the entire family, especially the hands-on caregivers. For some time now, you have anticipated, adapted and adjusted to significant changes in your lives and you learned new, meaningful ways to interact with each other.

During the mid-stage of this journey, one of the primary adjustments was learning the best ways to assist with everyday activities and personal care. During the later stages of the disease, the focus shifts from personal care to changing medical and physical needs.

The more difficult challenge associated with later stage care is the daily attempt to find that part of the person that is still there and to connect emotionally with the person that remains—to truly value that experience, however fleeting it may be. The challenge is to give comfort, reassurance and love

consistently, patiently and freely. *Consider love now as a verb, not just a noun.*

Like you, there are many family caregivers who are committed to providing care at home for loved ones in the later stages of Alzheimer's disease or another related form of dementia, for as long as it is feasible to do so.

Some families are not able to sustain a high level of home-based care, because they lack the personal care skills that later stage care requires. Others give up, because they did not anticipate and plan for the care-related problems before they occurred. In their zeal to live up to their commitment to home-based care, other caregivers so compromise their own health that it becomes impossible for them to continue. The commitment to keep someone with Alzheimer's at home throughout the course of the illness is not easy to maintain, but with proper planning, assistance, good information and the right attitude prolonged home-based care is truly possible.

This guide is designed to give you practical hands-on daily care information for the later stages of dementia. This guide also covers ways to keep you mentally and physically healthy, so that you can continue in your caregiver/advocate role throughout the course of this disease. We will also highlight the type of decisions you will need to make down the road, so that you can be the voice for your loved one when it is needed.

A philosopher once said, “Fate favors the prepared mind.” Your careful reading of this guide and your commitment to develop proficiency with the care giving skills we recommend can give you more control over the challenges you will face.



Characteristics of Later Stage Alzheimer's Disease

Alzheimer's disease is relentless. What may start as a little forgetfulness progresses over months and years to change every aspect of the life of the affected person.

By the time you read this guide, you are most likely very familiar with the care needs of someone who is in middle stages of Alzheimer's disease. Those in the middle stage need increasingly more assistance with their everyday activities of living. Things like eating, dressing, walking, toileting, grooming and bathing require more and more assistance as the disease progresses. The later stages of Alzheimer's disease require full care in all of these areas, plus more medically related care. For example:

- Being bedridden or chair-bound can result in joint problems, skin sores, skin problems and muscle breakdown—requiring your ongoing attention.

- Incontinence of bowel and bladder challenges caregivers—you will learn techniques in this guide that will help you manage this problem.
- Swallowing difficulties can cause food or liquids to be inhaled into the lungs and cause pneumonia—you will learn techniques that will help the person eat and drink more safely.
- Inability to move around can change the person's metabolism, cause pain and lead to infections and swelling—requiring learning how to assess for pain and how to reduce the risk of infections.

As the person with Alzheimer's disease loses brain function, she becomes more reliant on body language and reading the emotional status of the caregiver. You will learn new nonverbal ways to communicate reassurance and love to the person for whom you are caring and how to establish an emotional connection that is meaningful to you and your loved one. Perhaps most importantly though, you will learn how to enter the world of the person with Alzheimer's disease and see things from his or her perspective.

Later stage care information in this guide is relationship-based. You show love and earn compliance through building a relationship each time you attempt to provide care. You will learn how to “be in the moment” with the person.

Legal, moral or ethical issues may arise in the late stages of Alzheimer’s care because the person is unable to make an informed decision and/or unable to express his desires to family members. We will discuss some of the decisions with which families may be faced and the ways to anticipate and plan for these circumstances should they arise.



How to Use this Guide

You should take some time to read through the first sections of the guide to get an overall sense of the importance of establishing a positive emotional climate and caring relationship. We have alternately used “him” and “her” and avoided institutional references to “the patient” because this care is highly personal—to you and to your loved one. All advice applies, regardless of gender.

The section on possible legal and ethical issues should be read as a family. As a family, you should put legal plans in effect. The legal section should lead you to write up a set of contingencies. For example: If this happens, then plan A is put into play; and if this happens, plan B is in effect. The legal section is presented to help you avoid any surprises down the road, but should also be used in conjunction with advice from your own legal adviser or counsel.

This guide is devoted to the “nuts and bolts” of providing medically related care to a person with later stage dementia. A short description of a problem area will be followed by a set of bulleted steps in how to provide appropriate care. You can refer to those personal care issues that you are specifically dealing with at that time. Many of the skills will feel awkward at first, but with practice and patience, you will get better at providing each area of care. Do not expect to attain perfection quickly—give it time. You will find, in time, the skill will be easier for you to use. Be gentle on yourself and don’t give up.

You will need to have a care giving plan that takes into account the impact the disease is having on the family and on the primary caregivers. How will you take care of yourself so that you can remain the caregiver for as long as it is needed?

First, think about how you can draw on your personal network for relief from the 24/7 demands of later stage care. Could you ask family to give you a weekend day or a regularly scheduled afternoon or evening to give you an opportunity to replenish your soul, get some rest, or just do the errands? It is important that it be regularly scheduled so that you will have something to look forward

to. Don't deny your children or friends the opportunity to be with your loved one, because you think it is an imposition or that they have busy lives. With some basic training that you provide, others would welcome the opportunity to be with your loved one.

Second, what professional resources can you utilize to help you remain the primary caregiver for the long haul? Are there home health agencies that can provide you with aides a couple of times a week? Are there subsidized or lower cost state agencies that can bring a home health aide, homemaker or personal care attendant to your home? Call the Alzheimer's Association's 24/7 Helpline at 800.272.3900 for names of state and private homecare agencies that may be able to help you or to arrange for a free care consultation with Association staff.

You may also want to consider whether your loved one could participate in an Adult Day Health Center. Such centers provide programming several hours each day, even for later stage patients. Adult Day Health programs won't work for all later stage patients, but for some it gives the caregiver much needed respite from the intensity of care.

Some families have found that a private Geriatric Care Manager can be a valuable

resource, for a fee, to the planning process for later stage care at home. A Geriatric Care Manager can advise on the type of care that you may need and, in some cases, help you find providers of care that can come into your home. Again, a call to the Alzheimer's Association's 24/7 Helpline can help you identify Geriatric Care Managers in your area.

Hospice services can be another source of assistance to your family. Hospice programs provide comfort care and preserve the dignity of those in the later stages of a terminal illness like Alzheimer's disease, while also offering support services to your family. Comfort care covers a variety of care options and does not mean withholding all treatments. As a matter of fact, hospice doctors and nurses, because of their experience, may be the most knowledgeable in pain management as it relates to late stage Alzheimer's. Hospice care can be provided in home, hospital or facilities.

A hospice team includes a doctor that specializes in end of life care, a nurse, a social worker, a dietician, home health aides, clergy and trained volunteers. This team works together to address the physical, emotional and spiritual care of the person who is dying and the family as a whole. For Medicare

or other forms of insurance to cover hospice services your loved-one's doctor must determine that she has approximately six months to live. This determination is sometimes difficult to make with Alzheimer's disease, so there are provisions that hospice care can be extended and covered by insurance should the person live longer.

Finally, because there is a genetic component associated with many types of diseases that cause dementia, like Alzheimer's disease, it may be wise to consider building a genetic history for your family by planning for an autopsy. If a significant treatment for Alzheimer's disease is found, it may be the type of medication that is best given to people with a known genetic risk. A genetic history ensures that you'll be ready. To determine a family's risk, there must be a brain autopsy to determine the presence of Alzheimer's disease or another related disease definitively. You must plan for an autopsy long in advance of the person's death, especially if you would like to take advantage of an autopsy for research purposes, at no charge. There may be paper work that needs to be in place before your loved one dies in order to qualify for the "free" autopsy. Again, the Alzheimer's Association's 24/7 Helpline can assist with information on autopsies.

Overview: Later Stage Alzheimer's Care



Transitions and Ethics

As a caregiver, you have likely focused on helping a person with Alzheimer's maintain function. As the advanced stage progresses, goals of care change as the end of life approaches.

Now is the time to focus on quality of life, dignity and peace. As brain and body function diminishes, caregivers need to modify their expectations. You need to begin to accept that death may be near. Medical issues will arise that will require you to make decisions about care intensity and possible interventions. Questions you will encounter include:

- Does the medical intervention relieve a symptom and make the person feel better?
- Does the medical intervention only prolong the dying process?
- What would the affected person want if he or she could voice an opinion?

- Does he or she enjoy daily activities in noticeable ways?
- The answers to these questions may help you decide if treatment of some type (like antibiotics for an infection) is appropriate for your loved one.



Medical Team

A person with Alzheimer's disease needs a good support team of caregivers and of caring medical professionals. A physician, nurse practitioner, social worker, chaplain, and possibly aides who are involved in day-to-day care may significantly impact the quality of life of a person with Alzheimer's.

You should make sure you know the members of the team and communicate your desire that comfort and quality of life should be the foremost goals of care. If you have preferences about hospitalization and other medical treatments, then it is wise to make those known. Of course, if the person affected has expressed preferences in this area, then those should be discussed and honored.



Seizure Control

Nearly half of those with advanced dementia have at least one seizure. A seizure may be a one-time event or may recur. If a seizure recurs, then it is probably wise to use a medication that lowers the chance of further seizures. If seizures are difficult to control, or occur frequently, you may want to have medication available to treat/stop the seizure. Ask the physician or care team about seizure control if you have questions.



Fevers of Unknown Cause

Many people with advanced dementia experience fevers. Research shows their immune system is not as effective in fighting off bacteria and viruses. If a person develops a fever, then Tylenol® is usually given as it helps with comfort.

Fevers can be caused by a viral infection or a bacterial infection. Sometimes a urine specimen or an x-ray is done to determine the cause of the fever. However, some caregivers do not want tests or treatments such as

antibiotics because they are not as effective in people with very advanced Alzheimer's disease, and may cause discomfort.



Later Stage Non-Physical Care

Caregivers are faced with a multitude of challenges and losses which they must overcome, grieve and ultimately accept. It is easy, too easy, in light of all these demands to lose sight of the importance and value of what is left—what remains until the very last breath: the essential core, the unique fundamental identity of the ill individual. Those who are religious will identify this as the person's soul; those who are not may call it his humanity, his essence, his fundamental personality. Whatever you call it, it resides in the core of each individual and remains untouched by the ravages of disease and disintegration of the body.



Emotional Care

Deep in the brain, and the last to be affected by Alzheimer's and the related disorders, is the emotional center known as the *amygdala*. This is the primal source of all feeling, the reservoir of terror, joy, love and all other human emotional responses both positive and negative. No matter what cognitive and physical loss is caused by the illness, emotions remain our primary path to connect with the world around us. Caregivers can use this understanding to great advantage.

Understand that anger, anxiety and agitation are frequently rooted in fear rather than physical discomfort. Depression, withdrawal, and resistance may stem from sadness and a sense of helplessness in the face of uncontrollable change and loss of self esteem and self worth. Patients and caregivers both process the changes and effects of the illness, and both process the same sense of loss, frustration and grief. The problem is that they rarely process the same things at the same time. It is important for the caregiver, however, to recognize that the patient's behavior and quality of life can be affected by emotional causes. Furthermore the caregiver's

actions and responses can influence those emotions profoundly.

It will come as no surprise that negative emotions lead to negative behavior and negative reactions which in turn impact a patient's quality of life. It is the caregiver who must exercise control in these circumstances. Calm and affirming action can defuse negative emotions. A gentle, loving approach is far more likely to result in positive, or at least neutral, response.

Relational Care vs. Custodial Care

At some point in the course of the disease, the patient's physical needs, the custodial care requirements, are very likely to affect the historical relationship between patient and caregiver. A daughter may find she must help bathe her father; a wife may need toileting help from her husband. This activity, outside the realm of their previous relationship, is apt to result in resistance or perhaps even stronger negative response because it changes the previous relationship

and therefore is perceived as threatening by the patient. Recognizing this possibility and addressing it beforehand is much easier than repairing emotional rents in the relationship after problems are encountered. The ideal approach is to think through the needs and consequences of various approaches before taking positive action.

A caregiver's attitude and approach can make a significant difference in patient response, but even the best laid plans can cause havoc when custodial care needs threaten to change the relationship two people have developed over time. In such instances, every effort should be made to find temporary alternatives until new approaches acceptable to both individuals can be worked out. There are innumerable ways to provide required custodial care; there is only one relationship to be maintained between the patient and each caregiver (family member or friend).



Spiritual Care

Deep inside every individual is an essential being that is unrelated to role, age, class, or any other label humans apply to describe and judge one another. This essence is recognizable at birth and remains unchanged throughout life, regardless of the challenges and achievements encountered. It is not affected by Alzheimer's or any other disease, although it may be hidden or seem lost amid so many other losses. This essence, individual personality or spirit, known by some as the soul and by others as our basic humanity, is unique to each individual and related to all others. It is by nature immutable, dignified, and worthy of the utmost respect.

It is not always easy to connect with this spiritual reality, but it can be possible. The first step is to realize this potential. The second is to allow enough time while managing the multitude demands of physical care, to be still, to be open, to let the love you have flow between you. This takes time, it takes courage, and it takes persistence. Alzheimer's patients often learn how to simply *be* long before their caregivers, most likely because they can no longer *do* much

of anything, but sometimes it is the caregiver who can initiate the process.

There are a number of keys one can try to reach this essential being. Music is often a pathway two people can use to connect. For others, quiet will be more conducive to success. The physical contact of gentle touch may bring two souls together. Laughter can often lead the way and so can tears. For the religious, praying together can open doors that might otherwise remain closed; clergy and/or lay ministers may facilitate this process if doing so alone is awkward.

Ultimately, it is a matter of taking the time to make the effort that will make such a connection possible. As cognitive and physical abilities wane, emotional and spiritual aspects can emerge from behind the masks, roles, games and other devices humans use to protect the core of their being. It is the very loss upon which we tend to focus so intently, which may actually make it possible to maintain a meaningful relationship to a loved one amid so many changes; it may even make it possible to establish a new, more authentic relationship before it is too late.



Habilitation Care

One of the last capacities to be lost with Alzheimer's disease is the person's ability to perceive emotions, to feel emotions, to respond to emotions, to express emotions, to remember an emotionally charged event. Using emotion provides one of the few remaining avenues that give us access to the person in late stage dementia.

Habilitation Therapy is a technique that has as its ultimate goal to minimize difficult symptoms associated with mid and late stage dementia and maximize the person's abilities at any stage in the course of the disease—early, middle and even late stage disease. The short-term goal of Habilitation Therapy is to bring about a positive emotion and to maintain that positive emotion over the course of the day. If you can put together a string of positive days by focusing on positive emotions, then you can keep your loved one more connected with you, the family and the world around him or her.

Although a person with later stage dementia may lose the ability to communicate with words, she remains acutely sensitive to your emotions and the emotional environment

around her. You need to be aware not only of what you are saying to her, but also what your body language is communicating to her.

Don't be upset if your loved one does not know your name or recognize you. Your body language will make her aware that you and other close family members have a special relationship that is different from the relationship with others that provide her care.

Your loved one will reflect your mood. So, always be aware of how you are affecting her behavior. Although your loved one may require total assistance with all her personal care, her compliance in accepting that care is based on your "emotional" relationship with her. All care should be based on building an emotional connection with your loved one regardless of your history with her. Each time you begin care with her, is the first time for her, because her short and long term memory is so impaired. With habilitation goals in mind, it is important not to force personal care on the person if it results in a negative emotion. The goal should be to come up with a strategy that accomplishes the goal, but avoids the negative emotion—think creatively.

Behaviors that we may interpret as disruptive or agitated are often a reaction to either the external environment that we can control, or the internal environment that indicates something is physically wrong with the person. Things like a urinary tract infection, pain, fever, hunger, dehydration, depression, sleep deprivation, among other things, are internal triggers for challenging behaviors. Internal triggers to behavior often cause sudden changes. External triggers to behavior are more likely to take more time to develop. Medical professionals should be consulted when you suspect internal triggers may be causing the behavior.

In the case of external triggers, the caregiver needs to change the approach, or change the environment around the person with dementia. The 24/7 Helpline at the Alzheimer's Association may be able to help you determine how you can change the external environment around the person—leading to better management of a challenging behavior.

The more time the person with dementia spends doing nothing with little stimulation or human contact, the more likely it is that she will decline more quickly and with more difficult behavioral symptoms. Even in later

stage disease it is important to have some kind of simple activity planned that brings the person joy and affects her emotions. That could be as simple as music, holding hands, back rubs, praying, reading aloud to her, looking at pictures, tasting favorite foods (if swallowing is not a problem), watching birds at a feeder, and so on. The goal is to bring about positive emotion.

Give Reassurance

You should try to figure out the emotional message behind the words your loved one may use. For example: “I want to go home” may tell us that because of her eroding memory and lack of purpose and meaning in her life, she feels unloved and unsafe, and not that she literally wants to go to another place. She may need reassurance that she is loved and safe, and not a logical argument that she is indeed home. Attend to the underlying emotional message, not just the literal words she is saying.

Try not to rationalize with the later stage person and explain why they cannot do something. You will only be setting up an argument. Never use the word “no”— it tends to be a trigger for emotional outbursts. Rather, try to turn the person’s attention to

something else: *You look hungry, let me get you some ice cream.*

Never try to bring the person back to our sense of reality; rather, enter into her sense of the world. For example, if she insists that your son is her husband, don't correct her. You may say something like: *My, isn't he handsome? You are so lucky to have such a wonderful husband.* We call this a therapeutic "fiblette"—a small untruth that has therapeutic value.

Keep Environment Calm

For some people in the later stages of Alzheimer's disease, it is important that the environment not be too overwhelming—too loud, too much background noise, too many conversations going on at the same time, too much clutter or, overly stimulating. Try to keep the environment calm, predictable and simple.

Do not make the mistake, as some caregivers do, that people in the later stages of Alzheimer's disease require subdued lighting. Actually, the opposite is most likely true. The person in later stages of Alzheimer's requires more light, but less glare, in order to see at the same level of acuity. The person in this later stage of Alzheimer's may lose depth percep-

tion. All but the bright primary colors are perceived as gray. The person's visual field is restricted: she may only see things when they are directly in front of her, her recognition of faces may be impaired, she may have difficulty seeing moving objects, and her visual reaction time may also be longer than normal. All these factors require the caregiver to make modifications in the home and how things are visually presented to the person.

Generally, increase the amount of light in your home without increasing the glare coming in from the outside. Use bright primary colors to draw the person's attention to things you want her to see. Be aware that it may be difficult for the person to see moving objects, or that it may take longer to react to information that you show her. Because depth perception is so impaired, the person is at risk for falls, especially on stairs. Dark colored flooring with a lighter background may be seen as a hole in the floor. Be aware of the many visual changes that occur during late stages of dementia and try to anticipate what changes in the home can help make your loved one feel more comfortable.

Legal and Ethical Considerations

Health care decision-making for families faced with later stage Alzheimer's disease carries legal and ethical considerations. Effective planning and discussion are a necessity. In Massachusetts, a Health Care Proxy is essential. In New Hampshire, a similar advanced directive or a Durable Power of Attorney should be in place.

Equally important is a meaningful discussion and understanding of your loved ones core values. You cannot impose your own personal beliefs, values, and religious doctrines. The religious views of your loved one should be respected and valued as part of the overall health care decision making.

The following questions and answers are intended as a guide for discussion with your family and with your legal advisor and an elder law attorney.

Does a Massachusetts health care proxy allow an agent (decision-maker) to make end of life decisions such as removal of tube feeding, do not resuscitate order (DNR), and other major life-sustaining decisions?

- The simple answer is yes. More difficult issues arise when an agent does not fully understand the medical condition and options for care.
- Health care proxy in Massachusetts clearly allows an agent to make life-sustaining decisions including DNR and decisions about tube feeding for food and hydration. These are sensitive and difficult issues that must be discussed in advance with physicians and your loved one.

When should DNR orders be entered and in what situations?

- A DNR (do not resuscitate order) should be in place when a diagnosis of advanced stage Alzheimer's is made. In an ideal world, the individual with Alzheimer's, and her physician, have discussed these issues in the early stage of the disease. In fact, DNR discussions cannot be initiated with the

person during the later stages, if she is unable to give an informed decision.

- DNR orders must be noted in physician records. If there are no DNR orders, and an emergency situation arises, the absence of a DNR order will lead to aggressive medical intervention.

When are guardianships needed?

- Guardianships are essential when: there is no health care proxy or substitute decision maker, no health care proxy or advanced health care proxy or similar advanced directive in place, and the person is incapacitated and unable to make decisions.

Are there ways to avoid family conflict?

- Family discussions should focus on a broad range of core values of quality of life, communication and understanding of your loved one's ability to interact with you, and specific interventions including use of CPR, food and hydration, aggressive medical interventions and end of life decision-making as to care, comfort, and palliative measures.

What is the authority of a guardian in health care matters?

- In many situations, a guardian will not have to return to court for routine health care decision making. There may be situations as the illness progresses and more invasive medical procedures are required, for which a guardian may be required to seek the authority of the court before proceeding with authorizing the treatment.
- In Massachusetts, a guardian must secure court approval for the administration of anti-psychotic medications and detailed medical treatment plans must be filed with the court, and annual reviews of the treatment plan occur. An elder law attorney can advise you on your obligations.

Can an agent under a health care proxy consent to the administration of anti-psychotic medication?

- As general rule, an agent under health care proxy does have the authority to consent to anti-psychotic medication, unless the person is objecting to or refusing the treatment plan, which in itself constitutes a revocation of the health care proxy. In

such situations, an attorney may require the court to validate the health care proxy—or it is possible guardianship may be pursued. Refusing treatment creates a difficult and sensitive situation.

What standard is used to determine if hospice care is appropriate, and if health care agents will be making end of life decisions?

- The general standard for hospice care and end of life decision making is: when such a medical condition may result in death within six months to one year. This standard does not apply to many patients diagnosed with advanced Alzheimer's disease. A medical diagnosis as to the imminence of death is difficult. Therefore, criteria involving eating, communicating, mobility, and other important cognitive issues are important to evaluate.
- No generalizations can be made as to what is in the best interest of the person and how to make appropriate decisions relative to aggressive treatment. Many agents under health care proxies are faced with the more sensitive and difficult issue of withdrawing tube feedings for food and/or hydration.

These decisions should be discussed well in advance with caretakers and primary care physicians.

- Family members should discuss such matters early on with their loved ones, and become familiar with the existing ethical and medical guidelines that apply in such situations.
- These issues should not take any family member by surprise when there is a diagnosis of advanced Alzheimer's. Families that have discussed and reflected upon these difficult issues are well equipped, at a time of crisis, to reach consensus and discuss the proper handling of such matters with their physicians, with no court or ethic committee intervention.
- Where there is disagreement, elder law attorneys can advise you as to the appropriate options to pursue to resolve conflict situations. This should be the exception not the rule.

What role if any do personal beliefs play in end of life care decision making?

- An agent under health care proxy must be guided by the principal of what in fact the person would want in such a situation. If it is not known, then the agent must act in the best interest of the patient after being fully apprised and aware of all of the medical information available as well as the prognosis and the benefit and the risks of the proposed treatment. The agent can then make an appropriate decision.





**care for the
caregiver**



Care for the Caregiver

As the caregiver, it becomes important that you take care of yourself, first and foremost. Just like a battery, if you become worn out, you're not able to function properly and do the job you're trying to do. Please remember: this is not being selfish, this is necessary for you and your loved ones.

The old saying “No man is an island” is true. None of us can do it all by ourselves. At this time, it becomes important to remember that, and reach out for help in a variety of ways.

Approaches

- When a friend or coworker asks how they can help, ask them for something concrete. Ask them to prepare a meal, shovel the driveway, bake cookies for the school bake sale, take your pet to the groomer, whatever it is you can't get to this week. Make a list as things occur to you, so you will have an answer ready when help is offered. People offer to help you because they care... allow them to help you.

- Make a list of 5 things you enjoy doing to relax. Reading a book, watching a movie, meeting a friend for coffee, having a massage, sitting in the sun, taking a bath, watching a sunset, anything you enjoy. Now, do one of those things for yourself an hour a day. You may not finish that book today, but eventually you will.
- Take good care of yourself. Eat right and get plenty of sleep. Don't forget to exercise: every little bit helps. Try to resist the lure of fast food when possible. See your doctor and dentist as usual. Get your hair cut if it needs it.
- Try to get out of the house daily, even if you are a full time caregiver at home. Find someone who could sit with your loved one for a little while. Many churches have volunteers who are willing to do this, as well as family members and close friends.

- Common signs of depression include eating too much or too little, sleeping too much or too little, and losing interest in favorite activities. If you feel like any of these are happening to you, talk to your doctor. While it may be appropriate to your situation to experience depression at this time, there's no need for you to suffer. Depression can be treated. The more you take care of yourself, the better able you will be to care for your loved one.
- As you have questions about your loved one's condition, write them down to refer to when you talk to the doctor. This will help you to remember what you wanted to ask.
- If you're the president of the PTA and a Girl Scout leader and the chairperson of a work committee, step down at least for the current time. Explain the situation as you feel comfortable sharing, and let go of that involvement.



activities



Activities

The most effective way to connect is through emotions and senses—touch, smell, taste, hearing and vision. You can also add variety to the day by moving throughout the home and using different rooms for different activities. Take your cues from your loved one. You will know quickly if the idea is a good one—is she smiling? Interested? Remember that people in the later stage have a short attention span and tire easily, so keep things short.

Ideally, you should be to try to activate all of the senses on a daily basis. Choose ways that you find are well received.

Approaches

Touch is valuable and meaningful—allowing her to feel connected and loved.

- Give a hand or foot massage with scented lotion or herbal oils.
- Collect a variety of objects—warm, cold, rough, smooth, soft, hard and have her hold and feel them.

- Soft things can be a great comfort, so consider giving her a stuffed animal, or a soft washcloth.

Smell can be lost by mid stage, but you can test whether she is able to benefit from exposure to various scents and aromas.

- Try aroma therapy— potpourri, aroma therapy diffusers, candles (burned safely), and air fresheners.
- Consider fragrances that may evoke memories—cinnamon, curry, coconut, and peppermint. Talk about them. “Scent Kits” are available with numerous scents to try.
- Bake bread, from scratch, a mix, with a bread maker, or from frozen or refrigerated doughs—on a regular basis and create the wonderful, homelike aroma of baked goods. It is restful and rewarding for both of you. Try breads that are strongly scented, like pumpkin bread or cinnamon bread.

Taste, despite the many chewing and swallowing changes that occur, can still be a way to connect. Food is central to so many traditions and fond memories for people in all cultures.

- Try foods that are her longtime favorites, and develop creative ways to still do so. This may require softening foods, making flavored puddings or making milk shakes in a blender with delicious flavors like banana or blueberry.
- Remember variety and stimulation—focus on citrus, sweet, salty and aromatic flavors.
- If the food holds special memories, talk about the memories. You can use pictures and objects while you talk.

Hearing—music and voice are a wonderful way to continue to connect.

- Keep a variety of tunes on hand from her favorites, including religious music if that is appropriate.
- Use the radio or a CD player, but be careful of volume levels especially when using an individual player with head phones.

- Conversation is important, even if she doesn't always respond. Take time to share updates on the day, the weather, the family.
- If she still converses, ask her opinion on things to let her know how valuable her input is, but avoid asking too many questions. This is not a test!

Vision and seeing things that are meaningful is so important.

- Look together at a photo album, snow falling outside, grandchildren playing or a favorite movie on the TV.
- Watch short videos that show children and family, comedy or religious services.
- When watching a TV program or movie be sure that there are no distractions in the room.
- Family photos are a wonderful way to activate long term memory—be sure that photos are labeled clearly, identify the people in the photo, the location and why it is so special.



bathing



Bathing

You do not need to give a complete sponge bath every day. You might want to consider washing the face, hands, chest, underarms, genitals and anal area daily, but giving a complete sponge bath once a week.

If he is unable to sit for the length of the sponge bath, you might need to take the washcloth and towel and follow him as he moves about the room, and wash as you go. You also could divide up the sponge bath over several days.

You can purchase rinseless shampoo and soap at a medical supply store, well-stocked pharmacy or from internet sources. It works well unless the person is extremely soiled. Then, traditional soap might work better. You can also use baby shampoo to prevent stinging if the shampoo gets into his eyes.

You might want to consider having her hair washed at the hairdresser once a week if you can get the person there, and she does well at the hairdresser.

Approaches for Bed Bath

Materials:

- Bath sheet (or large towel)
- Rubber mattress cover
- Several wash clothes
- Towel
- Basin of warm water
- Warm blanket
- Soap (rinseless soap might be easiest)
- Moisturizer
- Rinseless shampoo
- Clean clothes

Procedure:

- Make sure that the room is warm enough and that you have a table large enough for your materials within reach of the bed. You should also have a rubber mattress cover on the bed.
- Gather all of your materials.
- If you are concerned about getting the sheets wet, place a bath sheet under him. If you are going to get him out of bed after the bath, you probably do not have to worry about getting the sheets wet and can change the sheets after the bed bath.
- Wash and dry his face without soap if possible. Soap is very drying to the face. Using moisturizer can also help prevent skin from overdrying.
- Pull down the sheets and blanket and cover him with a loose (untucked) blanket.
- Take off his clothes one article at a time keeping him as covered as possible.
- Uncover one body part at a time, starting with arms, legs, and chest to wash and dry each part.

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- Turn him on his side and wash and dry his back. Apply moisturizer to the back.
- Wash and dry the perineal area, front first and then turning the person onto his side to wash and dry his bottom.
- Moisturize the arms and legs one at a time keeping him as covered up as possible.
- Put a towel under his head and wash the hair using rinseless shampoo.

Approaches for a Sponge Bath (out of bed)

Materials:

- Several washcloths
- Soap (rinseless soap may be the easiest)
- Bath sheet (or large towel—beach towels work well)
- Towels
- Basin with warm water (optional)
- Moisturizer
- Rinseless shampoo
- Clean change of clothes

Procedure:

- It is easiest to do a sponge bath in the bathroom unless he gets too agitated in the bathroom. If he gets too upset in the bathroom, choose another private room where you can set up a basin of warm water and other materials.

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- Make sure that your room is warm.
- Gather your materials. If giving the sponge bath in the bathroom, fill the sink with warm water.
- Have him sit on the toilet, on a chair, or on the side of the bed.
- Wash and dry his face with water only if possible. Soap can be drying.
- Wash hands with soap and water and dry.
- Take off his top and wrap in a bath sheet.
- Uncover each body part separately and wash and dry starting with arms and then chest and back. Moisturize the back.
- Put on a clean top.
- Take off bottom clothes and cover lap with blanket.
- Wash and dry legs and feet keeping him covered as much as possible. Apply moisturizer to the legs and feet.

- Put on pull-up or underwear, pants, socks and shoes, but leave pull-up, underwear, and pants around his ankles. Make sure to leave the shoes for last.
- Have him stand up so that you can wash and dry the perineal area. Wash the front first and then the back.
- If using an adult diaper, apply it now.
- Pull up the rest of clothes.
- Have him sit down to wash hair. Put a towel around shoulders and use the rinseless shampoo to wash the hair.



**behavior
management**



Behavior Management

Managing difficult behavior that your loved one may be exhibiting can be a daunting challenge. Behavioral changes are an expected part of this disease process, as are hallucinations and delusional thinking.

Approaches

- Never argue with a person with Alzheimer's disease. Always remind yourself that the behaviors are part of the disease process. Try to find ways to appease whatever thought processes are being exhibited by your loved one.
- It is often pointless to try to redirect or reorient a person with Alzheimer's when he is having delusional thoughts. Sometimes you need to take the ride with him. Buy into what he is saying, because to him, the altered perception of events and circumstances is reality.

- Constant reassurance that everything is all right is appropriate. Even therapeutic lying is perfectly acceptable if it helps you to interact more effectively and makes him feel safe. Soon enough, the displaced thought or feeling will pass.
- Consult your health professional if there is a sudden change in behavior or mood, as it may be a sign of a physical problem such as an infection, pain, drug interaction, lack of sleep, or dehydration.
- If you need to bend the truth to accommodate your loved one, stay as close to the truth as you can. Even later stage patients can spot a phony and reactions are often negative.



conversation



Conversation

Sometimes even simple conversation and instruction can be very frustrating to her. Her comprehension is altered due to the way that the disease affects the brain.

Approaches

- Remember to use short sentences and explanations. Too much information for someone with this disease is at times very confusing. Less is more.
- Keep it simple. Always remind yourself a person's ability to comprehend information and instructions may become significantly altered as the disease progresses.
- In time, you will learn to say a lot by saying very little.
- Try to make your body language reflect your words. If he doesn't get one, he will often get the other.



**home
safety**



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Home Safety

Home environment is part of your care giving and can aid your efforts, or cause problems, if you do not understand your loved ones needs. Set up your home environment in a way that is safe for your loved one and yourself.

Approaches

- Avoid having throw rugs around your home unless they are secured to the floors with double-sided tape or rubber matting to avoid sliding and slipping.
- Small pieces of furniture like ottomans and magazines racks may be a tripping hazard.
- Set up cues in your home for places like the bathroom or bedroom. For example, loss of perception is a common problem with Alzheimer's disease. This means that she will not be able to tell how deep, long, wide, high, near or far things are, including doors and thresholds. By simply painting a door a darker, brighter color, and keeping it closed, you could detour your loved one from entering a room unattended when you don't want her to.



**walking
transfers
positioning**



Walking/Transfers/ Positioning

Using proper body mechanics can assure that you are both safe when walking, transferring from bed to chair or onto and off of a toilet. An occupational or physical therapist can teach you how to maneuver safely and comfortably. Ten minutes with a PT/OT can save hours of trial and trauma.

Approaches

- To avoid injury to your back, never twist or rotate your upper body when assisting your loved one. Stand with your feet shoulder-width apart for good support.
- Always bend your knees while lifting and use the strength of your legs, and not your back and upper body.

- Use special tools like a “gait belt,” which you can fasten around her waist to assist you in getting her up from a chair or toilet. Hold the back of the belt firmly, with your arms around her, as if you are about to hug her at the waist. Never lift her up by pulling on her arms. It hurts and is usually resisted.
- Consider renting a Hoyer lift, available from medical equipment suppliers, to assist with lifting. Check your insurance for coverage, as it may be a covered expense.



**giving
medication**



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Giving Medication

Your doctor and pharmacist can be very helpful to you. Contact them when you have questions about medication, rather than being unsure.

Approaches

- Before handling medications, wash your hands thoroughly with soap and water.
- Keep all medications together in the same place.
- Some medications may need to be refrigerated. Keep these medications on a shelf in the refrigerator, and away from open food.
- If the pill needs to be broken in half, ask the pharmacy to break them for you. It is important that each pill be broken exactly in half, to get the right dosage.
- Any time a new medication is ordered or a current one changed, ask the following questions: Why is this being ordered? What should it do? What are the side effects?

- Try putting pills in applesauce to make pills easier to swallow. Put a tablespoon of applesauce in a small cup, and add the pills to that.
- If a pill drops on the floor, flush it down the toilet. While it might not bother you to pick it up and take it, there is greater risk of infections for him.
- Use the same pharmacy for all medications. The pharmacist will check for interactions between the medications.
- Pills require that he is alert and sitting up in order to swallow safely.
- Check with the pharmacist before crushing or having him chew a pill. Some medications will not work as intended if they are crushed/chewed.
- Keep a current list of all medications and dosages. This is important for you, your doctors and other caregivers.



**care of
the skin**



Care of the Skin

The skin's prime function is to keep the body healthy, to prevent germs and viruses from entering the body. You can easily learn to monitor the skin and how to care for it. Cleanliness is important. When she is no longer able to shower or bathe independently, you will need to provide assistance.

Approaches

- Have on hand disposable bathing wipes. Many of these products are rinseless. There are also liquid rinseless soaps you can use with your current towels and linens.
- If you've never bathed another person, a visiting nurse will be happy to show you how.
- Pay attention to knees, elbows, ankles, shoulder blades, and the tailbone area. As she loses weight, these areas become even more at risk.
- Body pillows and/or soft blankets to lean against will protect the skin.

- Dress her in loose, but not baggy, clothes. Bunched clothing can cause irritating pressure against the skin. Cotton fabrics will feel cooler and draw sweat away from the body.
- Apply lotion to the skin, especially hips, heels, elbows and bottom, to help it from becoming too dry. A gentle unscented high quality lotion is best. Lightly rub the lotion into the skin until it is absorbed. Start with a dime sized amount of lotion, warmed in your hands. You can always add more if you need it.
- Be extremely gentle when you touch or move her.
- Use soft booties to keep her heels off the bed.
- Change her position in bed or in the chair at least every two hours.
- Examine her skin daily for tears, sores or red areas.
- Measure the size of the red area with a ruler and record the size. Keep an eye on the size of the spot—if you see it getting larger call your doctor.

- Touch the skin around the red area to see if it feels “mushy.” This could be a sign that you need to call your doctor.
- Use a special ventilated mattress cover, available at most pharmacies, to help protect the skin.
- Keep your own fingernails short and filed, so you don’t catch her skin and tear or cut it by accident.



mouth care



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Mouth Care

The person in later stages of Alzheimer's may not be able to tell you when her mouth is dry or irritated. It is important to keep her mouth clean and her lips and tongue moist. A dry mouth can cause discomfort and therefore cause behavioral problems. It can also lead to infection. She may not be able to follow directions to rinse and spit, request liquids, or open her mouth wide enough to allow you to clean it. She may not understand what you are doing. Also, due to weight loss, her dentures may not fit.

Approaches

- Choose a time of day that is quiet and relaxed.
- Get all of your supplies together before you begin.
- Sit with her for a few minutes and chat and get her calm.
- Explain what you are going to do.
- Do not force her mouth open.

- Demonstrate what you want her to do by opening your mouth (you may need to do this several times).
- Position her on her side so that any fluid will run out of her mouth while brushing.
- If needed take out her dentures.
- Use an ultra soft toothbrush to gently clean her teeth, gums and tongue.
- Make sure that you use very little toothpaste and water to avoid choking.
- Apply a small amount of glycerin on her tongue to increase the amount of saliva in her mouth.
- Offer frequent small amounts of fluids, thickened if swallowing is a problem, throughout the day.
- Put lip moisturizer on her lips several times a day.



**bowel
and bladder
control**



Bowel and Bladder Control

In the end of the middle or the late stages of Alzheimer's disease, the person loses control, at least occasionally, of bowel and/or bladder. In the past, you may have taken her to the bathroom. In this later stage you will need to adjust that schedule to every hour or two in order to keep her dry.

Approaches

- Maintain an accurate/fixed schedule by recording times and if anything was produced.
- Keep in mind that if you ask “Do you need to go to the bathroom?” you most likely will always hear “no, I don't need to go.” Don't ask. Simply say come with me and lead her into the bathroom.
- Help with clothing.
- You may need to stay there and prompt her to go.

- Clean her, and again help with her clothing.
- Use a rubber or plastic cover on the mattress.
- Use adult size diapers that fit well without gapping.
- If she is in bed, you can occasionally open the diaper to bring air to her skin.
- Use a gentle soap to clean her gently.
- Use a glycerin cream on her skin.



**assistance
with
moving**



Assistance with Moving

At this stage, the brain is no longer able to send the appropriate messages to various parts of the body to maintain control. She will become unable to physically control her posture. It is common for the person's muscles to contract—tighten up. The muscles that control her arms and legs will not be able to make the joints move easily. She may be limited to a chair or to a bed. She may be unable to turn over in bed, even when prompted by you. She may lean to one side while sitting up. She will be unable to help you move her to a more comfortable position.

Sometimes an excessive amount of certain medications can cause these symptoms—and not just the stage of the disease. Sometimes, the person may experience a stroke that can cause some of these symptoms as well. You should consult your physician to rule out these causes.

Approaches

- Change her position every two hours.
- Gently rub her skin if she has areas of redness to get blood to the area.
- Rent a “geri-chair” that can be put into several positions.
- Use pillows, wedges or chucks to keep her comfortably positioned.
- Make sure that her clothing is not bunched up under her.
- Slowly and gently unbend the arms and legs and move them. Do not force the joint to move. As you do this, watch her facial expressions to make sure that you are not hurting her.
- If she can help you, stand her up two or three times a day in order to get the blood flowing and for the exercise. Move very slowly when doing this and use a gait belt. You may need to get another person to help you get her up or move her from bed to chair. You can also rent a Hoyer lift to assist you.
- Consult your doctor for medications that may help with mobility problems and reduce pain associated with muscular changes.



eating



Eating

She will lose interest in eating. She may have problems with chewing and swallowing, thus increasing the risk of choking and the risk of taking bits of food into the lung and causing pneumonia. An occupational therapist can be helpful in teaching eating techniques.

Approaches

- Make sure she is in an upright sitting position before you attempt to feed her.
- Offer foods that she can pick up with her fingers.
- If she is unable to pick up the food herself, put the food in her hand.
- If she is unable to take the food to her mouth, then using hand on hand take the food to her mouth.
- If you are unable to use this method, then hand feed her.
- Try soft foods to avoid swallowing problems.

- Use a blender to puree food if she is showing signs of not being able to swallow soft food of a normal texture.
- Demonstrate using swallowing gestures.
- Sometimes, alternating a food that is sour and cold between spoonfuls of other food will stimulate the swallowing reflex. Lemon sherbet or Italian ice works well.
- Tickle her throat when you want her to swallow.
- Thicken liquids with a product called “Thick It.” The thicker the liquid, the easier it is to swallow.
- Write down a list of foods she will eat.
- Try putting sugar or syrup on a food to see if she will eat it.
- Make sure that she has swallowed before offering her the next spoonful.
- At the end of the meal check her mouth to make sure that she isn’t pocketing food in her cheeks.
- Keep her upright for at least 30 minutes after the meal.



**weight
loss**



Weight Loss

In the later stages of Alzheimer's disease weight loss is quite common. It may in part be due to the changes in the brain that make it more difficult to figure out "how" to eat. It may also be due to the fact that the person is not able to recognize the physical signs of hunger, or it may be due to the fact that in later stages it is common to lose the sense of smell and consequently the sense of taste is greatly diminished.

In addition to all of these changes, in later stages of dementia the person burns calories faster and therefore he may lose weight steadily. To maintain weight, he may need to eat more calories. Focus on high calorie foods that he will eat without problems.

Approaches

- Plan several smaller meals over the course of the day.
- Consider using calorie supplement products that come in shakes, puddings, soups and nutrition bars.

- Add protein powder, brewer's yeast, or wheat germ to foods such as meat loaf, soups, and oatmeal.
- If he likes something, offer it several times per day.
- Depending on if there are problems with swallowing, use high calorie finger foods as snacks. Try avocado, banana, French fries, cheese, tofu strips, nuts, bacon, and candy. Again, don't worry about nutrition—think calories, calories, calories, when weight loss is a problem.
- Talk to your doctor about using vitamin and fiber supplements.
- Simple carbohydrates like candy, jams, refined sugar, syrups, bread, baked goods, and soda generally cause an increase in appetite. Try using these foods for a day or two to stimulate eating, assuming that diabetes is not a factor.
- Certain medications, including anti-depressants, can stimulate the appetite. You may want to talk to your doctor about trying a medication, if the weight loss is too substantial.

- Don't ask "would you like?" Instead, say, "I got this just for you, take a bite and tell me what you think."
- Try heavy cream with protein powder mixed in it to enhance coffee, tea or cereal.
- Too much sleep can slow down metabolic rate, so try to avoid having him sleep during the day out of boredom.



**dying
and
death**



Dying and Death

How Do You Know When the End Is Near and How Do You Prepare for It?

In most cases, the journey with Alzheimer's disease is a long one, with many ups and downs requiring you to address a number of challenging issues around the sustaining of life or prolonging of death. How do you know when the person is nearing death? How do you know how hard to push to keep the person alive? What is the process that you use to make end of life decisions?

Hopefully you have planned ahead and you talked with your loved one in some detail at an earlier stage when she was able to tell you what she wanted. Hopefully, you have also had this conversation with your family to make sure everyone was informed about your loved ones wishes, who has the health-care proxy, and the guardian's or power of attorney's plan of action long before the end of life nears.

If that has not happened, the decision maker (proxy or guardian) needs to use “substitutive judgment” meaning that you have a moral/ethical obligation to follow only what you believe to be the dying person’s wishes, even though the person may have never said to the decision-maker explicitly what she wanted. The decision-maker is morally bound to be only the voice of the person with dementia, regardless of how the decision maker feels personally about life sustaining measures. The decision-maker must honestly assess what the person with dementia would want in each situation, and then follow that course, regardless of personal or other loved ones feelings or desires. This obligation should absolve the decision-maker of guilt and minimize family conflict.

Signs That the End Is Near

- Problems with swallowing
- Resistance or refusal to eat
- Loss of weight over a sustained period
- Fewer periods of alertness or wakefulness
- Seizures
- Rigidity in the joints and contractures in the hands
- Changes in the skin—thinning and bruising
- Increased difficulty managing pressure sores
- Limited or no language and weakness in the voice
- Loss of bowel and bladder control
- Slight increase in body temperature
- Swelling in legs, face, hands
- Hallucinations
- A fixed stare

These are general benchmarks, and they do not apply in all cases. Rarely will all of these signs occur.

Things to Consider

- What would she want you to do?
- If you initiate a life sustaining intervention like a feeding tube, what quality of life will she have with it? How invasive is it? Will it cause pain? What will you gain?
- If you choose to hospitalize the person every time she has pneumonia or some other emergency, what is the trauma you may be causing her?
- What is the cost vs. benefit for the patient?
- Are you truly sustaining life or really prolonging death?

Signs of Death

The following are signs that will tell you your loved one has died. Please call your physician or hospice nurse if you have not done so already.

Check

- Absence of breathing, no heart beat. If there is any air remaining in the lungs at the time of death, it will release, possibly even a moment or two after the actual death. Many caregivers are startled by this, but it is a normal function of the body.
- Release of stool and urine. This is a normal reaction at the time of death. Often people will wear a disposable undergarment in the last hours even if they had not been wearing one before.
- While he may appear peaceful and as if he were sleeping, he will not respond to your voice or touch.

- Pupils will be fixed, staring ahead. The eyes will not blink. The eyelids may remain open after death. You may gently close the eyelids with your finger if you wish.
- The body color will become paler, and the skin will look waxy as time passes after the death. The body will also become cooler.
- The mouth may fall open.
- You may wish to stay with him until medical personnel arrive. You may wish to wait in another room. Either decision is fine. Do what you feel most comfortable doing.



grief



Grief

Grief is a natural reaction to losing someone we love. When you are providing care to your loved one prior to his or her death, it is also natural to experience what is called “anticipatory grief.” Everyone experiences grief in different ways; there is no one right way to grieve. You may hear about stages of grief, and while those do exist, don’t worry too much about them. Not everyone goes through the various stages in the same order or even does all of them.

- It’s normal to feel sad while grieving the loss of a loved one. You may not feel sad 100% of the time, however. You may have moments where you laugh, or enjoy activities, or are focused on something else for a while. That is normal.
- If your grief becomes so overwhelming that you are unable to work, or take care of yourself, please talk to your doctor.
- A lot of people talk about grief lasting for a year. Your personal experience may be longer or shorter. Again, that is normal.

- Do not be surprised if your response to his death is relief. This is normal. You have been grieving each loss for a long time. Grief may come sporadically for some time. This too is normal.
- It is often helpful to talk to a qualified professional regarding grief. A counselor, social worker, clergy member or doctor is appropriate.
- You may benefit from a grief support group.
- Some people turn to substance abuse during their grief period. Try to avoid this, and seek help if you find yourself dependent on substances.
- It is normal to question your faith during a period of grief. It may be helpful to speak with your clergy. Hospital and hospice chaplains offer non-denominational support, and may also be helpful.
- While your loved one may have had specific funeral arrangements, it may be helpful for you to have a private ritual as well. Writing a goodbye letter and burning it, tossing flowers in the ocean or a stream, or a gathering of close friends are all ways people have done this.

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