

Encouraging Comfort Care

A Guide for Families of People with Dementia
Living in Care Facilities



alzheimer's  association®
Greater Illinois Chapter

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Important Note

This booklet is intended to provide helpful information about ways to encourage and provide comfort to people with dementia. The authors and publisher are not engaged in rendering medical, health or professional services in this booklet. The reader should consult a competent health care professional before adopting any of the suggestions in this booklet. The authors and publisher specifically assume no responsibility for any outcome of applying the booklet’s contents.

This booklet is intended for families and other decision-makers of people with dementia who are living in nursing homes and other residential care facilities. We want your loved one to be comfortable and to enjoy the best possible quality of life. Although these goals are achievable, many people living in care facilities today experience varying degrees of pain — physical, emotional, and spiritual. This booklet is aimed at providing you with information to promote your loved one's comfort and to prevent or minimize discomfort by working closely with the staff of the facility and your loved one's physician. In this booklet, we have three main goals:

- To prepare you to ask questions and receive honest answers about changes which typically occur over the course of Alzheimer's disease and other forms of dementia.
- To familiarize you with principles of comfort care and your role in decisions affecting your loved one's comfort.
- To enable you to feel connected to your loved one despite changes in abilities and needs.

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What is comfort care?

Dementia refers to a number of brain diseases that slowly destroy memory and thinking skills and, eventually, the ability to carry out the simplest tasks of daily living. Although some types of dementia can be reversed, most types of dementia cannot be reversed and are incurable. The most common type of dementia is Alzheimer's disease. In most people with dementia, symptoms appear after age 65. People with dementia are often subject to burdensome medical procedures, medications, and treatments that have no positive or lasting effect and do not improve quality of life. The

Comfort care, also known as palliative care, focuses on relieving pain and other distressing symptoms including agitation, anxiety, poor appetite, loneliness, and boredom. Although a cure for dementia has not been discovered, you should never expect to hear the words, "there is nothing more we can do." In fact, there is always something that can be done to improve the comfort of someone with dementia. Comfort care is provided by professional staff and organizations with expertise in treating physical symptoms, as well as the emotional and spiritual



overall goal of comfort care is to achieve the best quality of remaining life. When there is no medical cure for a disease, comfort care is the only realistic option. Although difficult to hear and sometimes to accept, it is important to know that dementia is a terminal condition and death should be expected at some time during the advanced stages.

concerns of chronically ill individuals and their families. Comfort care can be provided anywhere – at home, in the hospital, and in residential care facilities such as nursing homes. When a person is expected to live six months or less, specialized comfort care is available through a program known as hospice.



“Cure sometimes, treat often, comfort always”

—HIPPOCRATES, THE FATHER OF MEDICINE

You have the opportunity to be an advocate for your loved one who is no longer able to speak for oneself due to dementia. As a family member or decision maker, you have the option to insist upon comfort care practices from health care providers. You must communicate for your loved one what he or she would want in the present circumstances.

This chronic illness called dementia can last anywhere from three to twenty years with an average of about five years from the start of symptoms to death. Longevity depends upon many factors, including one's age when symptoms begin. The journey of caregiving has been compared to a marathon race. Be patient and gentle with yourself. You need to learn about dementia and effective ways of coping. Although you are doing the best you can with

your knowledge, skill, and resources, you will need help from many people along this personal journey. Do not be afraid to ask for help. The staff of the Alzheimer's Association's Helpline is available 24 hours a day, 7 days a week, so you can talk about your situation. Call at any time: (800) 272.3900.

To be the best advocate requires that you take good care of yourself. Talk to a friend, a family member, or a professional counselor about your concerns. Join a local support group sponsored by the Alzheimer's Association or another organization. Be sure to exercise regularly, get enough sleep, and eat well. Do things that you enjoy each day to handle today's challenges and to prepare for the road ahead.

Facts about dementia

Learning about dementia is essential if you are to navigate through this personal journey. Dementia is a general term used to describe deterioration of the brain, whereby the person's memory, speech, and thinking, slowly decline over time. Microscopic damage to cells in key areas of the brain impairs cognitive and physical abilities for reasons that are not well understood by scientists. Brain cells are supposed to communicate with each other to coordinate these complex abilities. However, dementia gradually kills these brain cells, resulting in progressive disability. The person with dementia slowly loses independence and the ability to care for oneself.



There are different types of dementia. Some types are curable, but most types are incurable and irreversible. The most common type is Alzheimer's disease, currently affecting more than 5 million Americans. Other types of incurable dementia include: Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, and more than 50 other rare types. All types of dementia are due to brain damage but each type has its own set of symptoms that worsen over time.

Treatment options for dementia are currently limited to four medications that may slow progression. Drugs approved for the treatment of Alzheimer's disease include (Aricept) rivastigmine (Exelon), galantamine (Razadyne), and memantine (Namenda). These drugs are commonly prescribed for other forms of dementia too. These anti-dementia drugs are not effective in all cases and may cause side effects such as nausea, diarrhea, and insomnia.

Many people with dementia eventually die from other conditions such as heart disease, cancer or stroke. In the absence of one of these life-threatening conditions, dementia ultimately causes death. Today, Alzheimer's disease is the fourth leading cause of death among older Americans. Among those who survive to the advanced stages of dementia and require full-time care, the vast majority live in nursing homes, while others live in other residential care facilities or in private homes.

The rate of progression seen in dementia varies from person to person. Some people decline to the point of needing full-time care within a few years, whereas others may be mildly impaired and need partial assistance for five or more years. Symptoms of dementia also vary from person to person, although forgetfulness about recent events is the hallmark symptom. Every person with dementia is unique but it is helpful

to know the typical course of dementia over time so you are better prepared to face the challenges ahead.

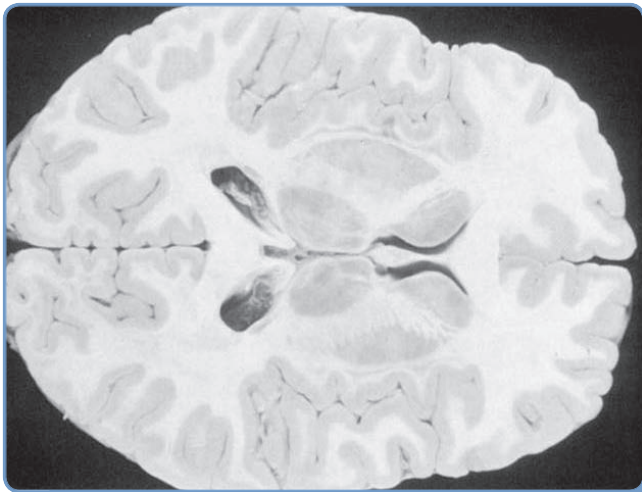
For the sake of simplicity, the course of dementia can be divided among four stages: early, middle, late, and final. Symptoms fluctuate and stages often overlap, so the following charts should be considered rough “road maps.”

Changes in Memory, Thinking, Language and Mood			
Early Stage	Middle Stage	Late Stage	Final Stage
Memory and Thinking Skills			
<ul style="list-style-type: none"> • Difficulty with short-term memory • Loses things • Poor attention • Difficulty with calculations and organizational skills 	<ul style="list-style-type: none"> • Difficulty with short-term and long-term memory • Forgets parts of one’s history • Has trouble solving simple problems • Becomes disoriented easily 	<ul style="list-style-type: none"> • Mixes up recent and past events • Forgets friends and relatives • Cannot follow a two-step command 	<ul style="list-style-type: none"> • No apparent awareness of past or future
Language			
<ul style="list-style-type: none"> • Trouble finding words or names • Repeats statements or questions 	<ul style="list-style-type: none"> • Has trouble tracking conversations • Has difficulty forming complete sentences 	<ul style="list-style-type: none"> • Unable to carry on a meaningful conversation • Words and sentences often disconnected 	<ul style="list-style-type: none"> • Cannot speak or uses only a few words
Behavior/Mood			
<ul style="list-style-type: none"> • May become depressed, withdrawn, or irritable 	<ul style="list-style-type: none"> • More easily upset or withdrawn 	<ul style="list-style-type: none"> • May express unmet needs by yelling/calling out • Difficult to engage 	<ul style="list-style-type: none"> • Severe decline in ability to show emotion

Changes in Ability to Care for Oneself			
Early Stage	Middle Stage	Late Stage	Final Stage
<ul style="list-style-type: none"> • Needs help with household affairs such as cooking and paying bills • Trouble managing money and medications • May get lost or confused when driving 	<ul style="list-style-type: none"> • Needs reminders or practical help with personal care • Slowed walking and reaction time • No longer safe to drive • Fatigues easily 	<ul style="list-style-type: none"> • Needs constant reminders or practical help with personal care • Loss of control of bowel and bladder • Trouble with balance and coordination • Sleeps often 	<ul style="list-style-type: none"> • Needs total assistance with personal care • Unable to walk and shows little movement • Poor appetite and has swallowing problems • Sleeps most of time

While these charts are helpful in understanding changes commonly seen in dementia, it is also helpful to see the physical damage to the brain. A healthy, normal brain typically contains about 40 billion cells and weighs about three pounds. The following photo is a cross-section of a normal brain. The darkest section in the middle of the photo shows the brain's ventricles, cavities that allow for the flow of spinal fluid and blood.

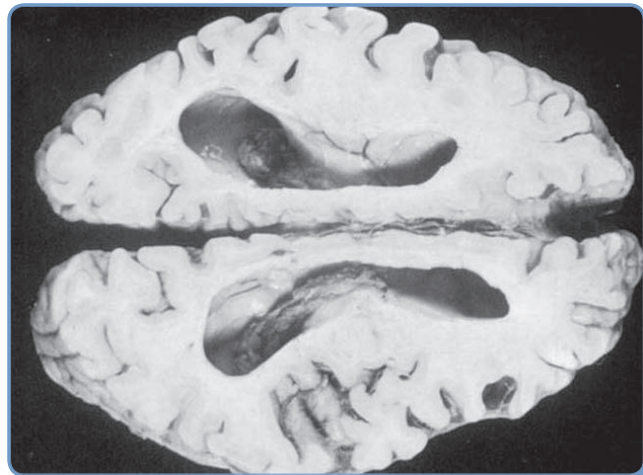
Cross Section of a Normal Brain



These two photos are used with permission by Duke University Medical Center and *Care of Alzheimer's Patients: A Manual for Nursing Home Staff* by Lisa P. Gwyther

The next photo shows a cross-section of a brain in the final stages of Alzheimer's disease. Early in the disease the damage to the brain occurs at a microscopic level. The damage becomes visible as more and more brain cells are killed off for reasons that are not yet understood. As Alzheimer's disease progresses over time, significant damage to key parts of the brain accounts for worsening memory, thinking, language, and behavior. As you can see, the ventricles or cavities are much bigger than in the other photo, evidence that millions of cells have died throughout the brain. Over time, the brain lost roughly a third of its size and weight. The person with dementia may "look the same" from the outside, but many destructive changes occur inside the brain. These changes in the brain result in the loss of memory, thinking, language, and self-care skills.

Cross Section of a Brain Severely Damaged by Alzheimer's Disease



Caring for someone with dementia is time consuming and stressful for families. As the person with dementia becomes increasingly dependent on others for 24-hour care, most families consider moving a loved one to a residential care facility. Families often must consider this major decision for the sake of a loved one's need for safety, supervision, and assistance with toileting, bathing, eating, and dressing. Approximately 90 percent of persons who reach the late and final stages of dementia live in residential care facilities, primarily nursing homes. Residential care facilities typically employ three shifts of staff, including nurses who are skilled and experienced in meeting the complex needs of people with dementia.

Historically, nursing homes were created for individuals who required rehabilitation following hospitalization and were expected to return to their private homes. Today more than two-thirds of nursing home residents have dementia and more than half of residents in assisted living facilities have dementia. Such facilities are likely to be the final home for these individuals. Most facilities today, especially nursing homes, are still based on the traditional hospital model, whereby the environment, daily schedules and routines revolve around the need for efficiency by

staff members. Residents with dementia are often viewed as patients within an institution rather than as residents within their homes. Medical problems are usually treated aggressively with medications, procedures, tests, and hospitalizations.

A growing number of residential care facilities are moving away from this traditional approach to a new approach that puts the individual's needs before the needs of staff. Institutions are being turned into homes in which medical needs are on par with the emotional, social, and spiritual needs of residents. Instead of everyone eating meals at the same time every day, residents are free to eat when they prefer, eat foods they prefer, and have snacks available at all times. In this nurturing environment, staff members engage residents in meaningful activities and leisure opportunities. Families are treated like true partners in care and have a strong voice in decisions affecting their loved ones. Aggressive medical care is replaced with a comfort care approach to medical problems in order to enhance each person's quality of life.



Now that your loved one lives in a nursing home or another residential care facility, your main role is to ensure his or her comfort. Staff members who are truly devoted to comfort care can be expected to abide by certain principles of care. Keep in mind that the following six principles represent goals that better facilities take seriously and put into practice. We encourage you to talk about these principles with the leadership team at the facility where your loved one resides.

Principle #1 Staff members anticipate the needs of people with dementia. Those with dementia need help with the most basic tasks that you and I take for granted. In simplest terms, anticipating their needs means offering food and fluids before hunger and thirst develop, managing pain before it is out of control, helping someone rest before fatigued, and engaging someone in pleasant activities before boredom and loneliness set in. Staff members carefully listen and observe to ensure the well-being of residents in their care.

Principle #2 Staff members know each person so well that basic needs never become major problems. Knowing each person refers to being knowledgeable about an individual's important life events, family members and friends as well as one's current interests and preferences. For example, the person with dementia may like to drink a particular type of tea or may like to listen to a favorite type of music. To know the person well means that staff members know exactly how to make someone comfortable. People with fading memories need others to hold on to their stories and history. You can help to preserve your loved one's sense of "self" by sharing his or her life history, proud moments, and accomplishments. Write down some personal facts or a brief story about your loved one's life and place this information in a visible location in his or her room. Such information will enable staff to better communicate with your loved one, personalize care, and form a closer relationship.

Principle #3 Staff members embrace the philosophy of "person-directed care." This describes a style of care suited to the needs of each person rather than routines and activities imposed by the organization. The comfort of each person is everyone's primary concern. For example, each person can awaken naturally rather than be awakened for medications or breakfast and can eat meals and snacks whenever preferred. Staff efficiency and schedules take a backseat to one's personal likes and dislikes. Moreover, care is organized around supporting existing abilities instead of focusing on the person's impairments. Individuals with dementia are referred to as "residents" or "elders" living in their home rather than dementia patients staying in a hospital. In a person-directed environment, dignified language is used to describe residents instead of dehumanizing labels such as "wanderers" and "feeders." The person's individuality and dignity always come first, ahead of one's diagnosis.

Principle #4 Staff members use a "soft approach." The manner in which people with dementia are approached by staff members through language and actions is a major part of comfort care. A "soft approach" refers to adapting one's pace to suit the needs of people with dementia whose memories, language, and thinking abilities have diminished. A soft approach involves using verbal and non-verbal ways to promote communication, decrease frustration, and increase a sense of trust and safety in your loved one. For example, staff members do not see care as just a set of tasks to be accomplished quickly. Instead, they see every interaction as an opportunity to encourage independence and to engage in a relationship.

A soft approach means that staff members use expert communications skills – listening and speaking carefully to make sure that messages are sent and received by people whose communications skills are diminishing. Staff members know the importance of approaching everyone with dementia from the front and using each person's preferred name. They make eye contact and use gentle touch to gain each person's attention.

They use a calm, friendly demeanor to ask residents for their help and opinions giving them two choices. Staff members use simple, concrete language and gestures to convey a message. They respond to the tone or feelings rather than the words that may be garbled. They understand how useless it is to correct or argue with someone with dementia. Instead, they use every means necessary to connect with each person in a meaningful manner. A soft approach means knowing how to use touch to comfort someone or how to distract someone who is anxious or agitated.

Principle #5 Staff members recognize and treat pain aggressively. Pain is common among older adults for a variety of reasons including arthritis, infections, headaches, poor circulation, heartburn, constipation, dental decay, pressure sores, and limited ability to move or turn. Unrecognized and untreated pain can have terrible effects on the mind, body, emotions and spirit of anyone – but pain has added negative effects on people with dementia. They often lack the ability to identify painful body parts or ask for help. They may no longer be able to respond to the question – are you in pain? They may communicate their distress through aggressive behaviors or other unpleasant ways such as crying, screaming, and moaning. They may become withdrawn, lose their appetite, sleep more often, stop walking or talking, and become more likely to fall. If you observe these changes, notify the nursing staff that pain may be the root cause. These changes do not indicate a worsening of dementia.

All nursing homes must use standardized forms to assess pain among residents. The Pain Assessment in Advanced Dementia (PainAD) scale is one such form that should be used because it relies on observations of behaviors instead of statements by people with dementia. Staff members look for levels of distress in terms of breathing, language (vocalization), facial expressions, body language and the ability to be comforted or consoled by another person. Be sure to ask about this form and how it can be used to assess potential pain in your loved one.

If pain is still a problem after basic physical needs such as hunger, thirst, toileting, and positioning have been addressed, other steps should be taken to relieve discomfort. First, the nurse should contact the physician or nurse practitioner about starting a regularly scheduled medication for pain relief or changing the dosage or type of pain medicine already being used. People who are in pain may require a variety of different medications to produce comfort. Persons with high levels of pain require medications strong enough to stop the pain sensation – medications made with morphine can be very effective in controlling pain. Do not be concerned about your loved one becoming “addicted” to pain medication. It does not happen among people with dementia.

Non-drug interventions may provide pain relief in addition to medications. Simple things like repositioning the body, applying ice or heat packs, offering favorite snacks, giving massages, and praying or singing with the person can ease discomfort. Let the staff know if you have discovered some activity that brings relief to your loved one.

Principle #6 Staff members recognize you as a true partner in care. Relatives and friends provide valuable information about the individual’s needs, history, values, beliefs and interests. You should be encouraged to work with care staff to assist in creating a positive caring environment. You should receive ample notice to take part in scheduled care plan meetings where your questions and concerns can be addressed.

In addition, at care plan meetings staff members should initiate discussion about medical decisions that you need to know about. You can benefit from the knowledge and experience of staff members who have cared for countless people with dementia. They understand the natural decline over time to the point of death, and they also know about the perils of aggressive medical care that can cause much discomfort.

Medical decisions you may face

You should not be surprised as memory, thinking, language, and physical abilities worsen due to dementia. This is simply the nature of dementia—it gets worse in spite of our best efforts. Knowing these changes are inevitable may better prepare you for common questions you may face including:

- *Should someone with dementia be hospitalized for an acute medical problem such as pneumonia or urinary tract infection?*
- *Should antibiotics be used in all cases of infection?*
- *Should screening tests be done?*
- *Should the person with dementia be treated with psychotropic medication?*
- *Should artificial nutrition be given if the person with dementia can no longer swallow food or fluids?*
- *Should cardiopulmonary resuscitation (CPR) be allowed if breathing or the heart stops?*
- *When should hospice be considered?*

You may be asked to make medical decisions on behalf of the person with dementia. Some common decisions will be discussed here but always discuss the risks and benefits of medical treatments with the physician and nurses.

Hospitalization

When people in the late and final stages are hospitalized, they can be severely stressed by the experience. A new environment and routine, unfamiliar faces, combined with painful needle sticks, invasive testing, forced bedrest, and new medications may escalate fear and anxiety. These factors can lead to increased confusion and combative behaviors. In an effort to keep the person “safe” and free from falling, sedatives and physical restraints are often initiated. Research indicates that restraints do not keep people entirely safe. In fact, restraints can trigger agitation, anger, despair, skin tears, and falls.

As an advocate, you can have a conversation with the physician and the facility’s staff about avoiding hospitalization. Some acute medical problems such as urinary tract infections can be treated better in the care facility rather than the hospital where confusion may be increased. Identify situations that might ordinarily warrant hospitalization and discuss alternatives. Look at the overall picture with the goal of comfort in mind.

Screening Tests

Medicare helps pay for many preventive services and screening tests. For example, bone density measurements can determine one’s risk for a broken bone, a blood test can determine a man’s risk for prostate cancer, and a mammogram can detect breast cancer. You have a right to know about the value of these tests for your loved one. If indeed a mammogram revealed a breast tumor, would it be appropriate to conduct a biopsy, surgery, or chemotherapy? Someone with advanced dementia is not likely to benefit from these tests or the treatments that may follow. Discuss the need for these tests with the physician or another healthcare provider.

Medications

The effectiveness of any medication should always be carefully evaluated and potential side effects should be closely watched too. For example, the four anti-dementia drugs mentioned earlier are not always effective in slowing down progression of dementia. It is often difficult to tell if indeed these drugs are showing any benefit and their side effects can be unpleasant. By the late and final stages of dementia, you and the physician should discuss the benefits and risks of these drugs.

Behavioral disturbances associated with dementia such as resistance to care, hitting, screaming, and wandering are challenging and distressing to family members, staff, and the person with dementia.

Currently, there are no medications approved by the U.S. Food & Drug Administration to treat these behaviors. However, it is common for a variety of medications known as psychotropics to be administered with the intent of reducing behavioral disturbances. Although these drugs may be effective in some cases, there can be many harmful side effects and safety risks associated with these medications, including stroke and sudden death. Types and brand names of commonly prescribed medications include:

Antipsychotics	Benzodiazepines
Abilify	Ativan
Geodon	Klonopin
Haldol	Restoril
Risperadal	Xanax
Seroquel	
Zyprexa	
	Sedatives/Hypnotics
	Ambien
	Desyrel
	Lunesta
	Sonata

Nursing home regulations dictate that legal decision-makers must give their written consent before psychotropic medications may be administered. Before agreeing with the staff to use these medications, first find out if the staff has looked hard for pain and provided prompt and effective pain medication. Undetected pain and poorly treated pain are major reasons for people with dementia to experience agitated behaviors. These behaviors are common ways in which people with dementia communicate their discomfort, rather than using language that may now be impaired. Psychotropic medications should only be considered after pain has been ruled out and other non-medical strategies have been used to reduce agitated behaviors. This “rule of thumb” is the official position of the Alzheimer’s Association.

Check out the Association’s website for further details at: www.alz.org

The following medical treatments were initially developed to extend life in persons with conditions that could be healed or improved. They were not intended to prolong life indefinitely. It is good to become familiar with them, as you may be asked to consider them for your loved one. Health care providers often wish to use these treatments without considering the potentially harmful effects in a terminal condition like dementia.

Artificial Nutrition and Hydration

People in the late and final stages of dementia often lose their appetite, lose weight, and experience swallowing problems. When the person in the advanced stage of dementia loses the ability to swallow, this change can mark the beginning of the dying phase. Forcing someone to eat food can cause the person to choke or aspirate. Forcing fluids through intravenous therapy may also result in swelling (edema) of the legs and difficulty breathing. Eating difficulties may raise questions about prolonging life through artificial nutrition and hydration – receiving food and fluids through a tube surgically placed into the stomach. This tube is also known as a gastric or G-tube.

At this time, you have the option of offering small amounts of soft, favorite foods. The goal is to offer pleasure through taste and smell, rather than a sufficient number of calories. For example, you can offer a teaspoon of chocolate ice cream or vanilla pudding every few hours. Just a taste can be pleasurable.

Your loved one will not “starve to death,” without artificial hydration and nutrition. As a result of dementia, body functions are naturally slowing down and no longer require additional calories or liquids. Comfort can be maintained by frequently swabbing the mouth with water and lubricating the lips. Avoid drying solutions such as lemon glycerin swabs and

alcohol based mouth washes. Alternately, swab the mouth with pineapple juice or place drops of honey or chocolate on the tongue for a more pleasurable taste. Pain medications may continue by mouth or may be changed to other forms such as small drops of liquid under the tongue, patches on the skin or rectal suppositories.

In the “best case” scenario, people have the opportunity to state in writing in advance of a disability whether or not they prefer a treatment. Unfortunately, many people do not declare their preferences beforehand, also known as “advance directives.” If you are the Power of Attorney for Health Care, think back about any previous conversations you may have had with the person with dementia regarding artificial nutrition and hydration or about the use of a feeding tube.

Cardiopulmonary Resuscitation

Normally, when someone suffers a heart attack, also known as a cardiac arrest, a procedure known as cardiopulmonary resuscitation (CPR) is initiated. An attempt is made to “jump-start” the heart with an electrical impulse, or rhythmically pushing on the breastbone to restore the heart to its normal rhythm. Because most persons with dementia are old and frail, the ribs are prone to breaking in this process.

In specific medical crises, CPR can help to save a person’s life. However, in persons with terminal or life-limiting illnesses, CPR is never helpful. In a hospital or residential care facility, unless there is a written order not to resuscitate, CPR will be given. If cardiac arrest occurs and paramedics are called, CPR will always be initiated unless a physician’s order known as “Do Not Resuscitate” has been written. Those who receive CPR are often put on mechanical ventilators, or breathing machines. These machines breathe for them, forcing air into the lungs. People are immediately transferred to the nearest hospital and placed in an intensive care unit.

Antibiotics

Antibiotic drugs have become a cornerstone of modern medicine. They are commonly given to treat bladder infections or pneumonia. Such infections are a common and almost inevitable consequence of advanced dementia due to reduced immune response, incontinence, swallowing difficulties, and immobility. However, the use of antibiotics should be carefully considered in terminal conditions. For example, pneumonia used to be called “the old person’s friend” because it triggered death. Today, pneumonia can be effectively treated with antibiotics. But if a person is close to death, is the use of antibiotics the best thing to do? For persons nearing the end of life, symptoms of an infection may be effectively managed for comfort without the use of antibiotics.

Comfort as the Goal of Care

In a comfort care approach, options must be carefully considered with each decision. Both the benefits and burdens of treatment and non-treatment should be discussed so that comfort of the person with dementia is the key to every decision. For example, is it necessary to continue administering all medications and over-the-counter drugs such as multivitamins? Comfort should be the ultimate goal and every effort should be made to avoid distress of any kind.

Decisions about CPR, hospitalization, antibiotics, and artificial nutrition must often be made on behalf of someone with advanced dementia. We turn now to the scientific evidence about the impact of these medical interventions so that you are better equipped to make informed decisions about their use.

Aggressive medical treatment that has traditionally been used with the goal of curing is often inappropriate for people with dementia for many reasons. In 2005, the Alzheimer's Association commissioned Dr. Ladislav Volicer to review all of the available research documents about medical treatments performed on people with advanced dementia. His review of the existing research studies revealed the limits of common medical treatments:

- *Cardiopulmonary resuscitation (CPR) is three times less likely to be successful in a person with dementia than in one who is cognitively intact. Those who initially survive CPR are taken to an intensive care unit of a hospital where most die within 24 hours.*
- *Hospitalization is more likely to occur among individuals with advanced dementia than those who are cognitively intact or have milder dementia. Those who are admitted to hospitals are at risk for poor outcomes such as changes in behavior, loss of appetite, incontinence and falls that are often managed by aggressive medical interventions. Although the most common cause of hospitalization is infection, most often pneumonia, hospitalization is not necessary for optimal treatment. Immediate survival and mortality rates are similar whether treatment is provided in a long-term care facility or a hospital.*
- *Antibiotic therapy does not prolong life and is not necessary for symptom control. When antibiotics are used, they may cause significant harmful effects, and the diagnostic procedures associated with use of antibiotics add to the resident's confusion and discomfort.*
- *Artificial nutrition through gastric tube feeding does not prolong life nor does it prevent pneumonia, malnutrition or pressure ulcers. Tube feeding also does not reduce the risk of infections or improve one's comfort.*

Decisions to allow CPR, hospitalization, antibiotics or artificial nutrition must ultimately be based upon your loved one's wishes. If his or her preferences about these treatments were not previously declared, you may be asked to make decisions about such treatments based on your personal knowledge of one's past values and best interests.

Who decides?

Aggressive medical care is still customary in most residential care facilities today, especially among people with dementia who rarely have a voice in decisions affecting their care. Many families and other decision makers may think they have no voice in decisions affecting their loved one's care. However, this should never be the case. Everyone with dementia deserves to have an advocate to represent one's best interests. The question of exactly who is legally authorized to speak in behalf of someone with dementia may not be clear.

In some cases, a family may reach a consensus about medical decisions on behalf of a loved one, or there may be a particular individual within the family who is seen as the chief decision maker. This informal arrangement for making decisions may be sufficient for some physicians and other health care professionals. However, what if there is disagreement within the family or what if the authority used by a particular individual is seen by others as harmful?

It is best if the person with dementia has appointed a trusted person in advance of incapacity to be Power of Attorney for Health Care. This trusted person is legally empowered to make medical decisions on behalf of the person with dementia. The Power of Attorney for Health Care includes advanced directives to help guide the legal representative to make medical decisions. The advanced directives tell health care providers whether and to what degree life prolonging interventions such

as CPR should be used. Advance directives also specify who is to be the decision maker on behalf of the person with dementia.

Hopefully, your loved one has already identified a person as the Power of Attorney for Health Care and completed a set of advanced directives to ensure that his or her medical preferences are carried out. If Power of Attorney was not determined in advance, the person with advanced dementia no longer possesses the mental capacity to appoint someone to this responsibility. In this case, the court process known as guardianship may be necessary to determine who will be the legal representative with respect to medical decisions. Some states, including Illinois allow for legal decision makers to be identified without this court process.

If you are the legal decision maker for someone with dementia, here are some questions to consider when making decisions:

- *Did your loved one previously express any opinions about the use of breathing machines or feeding tubes to treat people with chronic or acute illnesses?*
- *If your loved one was now standing at the foot of the bed and observing oneself as the subject of certain medical decisions, what would she or he have to say?*
- *Is life to be extended at all costs through artificial means, or is the quality of one's life more important?*

How to create meaningful and enjoyable visits

Research is informing us that one of the best ways to “connect” with persons who are no longer able to talk or care for themselves is through their five senses: taste, touch, sight, smell, and hearing. The smell of warm apple pie, the taste of chocolate, or the sound of familiar hymns can tap into long-term memories. The memories can recreate pleasant sensations in the

present time. Family and friends often grow more unsure and frustrated as their loved one becomes more impaired and seemingly more distant. Some family and friends talk about not knowing what to “do” during this time because the loved one's memory, thinking and language may be so difficult to understand. Some wonder if visiting is even useful.

In her memoir, Rita Bresnahan writes about moments of grace and possibility in the midst of her mother's Alzheimer's disease. Rather than taking a pessimistic view that her mother was already "gone," she chose to see her mother as very much alive, although quite changed. When other people asked if her mother still knew her, she would reply, "It is not Mom who must remember who I am. Rather it is I who must remember who my mother is. Who she truly is. Not merely 'an Alzheimer's patient.' Not merely 'my mother.'" Rita Bresnahan learned to have meaningful visits with her mother by adopting a new point of view about her relationship with her mother. She was able to enter her mother's world and accept her mother's changed condition.

Learning to sit in silence and use the five senses during visits takes practice—it does not seem natural at first. A new kind of relationship may be what your loved one needs at this time. Your visits may actually be very meaningful for your loved one—and for you. In her memoir, Ann Davidson writes about visits with her husband with Alzheimer's disease living in a care facility: "Whatever song I begin, Julian quickly hums the tune. If I abandon expectations of meaningful exchange, and don't sink into the greater gloom of all that has been lost, these moments feel fine. Emotional connection is what I value most in friendships, and it's amazing how, in our odd little way, we have this still."

Think about how to work with the five senses – one at a time, to recreate memories with something that your loved one enjoyed in the past and may still enjoy now. Your one-to-one activity may last for just 5 to 15 minutes, but it will be quality time. Is it the enjoyment of singing a song together, listening to jazz, classical or gospel music, or just eating a piece of apple pie? Watch for signs of pleasure in facial expressions or sounds.



"If this moment will mean nothing to me later, it means everything to me right now."

—A PERSON WITH ALZHEIMER'S DISEASE, AS QUOTED IN
THE ENDURING SELF IN ALZHEIMER'S DISEASE

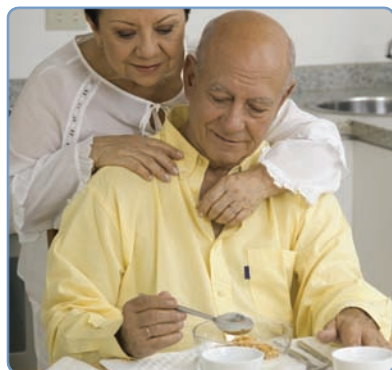
Other ideas for evoking memories or enjoying your time together include:

- *Massage hands or feet with body lotion*
- *Brush his or her hair*
- *Look at a colorful book or pictures*
- *Say favorite prayers or poems*
- *Sing familiar songs*
- *Introduce favorite smells: cinnamon, fresh grass, Old Spice cologne, White Shoulders Perfume, fresh baked cookies, and flowers*
- *Hold a cuddly pet like a cat or dog*
- *Hold hands and just be together*
- *Go outside to enjoy the air, the sunshine and the rest of nature*

One of the most meaningful ways to connect with your loved one is to create a "Comfort Care Kit." This can be a bag or basket filled with your loved one's favorite things that can be used by you, other visitors, and staff members to stimulate the senses. Label the bag or basket and include personalized items such as a music CD, body lotion, pictures, cologne, different textures of cloth, and religious articles.

Meals are not only times for getting proper nutrition, but for personal enjoyment, too. People with dementia often have difficulty using utensils, chewing, and focusing on the task at hand. Swallowing food and liquids may also become a problem as muscles and nerves that are used to swallow may become weak over time. People in the advanced stages of dementia are more likely to maintain weight if they are provided foods that they enjoy along with smaller, frequent snacks throughout the day. Thickened liquids may also be easier to drink than liquids like milk and water. The goal is to offer food and liquids that your loved one can safely manage and find tasteful, instead of providing a balanced diet.

Many people with dementia prefer soft and sweet foods when swallowing becomes challenging. Diets that restrict sodium and fat levels are generally not appetizing. The American Dietetic Association endorses “liberalized” diets for people with advanced dementia. In other words, restricted diets for people with conditions like diabetes, heart disease, and high blood pressure should no longer be considered. A liberalized diet including one’s favorite foods may increase food and fluid intake and improve enjoyment too. Talk to the primary physician about ordering a liberalized diet. With improved taste and frequent offerings of meals and snacks, liquid supplements or pills that are intended to help with the appetite can be avoided.



Soft food and drink ideas:

- *Yogurt*
- *Fruit smoothies*
- *Milkshakes*
- *Chocolates*
- *Peanut butter and jelly sandwiches*
- *Cheeses*
- *Vegetable juices*
- *Donuts*
- *Mashed potatoes and gravy*
- *Pizza*
- *Breakfast bars*

The dining environment plays a big role in encouraging a person to eat. Is it home-like and quiet? Remove distractions like a noisy television so that your loved one can concentrate on eating. If he or she uses a wheelchair, transfer into a chair with arms if possible. Soft, familiar music can play in the background. If food is delivered on a tray, remove plates and utensils so there are visual reminders that this is indeed mealtime. Assist your loved one in eating by offering one food at a time, keeping in mind the “accept and swallow” approach. If your loved one spits it out, offer something else. Helping someone to eat and drink is an intimate experience. See this shared time as an opportunity for a meaningful personal connection.

The inability to chew and swallow effectively is a sign that dementia has progressed to the final stages. The brain can no longer direct the mouth, tongue, and the esophagus to chew and swallow properly. This is the time to consider your loved one’s end-of-life wishes and to enroll him or her in hospice care. This is the time to change the form of nourishment from food and fluid to nourishment for the emotions and spirit. There are other ways to show your love and commitment.

Hospice continues the comfort care approach for persons with a short life expectancy. Hospice refers to a specialized program of care by healthcare professionals and volunteers with experience and expertise in enabling terminally ill people to die comfortably and in assisting families to cope with the loss. Individuals may be enrolled in hospice if one's primary physician and the hospice's physician agree that the person has a remaining life expectancy of six months or less. For persons with dementia, the following signs and symptoms must be present to meet hospice criteria:

- *Unable to walk without assistance*
- *Unable to dress without assistance*
- *Unable to bathe without assistance*
- *Loss of control over bowel and bladder*
- *No meaningful verbal communication or the ability to speak is limited to six or fewer intelligible words*

In addition, one of the following conditions must have been experienced within the past 12 months:

- *Inhaling food or liquid into the lungs – called aspiration pneumonia*
- *Kidney infection or other upper urinary tract infection*
- *Blood infection known as septicemia*
- *Multiple skin pressure or bed sores*
- *Fever that recurs after antibiotic therapy*
- *Inability to maintain sufficient fluid and calorie intake, with 10 percent weight loss during the previous six months*

Hospice team members include social workers, nurses, chaplains, physicians, nursing assistants/aides, volunteers, and bereavement counselors. Hospice care is provided in the person's home, whether that is a private residence or a residential care facility. Hospice care may also be provided in freestanding hospice centers and hospitals. Hospice providers are not intended to



substitute for the facility's care or staff. Hospice and facility staff members are intended to work together to provide additional care and expertise. For example, a nursing assistant from a hospice may spend her entire visit bathing, grooming and providing tailored care to your loved one. Hospice's expertise in managing pain and other symptoms will enable you and the facility's staff to keep your loved one comfortable.

Some hospices also offer complementary and alternative therapies such as music therapy, massage therapy, aromatherapy, acupuncture, and therapeutic touch. These therapies may relieve distressing symptoms and promote comfort. During and following the death of your loved one, hospice staff members offer counseling and grief support to the family. The many services provided by hospice are funded by Medicare and other types of insurance.

Families, nurses, social workers, and physicians can make a referral to a hospice. Not all hospices are the same so you should be offered a choice of several hospice organizations in order to make the best choice. Ask for visits by hospice representatives and make a decision based on their services, responsiveness, and recommendations by others. Be sure to discuss advanced directives and funeral arrangements before you make a final decision.

If you decide to use the services of hospice, it is better to begin sooner rather than later so that your family can benefit from all of the services. Unfortunately, hospice is often called in too late so be sure to raise the topic with the physician and the facility's staff. If you wait until your loved one is actively dying in the final days or weeks, it may seem overwhelming to introduce additional caregivers at this critical time. Signs of active dying include:

- *Loss of appetite and ability to swallow*
- *Decreased urine output*
- *Less responsive and sleeps most of the time*
- *Pain may be evident*
- *Increasing weakness*
- *Loss of ability to close the eyes*
- *Breathing changes – can fluctuate between slow and labored, quick and shallow*
- *Skin becomes cooler and blotchy in the feet and hands*

When a person with dementia stops swallowing, the body is telling us that it is slowing down. Kidney function starts to slow down too. The body no longer requires food or fluid nor do dying people complain of hunger or thirst. Although some family members and friends wish to be present at the moment of death, it is difficult to sit vigil or for long periods of time without any relief. Invite other family members and friends to visit with you. Ask for food and drink to be on hand for everyone to share. Invite one's own priest, rabbi, minister or other pastoral care member to visit too.

Assume that your loved one can hear everything that is said. Speak in a gentle and loving tone and share your thoughts and feelings. Sing favorite hymns, play soothing music, and recite favorite poetry or prayers. Your loved one can also be comforted by offering a gentle massage, frequent repositioning of the body,

and by administering pain medications through suppositories or medications absorbed under the tongue. Also, frequent mouth care is important for avoiding discomfort, so ask the nurse for useful tips to keep the mouth clean and fresh.

In the birthing process, special rooms and rituals are often used to mark the entrance into the world. The transition out of the world can be made just as meaningful for everyone involved by acknowledging the loss, recounting memories and celebrating the dying person's life. During this special time:

- *Obtain a private room if possible.*
- *Place chairs near the bed for visitors.*
- *Put pictures, flowers, or religious objects on the bedside table.*
- *Place a sign on the door to indicate the significance of this time and to make known the need for privacy and quiet.*
- *Face the bed toward the window if it is not too bright. Reduce bright lights. If the weather is nice, open a window if possible.*
- *Spray the pillow or room with the person's favorite scent.*

Funeral arrangements should be discussed with the facility's staff well in advance of death. Likewise, what you expect to occur at the time of death should be discussed. Let staff know if it is important for you to be at the bedside at the moment of death, however it is not always possible. For this reason, say goodbye whenever you leave the room.

People who are dying may look alert and responsive temporarily. This type of up and down is normal, making the time of death unpredictable. Death has occurred when breathing ceases, there is no pulse, the pupils are fixed and dilated, and the jaw is relaxed and slightly open. At the time of death, spend as much time as you need with your deceased loved one. Depending on your faith tradition and level of



comfort, some people help with cleansing and dressing the body. Follow your religious rituals as appropriate. If other family members are present, allow time for goodbyes by everyone. Invite staff members who cared for your loved one to join the family for a short ceremony at the bedside.

If the body is to be transferred directly to the funeral home, cover your loved one with a special blanket or quilt. A special way to honor your loved one is to walk in procession with the body through the front entrance to the awaiting hearse. With select staff, you may choose to light a candle, ring a chime, or sing a favorite hymn during this procession. Once the body has been removed, place a rose on the bed for a period of time as a symbol that marks the significance and sacredness of this time.

A Final Reflection

“There is no joy without hardship. If not for death, would we appreciate life? If not for hate, would we know the ultimate goal is love? At these moments you can either hold on to negativity and look for blame, or you can choose to heal and keep on loving. Those who learned to know death, rather than to fear and fight it, become our teachers about life.”

—ELIZABETH KUBLER-ROSS

If you cannot be present at the time of death, talk to the nursing staff and administrator about what special comfort measures or rituals you would like to take place during the dying process. Although death is expected, it may still seem to happen too soon or come as a bit of a shock. Arrange time to talk with the staff who were present or the physician to talk about the experience and if you have any questions. Ask the administrator about a memorial book to leave in a foyer of the facility for others to write down their thoughts or pay tribute to your loved one.

A checklist for encouraging comfort care

This list is intended to encourage your loved one's comfort and to anticipate his or her care needs. Use these items as prompts for discussion with the facility's staff, other health care providers, or relatives and friends.

- _____ Staff know your loved one's preferences for food, drink, clothing, bathing, etc.
- _____ Staff routinely anticipate needs such as hunger, boredom, toileting and fatigue.
- _____ Your loved one has no dietary restrictions.
- _____ Snacks are available 24 hours a day.
- _____ Pain is evaluated daily and relief is provided with medications and non-drug measures.
- _____ Psychotropic drugs are administered only with your permission.
- _____ Staff use the preferred name of your loved one.
- _____ Staff consistently interact with your loved one in a calm, kind manner.
- _____ Staff use language that promotes your loved one's dignity and individuality.
- _____ Staff tap your loved one's remaining abilities and strengths whenever possible.
- _____ Staff address your questions and concerns in a timely fashion.
- _____ Staff encourage you to be involved in care and decision making.
- _____ Based on your loved one's wishes and goals of care, you, the physician, and staff have discussed if and when hospitalization should be considered.
- _____ Based on your loved one's wishes and goals of care, a decision has been made if cardiopulmonary resuscitation (CPR) should/should not be initiated.
- _____ Based on your loved one's wishes and goals of care, you have discussed with the physician and staff if artificial feeding and hydration (tube feeding) should/should not be initiated.
- _____ Based on your loved one's wishes and goals of care, you have discussed with the physician and staff if oral or intravenous antibiotics should/should not be initiated.
- _____ Staff know your preferences/decisions about hospice care.
- _____ Staff routinely engage your loved one in one-to-one activities involving the five senses.
- _____ Your loved one's spiritual needs and practices are addressed.
- _____ Funeral arrangements are completed and communicated to staff.
- _____ Ways of caring for yourself are practiced on a daily basis.

Notes: _____

Resources

Alzheimer's Association is the national leader in Alzheimer's research, support, and advocacy. Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. The Association is based in Chicago and has more than 70 local chapters throughout the United States. Contact at (800) 272-3900 or www.alz.org

Caring Connections is a program of the National Hospice and Palliative Care Organization aimed at improving care at the end of life. Contact at (800) 658-8898 or www.Caringinfo.org

National Hospice and Palliative Care

Organization is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. It offers a wealth of information about end of-life-care and referrals to local hospices. Contact at (800) 658-8898 or www.nhpco.org

National Health Care Decisions Day is an initiative to encourage people to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be. For information about advance directives, contact www.nationalhealthcaredecisionsday.org

National Long-Term Care Ombudsman

Resource Center can direct you to professional and volunteer advocates for residents of nursing homes, board and care homes and assisted living facilities. Ombudsmen provide information about what to do to get quality care and are trained to resolve problems and assist with complaints. Contact (800) 677-1116 or www.ltombudsman.org

Center to Advance Palliative Care provides clear, comprehensive palliative care information for people coping with serious, complex illnesses. Contact www.getpalliativecare.org

The Alzheimer's Store is an online retail business that sells hundreds of products that may benefit individuals with dementia and their families coping with all stages of dementia. Contact (800) 752-3238 or www.alzstore.com

References

Alzheimer's Association. (2006). Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes: Phase 3 End-of-Life Care. Chicago: Alzheimer's Association. Available at: www.alz.org/national/documents/brochure_DCPRphase3.pdf

Bresnahan R. (2003). Walking One Another Home: Moments of Grace and Possibility in the Midst of Alzheimer's. Ligouri, MO: Ligouri/Triumph.

Davidson A. (2006). A Curious Kind of Widow: Loving a Man with Advanced Alzheimer's. McKinleyville, CA: Fithian Press.

Fazio S. (2008.) The Enduring Self in Alzheimer's Disease: Getting to the Heart of Individualized Care. Baltimore: Health Professions Press.

Volicer L. (2005). End-of-life Care for People with Dementia in Residential Care Settings Chicago: Alzheimer's Association. Available at: www.alz.org/national/documents/endoflifelitreview.pdf

Warden V, Hurley AC, Volicer L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. Journal of the American Medical Directors Association, 4, 9-15.



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