Dementia Care:

A Guide for Individuals, Families, and Caregivers

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Introduction

Alzheimer’s disease and other related dementias have become the fifth leading cause of death in Iowa (IA Dept of Public Health, 2008) and the seventh leading cause of death of all ages in the United States (Alzheimer’s Association, 2010). More than 69,000 Iowans have Alzheimer’s disease or another form of dementia, and the numbers are expected to rise (Alzheimer’s Association, 2010; Iowa Department of Public Health Center for Statistics, 2008; Centers for Disease Control (CDC), 2010). Iowa City Hospice specializes in end-of-life care of patients with dementia, their caregivers, family and friends. We believe that comfort, meaningful connections, and improved quality of life are all possible – even in the final months of a person’s journey with dementia.

Dementia is an umbrella term describing a category of more than 70 diseases that results in impairment of language, memory, personality, behavior, and judgment (Valeo, 2009; Radin & Radin, 2008; Bell & Troxel, 2002). Alzheimer’s disease is the most common type of dementia and affects an estimated 5.3 million Americans. One in eight people aged 65 or older have Alzheimer’s disease. Due to the increasing number of older adults in our society, 11 to 16 million Americans could have the disease by 2050 (Alzheimer’s Association, 2010).

This guide addresses many of the common questions and concerns of people with dementia, their families and friends, and their caregivers. For some readers, this guide may review or reinforce many of the things you have learned or experienced. For others, this information may help to reassure you that your loved one is receiving the best possible care that Iowa City Hospice staff and volunteers can provide.

How do I know if I have or my loved one has dementia?

Due to the prevalence of Alzheimer’s disease, many people ask themselves: Do I have Alzheimer’s or will I get dementia? Does my loved one have dementia? The Alzheimer’s Association recommends seeking medical care if you or your loved one has any of the following ten signs:

1. Memory changes that interrupt daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking and writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

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**Diagnosis**

Diagnosing dementia involves a careful history and review of symptoms, along with a thorough physical exam to rule out other conditions that can mimic dementia. Part of the evaluation may include blood work, a brain scan and/or neuropsychological testing. Depression, delirium, medication side effects, thyroid conditions, problems with vision and hearing, and nutritional imbalances are all potentially treatable conditions that can look like a dementia-type syndrome.

Alzheimer’s disease leads to nerve cell death and tissue loss throughout the brain. Over time, the brain shrinks dramatically, affecting nearly all of its functions. Although brain autopsy remains the only way to definitively confirm that an individual had Alzheimer’s disease or another type of dementia, memory loss specialists are now able to diagnose most types of dementia with up to 90% accuracy (National Institutes of Health, 2010; Radin, 2008; Bell & Troxel, 2002). PET (Positron Emission Tomography) scans have been used to demonstrate the damage done to the brain in dementia syndromes. In the case of Alzheimer’s disease, in particular, there is an accumulation of something called beta-amyloid plaques in the brain, and these plaques are believed to impair brain function.

The PET scan below shows the brain of a cognitively healthy person and of a person with Alzheimer’s disease. The radiolabeled compound called Pittsburgh Compound B (PiB) can be used in PET scans to image beta-amyloid plaques in the brain.

![PET scan](https://www.nia.nih.gov/Alzheimers)

In this PET scan, the red and yellow colors indicate that PiB uptake is higher in the brain of the person with AD than in the cognitively healthy person.

There are many types of dementia. The type may be determined based on the person’s symptoms, and areas of the brain showing damage.

- **Alzheimer’s disease (AD)** is the most common form of dementia, accounting for 60-80% of all dementias (Alzheimer’s Association, 2010). The greatest risk factor for Alzheimer’s disease is age. It is typically characterized by a *gradual onset* of memory loss, followed by a *continual decline* in other areas of mental, and eventually physical, functioning. Common losses begin with difficulty in managing everyday activities followed by the ability to care for oneself. Communication abilities may be lost over time, along with walking, bladder, and bowel control.

- **Vascular dementia (VaD)** is the second most common type of dementia. Vascular dementia is caused by decreased blood flow to parts of the brain, resulting in multiple, small strokes (multi-infarcts) (Alzheimer’s Association, 2010). The *onset may appear suddenly*, depending on the size and location of the stroke. Although VaD is not reversible, treatment of risk factors, particularly high blood pressure, may modify or slow the progression of the disease process. Losses in function, memory, and language may appear much like AD, although due to continued strokes, sudden changes may be more evident (Radin, 2008).

Other common types of dementia include:

- Dementia with Lewy bodies including Pick’s disease
- Frontotemporal dementia
- Mixed dementia (having signs of more than one dementia syndrome)
- Dementia associated with Parkinson’s disease
- Creutzfeldt-Jakob disease
- Huntington’s disease

**Treatment**

Currently, there is no cure for Alzheimer’s disease, but there are medications that may slow the progression of symptoms of the disease for a period of time. Four drugs have been approved to treat Alzheimer’s disease. For mild to moderate Alzheimer’s disease, donepezil (Aricept®), rivastigmine (Exelon®), or galantimine (Razadyne®) may be prescribed. Namentine (Namenda®) may be used to treat moderate to severe Alzheimer’s disease and may be prescribed along with Aricept (National Institute on Aging, 2010). By the end-stages of Alzheimer’s disease, however, these medications may have little benefit. Discuss the benefits of continuing these medications with your physician, health care providers, and family members. Whether or not these medications should be given is a personal choice and should be up to the individual and those involved in the care of the person (Reisberg, et al., 2003; Wilkinson, et al., 2003; Wilkinson & Anderson, 2007).
Progression
The progression of dementia varies according to the type of dementia and other health conditions. The Functional Assessment Staging of Dementia (FAST) scale is one tool that is used to chart the progression of Alzheimer’s disease and other forms of dementia.

<table>
<thead>
<tr>
<th>FAST Scale Stages</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Normal adult</td>
<td>No functional decline.</td>
</tr>
<tr>
<td>2. Normal older adult</td>
<td>Personal awareness of some functional decline.</td>
</tr>
<tr>
<td>3. Early Alzheimer’s disease</td>
<td>Noticeable deficits in demanding job situations.</td>
</tr>
<tr>
<td>4. Mild Alzheimer’s</td>
<td>Requires assistance in complicated tasks such as handling finances and planning parties.</td>
</tr>
<tr>
<td>5. Moderate Alzheimer’s</td>
<td>Requires assistance in choosing proper attire.</td>
</tr>
<tr>
<td>7. Severe Alzheimer’s</td>
<td>Speech ability declines to about a half dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up.</td>
</tr>
</tbody>
</table>


While one study showed that the average life span after initial diagnosis from Alzheimer’s disease is four to six years (Larson, et al., 2004), many specialists recommend that families plan on a span from 7 to 10 years after receiving a diagnosis of Alzheimer’s disease (Brookmeyer, et al., 2002). Because dementia damages the brain, physical and mental functions are affected, such as thinking, memory, self-care abilities, and mobility. Alzheimer’s disease is a progressive, terminal illness and cannot be reversed. A person with end-stage Alzheimer’s disease or another type of dementia experiences a decline that is gradual and unrelenting; eventually leaving the person completely dependent upon others for comfort care.

Planning for Disease Progression

“You cope with what you need to do now. At the same time, you have to look ahead....”

-An Alzheimer’s Caregiver
(Alzheimer’s, Dementia & Memory Loss: Straight Talk for Families and Caregivers, Wheeler, 2008, p. 93)

Once a patient reaches end-stage dementia or has another terminal condition and dementia, Iowa City Hospice can be very beneficial. Iowa City Hospice attends to the management of physical, emotional, spiritual, and social needs of individuals and their families. The focus for the patient is comfort and quality of life until death. The focus for families is comfort, education, and support.
Iowa City Hospice firmly believes that it is our goal to honor people’s wishes regarding care. We encourage individuals and families to discuss their preferences for care, and discuss ways to implement plans while people are able and before a crisis occurs. Appointing a Durable Power of Attorney for Health Care and sharing wishes regarding care with your circle of support such as friends, family, and religious and/or spiritual leaders will help ensure that your wishes are honored. Seeking legal, financial and medical consultation with professionals will help prepare for care and needs that lie ahead.

Person and Family-Centered Care
Every person experiences dementia in different ways. Each person is unique, and care needs to be tailored to the individual to help ensure comfort and the highest quality of life possible. Learning about a person’s past history, preferences, dislikes, and how they respond to personal care is essential as a part of every assessment (Kitwood, 1993 & 1997; Crandall, et al., 2007).

Iowa City Hospice staff will ask questions about the individual and family upon admission. The tool, My Story (Appendix C), will be utilized as a part of the assessment process and development of the plan of care. Sharing the person’s life story can provide a time for the family to reminisce and celebrate the person’s life. It can also be a source of comfort for family members as they care for their loved one (Bell & Troxel, 2002).

Creating and Maintaining Meaningful Connections
Families and friends may feel uncomfortable being with a friend or loved one with advanced dementia. People may remark, “I don’t know what to do or say.” “They don’t recognize me.” “My visits don’t seem to make a difference.” Recent research suggests that a person with dementia may not remember details about a specific encounter or visit, but the underlying emotion or feeling from an interaction may remain and alter mood (Feinstein, 2010).

It is possible, with patience and creativity, to find ways to connect with a person with dementia that improves quality of life not just for that moment, but throughout the day. One of the most successful ways to build and maintain a connection is through sensory stimulation. In dementia, the sensory and visual parts of the brain are some of the most preserved. Sensory awareness does not require higher thinking abilities of the brain. By stimulating the senses, there is an opportunity to tap into remaining abilities in order to create an increased awareness of self and the surrounding environment.

Iowa City Hospice has specially trained staff and volunteers equipped with sensory kits. These intervention tools may foster a connection and bring comfort to the person with dementia. The kits include items such as lotions and sprays made from essential oils, bubbles, textured balls, music, and chocolate.

Sensory stimulation that draws upon lifelong preferences, interests, and habits is likely to spark connections, thereby increasing pleasure and quality of life. Before utilizing sensory items, it is imperative to learn about the person’s history, likes, dislikes, and preferences. It is also important to ask if there are any known allergies or sensitivities to scents, smells, sounds, fabrics or other materials.
Suggestions for Stimulating the Senses

“Thelma was sitting in a small group when I arrived. Everyone had blank expressions. When I started to blow bubbles with Thelma, the entire mood of all of the residents changed. You would have thought that we were at the grand ball! I wish I had a camera to capture the moment!”

-Tia, Hospice Aide

Blowing bubbles is a way to observe if the person is tracking, and is an activity that can be enjoyed by multiple generations. Other visual cues such as pictures or showing a familiar object may bring comfort. Sharing photo albums and stories may create enjoyment.

“I gave a person with dementia a squishy ball, and she held it every day.”

-Joan, Hospice Volunteer

Tactile cues include textures that are pleasant to feel and to hold (e.g., soft fabrics, balls, stuffed animals, a pillow, etc). A person’s favorite shirt, sweater or blanket may be a source of comfort.

“When I spray lavender in the room, my patients relax and become calm.”

-Dawn, Hospice Aide

“Violet loved to smell and touch flowers. She would begin to talk when I handed her a fresh flower.”

-Jane, Social Worker

Essential oil sprays and scented lotions trigger olfactory (smell) cues. Perfumes, smells, and spices can bring forth memories and provide comfort (Baker, et al., 2003). For example, lavender and vanilla have been shown effective in calming a person with dementia. Citrus scents, such as lemon balm, have been effective in providing stimulation (Gray & Claire, 2002). Other ideas include cinnamon, rosemary, and/or scented flowers.

“My patient was at the end of life and had not spoken in days. I gave her the tip of a chocolate kiss and she said, ‘Yummy, yummy’.”

-Lavon, Nurse

Chocolate kisses are an example of food that may be enjoyed at the end of life. Place the tip of the chocolate kiss in the person’s mouth. The remainder of the chocolate may be enjoyed by the caregiver. Other favorite foods may be placed at the tip of the tongue (very small amounts are recommended to reduce the risk of choking). The person with dementia may more readily accept food that is soft in texture and sweet in taste. Examples of other foods to consider include ice cream, yogurt, applesauce, jam, and mashed potatoes with gravy.
Sharing favorite memories may trigger positive memories and feelings. The person with dementia may feel joy, humor and other emotions that are expressed through reminiscence. Humor, in particular, may remain intact for those who used humor throughout their life. While verbal communication may be provided almost solely by the family, the intent is to create a sense of warmth, love, and remembrance for both the person and the family. Other auditory cues could include favorite songs or sounds, such as musical instruments, sounds of nature, or children’s voices.

Musical Connections

“Mary was restless, talking rapidly with jumbled vocabulary, and calling out from her bed. As I sat beside her and offered music as a focus of attention, she watched me intently and was quiet throughout a whole song that I sang. At the end of the song she stated ‘wonderful.’ In between songs she would talk less and less quickly and she was quiet during the actual music. With each piece of music she became calmer and was resting quietly by the end of the session.”

- Joey, Music Therapist

Music provides structure in order for people to actively or passively participate with others. Emotional expression or a change of emotions is often a response to live music.

Music therapists have worked toward nonmusical goals for people with dementia since the 1950’s. Because music is processed in many parts of the brain, people with dementia often have an intact memory for music. Instead of challenging those with dementia to regain lost function, a music therapist will use music with structure, familiarity and predictability to support and aid mental organization.

People with dementia may be able to respond to music in meaningful ways, whether music is provided by a music therapist or by caregivers who know them well. In fact, people with dementia may prefer to listen to familiar and flexible singing from a caregiver rather than a recording (Rio, 2009). The quality of your voice is less important than the love and intention for communicating that will be understood by your loved one.

Music is considered a nonverbal means of expressing emotion and is effective for altering mood in a positive way.

General Considerations for Music

Music chosen for a person with dementia should be familiar, such as songs with pleasant memories that have been heard over a lifetime. Musical selections based on the person’s past interests and pleasures will provide the best opportunities for making meaningful connections. If preferences are unknown, the most appropriate music is from the era when the person was 15-25 years old. People may respond most to music activities that do not involve much verbalization, like moving or using rhythm.
Music can be used to help provide structure to the day. For example, playing some quiet, comforting music to help your loved one relax or go to sleep may help them keep a consistent schedule. Providing some short periods of stimulating music during the day may keep your loved one awake so that they may be more likely to sleep at night.

**Singing**

Responses will vary depending on the level of decline. In the mild stage of dementia, whole songs may be sung even when loved ones do not verbalize much. If you adjust the speed of your singing to the needs of your loved ones, they may be able to sing more successfully with you. In the moderate or advanced stages, people may only be able to sing a few lines of a song, mouth the words, or sing a word in the chorus. As a loved one declines, they are less likely to respond through singing, but may tap toes or fingers, conduct, or move with the music.

Making sounds is easier than speaking; your loved one may be able to participate by making sounds, humming or whistling. Singing promotes deeper breathing, helps develop lung capacity, and provides more oxygen to the blood. This helps relax the body and mind of the loved one as well as the caregiver (Rio, 2009).

**Connecting through Art**

> “In some instances, there is a form of knowing and remembering that cannot be articulated verbally yet is accessible when an alternative path of communication is opened through the language of art.”

*(R. Abraham, When Words Have Lost Their Meaning: Alzheimer’s Patients Communicate through Art, 2005, p. 105)*

People affected by dementia may be able to express themselves through drawing, painting, sculpting, or other forms of art although they may no longer be able to communicate verbally. Ruth Abraham (2005) writes that art with people affected by dementia supports current capacities, enhances creativity, and increases self-worth. Through artistic expression, they may find comfort and a way to release emotions non-verbally. Abraham suggests providing pictures from which to copy, providing a frame or outline, or setting out an object to draw.

Gerontologist Gene Cohen (2004) noted that seniors participating in another art program, *Memories in the Making*, were less depressed and lonely than others who did not participate in the activity. Persons with dementia were able to express feelings through different mediums, primarily painting (Heinly, 2005; Cohen, 2004).

Looking at art or pictures may trigger memories and promote communication. *Memories in the Making* and *TimeSlips* (Basting, 2003; Fritsch, et al., 2009) are activities geared toward creative engagement. A person with diminished verbal skills can still communicate through creative expressions such as *TimeSlips* storytelling. A facilitator guides a small group to tell a story utilizing a black and white picture, and then shares the story with the group (Basting, 2003).
Touch
The need for human touch is a basic one. Holding the hand of a person with dementia can communicate love, warmth and safety. This can be done in conjunction with conversation, music, or simply by itself. Light hand massage and intermittent gentle touch on the arm or shoulder complimented with calm soothing speech has been shown effective in reducing anxiety and promoting positive behaviors (Kim & Buschmann, 1999).

“As my dear grandmother's dementia progressed, she was often agitated, and I worried that we could no longer enjoy the special connection we had my whole life. I was concerned and felt helpless - until I discovered what a calming effect my simple touch could provide. Through gentle hand massage with scented lotion, or simply brushing her hair and stroking her brow, I was able to reconnect with my beloved grandmother, and once again enjoy some serenity together; a few words at times; and always smiles on both of our faces.”
- Susie, Family Member

Reading
If the person with dementia enjoyed reading before their diagnosis, they may enjoy reading with larger print or listening to someone read to them. As previously noted, it is important to consider their interests and preferences. Pictures related to the readings may elicit conversation and improve quality of life.

“Bob had been walking around the halls of the nursing facility for over an hour when I arrived. After walking with Bob for 20 minutes, I invited him to sit down. I pulled out a magazine I had brought along to the visit – it was dated October 1968. At first, Bob didn’t seem interested and he stood up. Then, I turned the page to pictures of different pickup trucks. Bob sat back down and looked at the pictures intensely for the next three or four minutes while I read the captions. Then, he turned to me and said, ‘I had a pickup just like that one.’ He pointed to a yellow pickup. Bob had a smile on his face for the remainder of our visit. We had made a meaningful connection.”
- Peggy, Volunteer

Spirituality and Faith
Persons with dementia do not lose their faith once a diagnosis is determined and as the disease progresses. An emotional connection is still possible but may need to be reached in different ways. Your loved one may remember familiar prayers such as the Lord’s Prayer and want to say the words with you, or they may remember songs of faith and want to sing along. They may also like to hear short readings from books of faith. With prompting, it is possible for them to quote passages of scripture that they learned in childhood or say prayers or phrases of faith.

“During a spiritual care visit, I offered communion to Mr. K. His vascular dementia had seemingly robbed him of his ability to talk and he usually responded with his eyes during our visits. As he received the bread and juice on his tongue, his eyes welled up with tears. After receiving them, he said quite clearly, ‘Thank you’.”
- Rebecca, Spiritual Counselor
Special services such as Holy Communion or a Seder meal (Passover) can provide the opportunity to experience faith through other senses—taste, touch, and smell. Through the use of sensory stimulation, water can symbolize baptism or ritual bathing; bread can remind you or your loved one of meals or holy gatherings; fabric can symbolize warmth and comfort. Walking in nature stimulates a connection with something outside of ourselves; watching birds fly or feeling the breeze blow gently can be a renewal of the spirit.

Symbols are important too. These may include a cross, holy pictures, a rosary, a prayer shawl, candles, or incense. What is important is to provide the opportunity for the person with dementia to connect with the spiritual being within and with the spirit of faith that surrounds them.

Persons with dementia may grieve for family members who died many years ago—sometimes visiting a cemetery can help them remember and grieve. Your loved one may also have conversations with family who are no longer alive. It is important to stay in the moment and to participate with them as they allow. This can be done through a gentle touch, a hug, or by holding the loved one’s hand. A word of thanks for the loved one they miss and the memory they share with you can provide validation and comfort.

Pets
Animals may spark unique connections with persons with dementia. Pet therapy may allow a person to reminisce about pets and animals that they had. Pet therapy also stimulates the senses through touch, and may bring comfort and relaxation. Please consult with your Iowa City Hospice team if you would like a referral for pet therapy.

“As Auggie, a Newfoundland dog, and I approached the patient in the wheelchair, her head hung low as if she were asleep. The moment she saw the dog before her, her head lifted and you could see the thrill in her eyes. When he gently licked her cheek, she said, ‘Well, it’s about time.’ For the rest of our extended visit, she ran her fingers through his hair. She shared story after story of dogs she had loved throughout her life.'”

-Michelle and Auggie
Pet Therapy Team

Suggestions for Making the Most of Each Day: Enhancing Activities of Daily Living

Many people engage in leisure activities (sports, gardening, cooking), but the person with Alzheimer’s disease or a related dementia becomes unable to initiate activities (Bell & Troxel, 2002). It is important to assess the person’s current personality, needs and preferences, and modify activities to match their current abilities. Refer to the person’s life story, and previous hobbies and interests.
The process of the activity is always more important than the end product (Bell & Troxel, 2002; Basting, 2003). A person who loves backgammon or cribbage may no longer care if they are following the rules exactly, but will enjoy the time spent with you, laughing and playing the game. The following are additional guidelines to help you enjoy the day and time with your loved one.

- Make sure basic needs (such as meals or toileting) have been attended to prior to starting the intended activity.

- Remember that meals and bathing are activities in themselves, and can be adapted to suit the person, and be a time of joy and comfort.

- Plan activities during the best time of day for the individual (usually when the person is well rested). Plan ahead for adapting the activity for the person. For example, if a person hates cold bathrooms and is upset by the idea of bathing, warm up the room, prepare warm towels, and set up the room ahead of time. Consider aromatherapy, sponge bathing, or treats before or during the activity.

- Call the person by his or her preferred name, and let him or her know who you are and what you would like to do. Remember that the preferred name may be a first name or a more formal name such as Mr. Jones. However, it could also be a childhood nickname such as “Bud” or “Junior.” Because of the cognitive decline, the person may no longer see himself as “Mr. Jones,” but instead as “Bud.”

- Begin the activity in a calm, gentle manner.

- Observe any signs that indicate the activity is causing a negative reaction or discomfort, such as distressing facial expressions, tense muscles, or restlessness. If this occurs, stop the activity and comfort the individual.

- Provide the activity over a 10 to 15-minute period. Adjust as needed with the goal of providing comfort to the individual.

- Recognize the need to try more than one thing. What works one day may not work another day. Take a deep breath and keep trying.

- At the conclusion of the activity, determine how enjoyable it was for you and your loved one. Did you notice any positive changes in the way the person appeared to feel or behave? Remember, some individuals with dementia may experience a delayed response from the activity.

Most people have a desire to be productive, to feel that they are contributing to society. People with dementia maintain a desire to help, and to feel connected to you, the community and the world. Activities can help persons with dementia meet this need (Bell & Troxell, 2002; Taylor, 2007). Activities need not be fancy or expensive. Many people enjoy music, creative arts, word games, activities with children, or reminiscing. Group reminiscence has been found to be more engaging among persons with mild to moderate dementia than crafts, games, or unstructured time (Kuhn et. al, 2004; Brooker et al., 2000).
Adapting Activities as Dementia Progresses
Activities will need to be adapted to meet the changing needs of the individual with dementia. The following is an example of how to adapt an activity through the progression of the disease.

<table>
<thead>
<tr>
<th>Step</th>
<th>In this step you:</th>
<th>For example:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Review the initial participant assessment to learn:</td>
<td>Helen always loved to garden. She canned many fruits and vegetables for her large family. She loved flowers, especially peonies and gladiolas.</td>
</tr>
<tr>
<td></td>
<td>• Past primary occupation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Other jobs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Hobbies</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Find related activities that the participant finds stimulating.</td>
<td>Helen enjoys the garden in the courtyard and watching the birds. While attending the adult day health center, she planted and watered flowers.</td>
</tr>
<tr>
<td></td>
<td>Make modifications to the participant’s past activities.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Further modify activities to meet the participant’s current/changing abilities.</td>
<td>Helen can no longer plant seeds or remember to water plants by herself. A caring adult can organize the supplies that Helen needs. Helen can assist with watering or planting if guided with assistance and affirmation.</td>
</tr>
<tr>
<td></td>
<td>For example, break down tasks to meet the participant’s abilities.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Further modify activities based on the participant’s preferred role or choice,</td>
<td>Helen can be assisted outside to enjoy the sounds, smells, and colors of the garden. In the winter months, she can look at pictures of her gardens, or other flowers, and reminisce.</td>
</tr>
<tr>
<td></td>
<td>and as the disease progresses.</td>
<td></td>
</tr>
</tbody>
</table>

(Rural Iowa Alzheimer’s Demonstration Grant; AoA Grant #90AZ2774, 2004-2007. *Enhancing capacity for dementia specific adult day care and respite for rural and emerging minority populations*. Iowa Department of Elder Affairs with the University of Iowa College of Nursing.)

For the sports lover, a person with dementia can attend games with assistance. The person may enjoy local junior or high school events, especially if they have grandchildren in that age group. When going to an event becomes too challenging, sporting events may be watched or heard on TV or the radio. The caregiver can spend time with the person, reviewing significant plays, and enjoying favorite snack foods. If the person resides in a care facility, parties may be offered to residents. Adapt sound levels and stimulation to the person’s preference.

Most board/card games can be adapted as needed. People can enjoy dominoes, bingo and other activities as long as you modify the game, and don’t make the person feel that there is a “need to win.” Being with the person and creating meaningful time together is the goal.
Enhancing Communication

Alzheimer’s disease not only causes difficulty with thinking and memory, it also affects language skills. Persons with dementia struggle to find words, put sentences together, and stay on track with a topic. Eventually, persons in the end stages of dementia may lose the ability to communicate verbally and may have difficulty understanding what is being asked of or said to them. Therefore, it is essential that caregivers adapt their communication styles to enhance communication and maintain meaningful connections with their loved one.

While previous ways of communication may not work, it is possible to find verbal and nonverbal ways to communicate. Tapping into old and familiar social skills, as well as tapping into all of the senses, allows connections to be made. Remain open to the possibilities, and share what works well with your family, friends, and the Iowa City Hospice team so that we, too, can communicate with the person that we are serving.

Suggestions for Communicating:

- Always be respectful.
- Create a calm environment and minimize or eliminate background noise.
- Approach the person from the front and at eye level. Try to make eye contact.
- Show signs of caring in your tone of voice and facial expressions. The adage, “it’s not what you say, but how you say it” is very important, especially as language skills become impaired. Nonverbal body language is often well understood by persons with dementia. They are quick to note your frustration and anger, and may react to it.
- Simplify your conversations and questions. Allow enough time for the person to understand your message. It may take a minute or two for the person to try to respond. Repeat the message using simpler words or shorter phrases.
- Reassure the person. If the person is having difficulty communicating with you or understanding your message, validate his or her experience. “Take your time” or “It’s OK” may be comforting responses.
- Use gestures to get your message across. A gentle touch of the person’s hand, arm or shoulder may assist in communicating your message. For example, greeting the person by name and extending your hand may elicit a positive response.
- Focus on providing pleasant (often one-direction) conversations using photos, picture books, fond memories, music, or even a favorite movie. The focus of the conversation should be on creating comfort rather than relaying content. If the person appears to become agitated, stop what you are doing.
- Never talk about the person as if he or she were not present. The person with dementia may be able to comprehend what you are saying and respond to you throughout the progression of the disease.
- Avoid confrontation, and do not argue with the person over facts. There is a saying, “No one ever won an argument with an Alzheimer’s patient.”
- Avoid quizzing the person on names, dates, or other facts. Not knowing the answer can be embarrassing. Instead, try to use more “yes” and “no” questions.
- Encourage unspoken communication. Ask the person to point or gesture.
- Focus on the emotion being expressed. What is the person trying to tell you? (Alzheimer’s Association, 2010).
Understanding Behavior

As the disease progresses throughout the brain, day-to-day living may become increasingly challenging, frustrating, and stressful. What was once done independently may require assistance from a caregiver. Behavioral symptoms in dementia may be troubling to family members, caregivers, and others. Most behavior is a form of communication and indicates an unmet need that the person is trying to signal to caregivers. Smith and Buckwalter (1990, 1993, rev.2006) introduced the ABC’s method to assess distressing behavior with the goal of assisting caregivers to reduce and avoid behavioral problems.

Remember to consider:

**Antecedent or Assessment:**
What is the behavior? How often does the behavior occur? What happened before the behavior? What was a possible trigger?

**Behavior:**
Is the behavior new or has it increased in frequency? Is it harmful? When does it occur? Is this behavior associated with a change in mood? Is this behavior a sign of pain?

**Consequences:**
What are the consequences for the individual and those around them? How did caregivers respond? What can be done differently? Review options, and develop a plan to address needs. Reassess at designated intervals.

Some unmet needs may include the need for rest, a bathroom break, companionship, or a change in the level of stimulation. Late afternoon or evening can be particularly challenging as the person becomes fatigued. Cumulative fatigue caused by the demands of the day, along with memory difficulties and the inability to recognize and effectively communicate basic needs, often results in what is called “sun downing.” The person who is sun downing usually displays increased physical and/or verbal agitation. A common theme is the person requesting to “go home.” Sleep may also be disturbed. Even though people with end-stage dementia tend to sleep more, many experience disruptive sleep patterns and are restless sleepers, which contribute to the fatigue.
Boredom can be another cause of behavioral challenges. Without structure and routine, individuals may become bored and begin searching for something meaningful to do.

Over-stimulation may also cause behavioral challenges. The most common causes of over-stimulation include exposure to large groups of people; overwhelming, complex tasks; a noisy environment (i.e., TV or radio). These triggers, along with lack of rest periods throughout the day, may result in increased stress by the person affected by the disease. It is important to try and reduce stimuli when it obviously causes stress, and to learn to recognize verbal and nonverbal cues (Smith, et al., 2006).

Change may be difficult for the person with dementia because he or she can no longer predict or plan for the day ahead. Due to short-term memory problems, the person cannot adapt to changes as they have in the past. Continuity, structure, and appropriate levels of activity can provide comfort to the individual. With too much stimulation, change, and lack of rest, the person may exhibit aggressive behavior.

Aggression may be exhibited through verbal outbursts, such as yelling and name-calling. The aggression may also be physical, such as hitting, striking out or pushing. The aggression may occur suddenly with no apparent reason, or it may be the result of a frustrating situation. It is important to try to understand what is causing the aggressive behavior. Think about what happened right before the reaction that may have triggered the aggressive behavior.

Hallucinations are false perceptions of objects or events involving the senses (American Heritage Dictionary, 2001). When individuals with Alzheimer’s disease have a hallucination, they see, hear, smell, taste or feel something that is not there. For example, the person may hear voices. If the hallucination does not cause problems for the loved one, you may want to ignore it. However, if they happen continuously, consult a physician to determine if there is an underlying physical cause.

Health problems may cause behavioral changes. Be aware that any new, increased, or sudden change in behavior could be an indication of a health problem that needs attention. Infections (such as urinary tract infections) are common in dementia, and often cause increased confusion and sudden changes in behavior.
Common Unmet Needs

1. Basic Needs – Focus on meeting basic physical needs:

- Help the person to the bathroom or change a soiled brief.
- Offer something pleasurable to eat and/or drink.
- Adjust room temperature; typically, older persons prefer warm environments.
- For those unable to move, (re)position them in a comfortable chair.
- Offer a rest period.
- Address pain; the discomfort of arthritic joints and lack of movement may contribute to behavioral outbursts. Communicate concerns to your Iowa City Hospice team.

2. Emotional Needs – Consider the following:

- Do not be afraid to talk with the person about the losses he or she is experiencing. Let him or her know that you care.
- If there is continued or prolonged sadness and/or crying, the person may be depressed and may benefit from antidepressant medication. Inform your physician and Iowa City Hospice team of symptoms.

3. Routine and Structure – Consider the following:

- Develop and implement a routine.
- Make sure rest periods are scheduled throughout the day.
- Carefully pace activities throughout the day.
- Prevent boredom or over-stimulation.
- Make sure that activities do not create frustration or fatigue for the person; he/she deserves to feel successful during activities.

Adapted from Hospice of the Valley’s Joining the Journey: A Guide to Dementia Comfort Care. Reprinted with permission.
Responding to Dementia-Related Behavior

The way you approach a person with dementia is extremely important because caregiving often involves very intimate care. Remember to use the following principles:

- Smile, approach slowly from the front, and stay relaxed.
- Be aware of the environment.
- Talk directly to the person and assume that the person understands.
- Use calming phrases and a soothing tone of voice.
- Calmly approach the person at his or her physical level (for example, kneel or sit down). If you are rushed, anxious or agitated, the person with dementia may become anxious or agitated as well.
- If the person says, “No,” to a requested task, leave and come back five minutes later. Try a different approach. Ask the person to join you in an activity.
- Be flexible in accomplishing the task at hand. Go with the flow; eventually the task will get completed.
- Remember to try to identify what could be triggering the behavior so that a plan can be developed to address needs.

Utilize distraction or engage the person in a pleasant activity during caregiving tasks. Activities, such as bathing, grooming, changing undergarments, and providing mouth care can be unpleasant and uncomfortable tasks for the person with dementia. Consider one of these strategies:

- Talk about topics the person enjoys.
- Have the person hold a soft object, such as a warm wash cloth; or a meaningful item such as a family picture.
- Give the person something to eat or drink that he or she enjoys.
- Sing a favorite song to or with the person.
- Recite a familiar prayer, scripture, or poem.
- Be creative until you find something that works.

Most importantly, never accept new behavior as “normal.” Sudden behavior changes can be a source of discomfort for the person with dementia. Please share your concerns with your Iowa City Hospice team.
Addressing Pain Concerns

People with mild memory loss may be able to verbally express their pain; whereas persons with advanced dementia may have difficulty understanding and communicating their pain. Multiple studies show that cognitively impaired persons were 80-85% less likely to be treated for pain (American Geriatrics Society (AGS) Panel, 2009; Herr, 2002 & 2006). Professional caregivers have an obligation to assess and treat pain.

Family members and caregivers are often the first to recognize pain. Pain is more likely to be seen while providing daily care, when a person gets in or out of a chair or bed, or as the day progresses. Please report any symptoms that you observe to your Iowa City Hospice team so that the treatment plan may be changed or adapted.

In addition to routine medications, a variety of comfort measures may also be helpful. Consider using the following ideas:

- **Distracting activities** may reduce the person’s discomfort by focusing attention on something more pleasant. Examples include listening to favorite music, or watching an uplifting TV program or movie.
- **Relaxation** can relieve pain. Techniques for relaxation include listening to calming music, aromatherapy, providing a light hand or foot massage, or adjusting the lighting.
- **Music therapy** may be beneficial in reducing pain (Gfeller, 1995). You may request a referral for an Iowa City Hospice music therapist at any time.
- **A warm blanket or towel** over a sore joint may bring comfort. Use care when applying heat to avoid a burn.
- **Movement and positioning** may be helpful as the person loses the ability to move freely. Anticipating the need for movement and allowing for a frequent change in position, or taking a few steps may be helpful. Finding a favorite chair and using pillows for positioning may also help. Ask your Iowa City Hospice nurse or aide for ideas on positioning in a bed or chair.

Iowa City Hospice strongly believes that patients with dementia deserve the best possible care. They have the right to be treated with the best pain and symptom management possible. By working and communicating together, caregivers and the Iowa City Hospice team can increase the comfort of the patient and improve his or her quality of life.

Your Iowa City Hospice nurse will assess pain at every visit. As a part of his or her assessment, he or she will use the PAINAD Scale, an evidence-based tool used to assess pain in people with advanced dementia.
**Pain Assessment in Advanced Dementia**

**PAINAD Scale**

**Purpose:** This pain behavior tool is used to assess pain in older adults who have dementia or another cognitive impairment.

**How to Use:** Observe the older adult for 3-5 minutes during an activity with movement (such as bathing, turning, or transferring).

For each item included in the PAINAD, select the score (0, 1, 2) that reflects the current state of the behavior.

Add the score for each item to achieve a total score. **Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score suggesting more severe pain (0= “no pain” to 10= “severe pain”).**

**After each use, compare the total score to the previous score received.** An increased score suggests an increase in pain, while a lower score suggests that pain has decreased.

### Pain Assessment in Advanced Dementia- PAINAD

<table>
<thead>
<tr>
<th>ITEMS</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negative vocalization</strong></td>
<td>None</td>
<td>Occasional moan or groan. Low level of speech with a negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
<td></td>
</tr>
<tr>
<td><strong>Facial expression</strong></td>
<td>Smiling or inexpressive</td>
<td>Sad, frightened, frown.</td>
<td>Facial grimacing.</td>
<td></td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch.</td>
<td>Unable to console, distract or reassure.</td>
<td></td>
</tr>
</tbody>
</table>

- Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0=“no pain” to 10=“severe pain”).


Developed at the New England Geriatric Research Education & Clinical Center, Bedford VAMC, MA.
Medications

Medications are often used to manage symptoms and behavior throughout the course of dementia. Before using medications for behavior, it is important to understand the source of the behavior. In other words, what is the person trying to communicate through this behavior? As mentioned previously, the first step in managing behavior is to fulfill unmet needs, such as toileting, hunger/thirst, boredom, over-stimulation, etc. Addressing unmet needs will often alleviate challenging behavior.

Medications to Avoid

- Sleep medications, such as Tylenol PM® and Benadryl®, and cold medications, such as Sudafed® and Afrin®, should be avoided. These medications contain ingredients that can cause confusion, urinary retention, constipation and dry mouth, as well as an increase in confusion and the risk of falls (Castelino, et al., 2010).
- Tranquilizer medications, such as Ativan®, Xanax® and Valium®, should also be avoided if possible as they can cause drowsiness, confusion, increased memory deficits, falls, and increased agitation (Berdot, et al., 2009). If prescribed, they should only be used under close supervision by a physician.

The following list includes common medications for dementia and their suggested treatment use:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitation</td>
<td>Routine administration of Tylenol® is often very effective to manage behaviors such as agitation caused by pain.</td>
</tr>
<tr>
<td>Severe agitation, paranoia, hallucinations</td>
<td>Careful administration of an antipsychotic medication, such as Risperdal®, Seroquel®, or Haldol®, can be beneficial. Use only as directed to decrease the risk of side effects.</td>
</tr>
<tr>
<td>Disrupted sleep</td>
<td>A medication called trazodone can be effective in helping the person with dementia to sleep without side effects caused by most sleeping medications. However, it is important to remember that changes in sleep patterns are common with most dementias.</td>
</tr>
<tr>
<td>Poor cognitive function</td>
<td>Cholinesterase inhibitors, such as Aricept®, Exelon®, and Razadyne®, and/or memantine (Namenda®), can be considered. These medications are effective in about one-third of persons with dementia. When effective, they slow the course of memory loss by about 6 months.</td>
</tr>
<tr>
<td>New or increased behavioral problems</td>
<td>These symptoms often indicate that there may be an underlying illness, such as a urinary tract or other infection, or a reaction to a new medication. Be sure to consult with your physician or hospice team.</td>
</tr>
</tbody>
</table>

Health Care Decisions

Progressive forms of dementia like Alzheimer’s disease are terminal illnesses. Patients with dementia typically die from complications of the dementia (i.e., urinary tract infection, pneumonia). Ideally, discussions about health care choices and the completion of health care advance directives occur while the person with dementia has the ability to make decisions. It is important to ask oneself, what health care measures will I want? Who do I want as my Durable Power of Attorney for Health Care (DPOA-HC)? Have I relayed my wishes to my DPOA-HC? If the person has advance directives and becomes unable to make decisions, the designated DPOA-HC will inform the hospice team of the person’s wishes, which will guide the plan of care.
Common health care decisions that people with dementia and their decision-makers face pertain to:

- Cardiopulmonary resuscitation (CPR)
- Do not resuscitate (DNR)
- Feeding tubes
- Hospitalization
- Intravenous (IV) hydration
- Antibiotics to treat pneumonia and urinary tract or other infections

Upon admission to Iowa City Hospice, individuals and/or their decision makers are asked if the patient would like **Cardiopulmonary Resuscitation (CPR)**, which is attempted if the heart stops beating or the patient stops breathing. CPR involves putting a tube down the patient’s throat, chest compressions, and defibrillation. These efforts may or may not succeed in restarting the heart or breathing, may be painful, and may even cause bodily injury.

Some people prefer to avoid CPR, and choose a natural death. Sometimes this is referred to as **Do Not Resuscitate (DNR)**. This means that when a patient dies, he or she is allowed to go naturally and artificial means are not used to attempt to restart the heart or breathing. Regardless of the decision about CPR, every effort will be made to keep the patient as comfortable and pain-free as possible.

Studies provide little evidence that **feeding tubes** extend life, prevent infections, or improve comfort (Li, 2002). Some studies have shown that feeding tubes exhibit higher instances of aspirating into the lungs, which could lead to pneumonia (Cervo, et al., 2006). Feeding tubes may become a consideration in advanced dementia if eating and swallowing difficulties lead to weight loss or problems with aspiration pneumonia. Careful feeding programs are alternatives to tube feeding and can help the patient continue to receive comfort and pleasure from food and eating.

**Hospitalization** needs to be considered carefully because changes in the environment can be stressful and disruptive for persons with dementia, even for those in the early stages. Hospitals are particularly challenging environments because they typically lack the calmness, familiarity, and predictability of settings that are beneficial for the person. Alternatives to hospitalization include the delivery of services in the home, an assisted-living facility, or a nursing home.

**Intravenous (IV) hydration** may provide temporary fluid replacement; however, it cannot maintain nutrition and may increase pain by giving fluids that the body can no longer handle. When a person receives more fluid than the body can handle, the extra fluid can accumulate in the lungs, causing breathing problems, or in the body, causing swelling of the arms, legs, or face (Hospice and Palliative Nurses Association (HPNA), 2004). In the absence of nutrition and hydration, the body develops endorphins, which are morphine-like substances that blunt nerve endings. This is the body’s way of helping a person stay comfortable through the dying process.

**Antibiotics** may or may not improve infections (such as pneumonia and urinary tract infections) (Sachs, et al., 2004). If a person decides against the use of antibiotics, pain medications and other comfort approaches are utilized to manage discomfort.
Recognizing Caregiver Grief

Families and friends spend a significant amount of time, as well as emotional and financial resources, in caring for the person with dementia. Approximately one-third of unpaid caregivers of people with Alzheimer’s or other dementias spend five years or more providing care, including 12 percent who provide care for 10 years or longer (Alzheimer’s Disease Fact and Figures, 2010, p. 27). Because of the gradual, yet significant decline experienced by people with dementia, caregivers often grieve many losses throughout the journey (Sanders, et al., 2008). In addition to multiple losses, caregivers live with the ambiguity of when death will occur. These experiences of loss and uncertainty are often referred to as “the long goodbye” (Ott, 2006), “ambiguous loss” (Boss, 1999), and “the ambiguous dying syndrome” (Bern-Klug, 2004).

One of the most difficult aspects for the caregiver of a person with Alzheimer’s disease or another form of dementia is the progressive deterioration, especially the gradual loss of the person and the relationship you once knew. Iowa City Hospice staff are available to caregivers and families to provide emotional and spiritual support. We recognize that you may be experiencing an emotional roller coaster with varied feelings, thoughts, physical sensations, and behaviors while encountering grief and emotional pain. We want to listen to your stories and gain a better understanding of your caregiving experience.

During the course of dementia, caregivers may experience feelings of:

- Personal sacrifice in order to meet the person’s care needs
- Personal sadness about the effects of the disease
- Longing for the person and the relationship before dementia
- A depression-like sense of uncertainty (ambiguity)
- Isolation/withdrawal from others (Ott, 2006)

Health care professionals may mislabel the grief experienced by caregivers with a loved one affected by dementia as depression and anxiety. This may result in a doctor prescribing antidepressant medications. While medications may help with depression or anxiety, overlooking the role of grief in caregivers’ experiences can disrupt emotional coping and healing. Caregivers’ experiences of grief will change throughout the course of the dementia. The experience will also vary depending upon their relationship with the person with dementia.
Spouses and Partners usually experience gradual increases in their grief over the course of the disease. By the end stages of dementia, they may have experienced feelings of sadness, uncertainty about the future, loneliness, and general emptiness (Marwit & Meuser, 2002).

Adult children often feel the highest level of grief during the middle stages of dementia. It is during this time that they are actively caring for their parents while balancing other demands, such as family and work responsibilities. As a result, adult children may express feelings of anger, guilt, and resentment. As their parents move into the late and end stages of dementia, these feelings often give way to sadness and regret as they recognize the loss of their relationships with their parents (Ott, 2006).

Coping with Grief and Loss
Iowa City Hospice recognizes that individuals grieve the losses associated with dementia in their own unique ways and in their own time. Experiencing grief is a journey, and what is helpful for one person may not be helpful for another. Our experience has shown that many caregivers may find the following suggestions to be beneficial:

Support groups can help caregivers cope with grief and loss. Being with other caregivers and expressing thoughts and feelings without being judged can be therapeutic (Ott, 2006).

Sharing feelings with a friend, spiritual leader, social worker or counselor may be beneficial. For others, creative writing, keeping a journal, maintaining friendships, doing favorite hobbies and exercising are examples of healthy ways to deal with the on-going stress of caregiving. Allowing friends, family, professional caregivers, Iowa City Hospice volunteers, and others to assist with care can give the caregiver time to do things that are important to him or her.

Putting together a scrapbook or “Memory Book” can be therapeutic in helping the family remember the loved one throughout his or her life. A Memory Book can help caregivers reminisce and journal about fond memories with their loved one. This book can be shared with family members, professional caregivers, and Iowa City Hospice staff and volunteers.

If you are interested in gaining new insights about your unique experience with grief and loss, please consider completing the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) in the Appendix. This questionnaire was developed to help families identify grief related to caregiving.

Three specific themes are identified in the MM-CGI:
- Personal sacrifice related to caregiving
- Sadness and longing for the relationship as it was prior to dementia
- Worry about the future and feelings of isolation

Following the MM-CGI are suggestions for coping and healing based on your scores. As a caregiver, you do not need to feel alone. Iowa City Hospice staff are available to assist caregivers in coping with grief, accessing community resources, finding respite care, connecting caregivers with a volunteer, providing education and support, and assisting in other ways as needs arise.
Communicating with Your Iowa City Hospice Team

Your Iowa City Hospice team wants to maintain communication with you. Our hope is to provide the highest quality end-of-life care possible according to your needs, preferences, and wishes. It is our responsibility to follow the patient’s, the patient’s Durable Power of Attorney for Health Care (DPOA-HC), and family’s treatment goals for care, develop a plan for communicating, provide updates, communicate changes, and be available for questions, education, and support. Iowa City Hospice also works closely with other primary caregivers such as nursing home staff, assisted-living facility staff, adult day health center staff, in-home providers, and hospital staff to coordinate care.

Other Iowa City Hospice Team members include:

The Attending Physician
The attending physician and Iowa City Hospice Medical Director approve admission to Iowa City Hospice. The Iowa City Hospice Medical Director, Nurse Case Manager and attending physician consult with one another and coordinate care.

Nurse Case Managers
Iowa City Hospice nurses specialize in pain and symptom management. The patient and family are assigned to a nurse case manager, who is responsible for planning and coordinating care. He or she also supervises the hospice aides. The nurse case manager visits one to three times per week – or as needed. Visits may increase as the patient declines. Iowa City Hospice on-call nurses are available 24 hours a day, seven days a week.

Social Workers
Iowa City Hospice social workers specialize in helping individuals and families cope with emotional and social issues related to dementia and other terminal illnesses. They provide education and support, facilitate family meetings, and connect people with resources in the community.

Medical Directors
The Iowa City Hospice medical directors are specialists in palliative (comfort) and end-of-life care. They advise the team and work with the attending physician to guide care.

Pharmacists
Iowa City Hospice pharmacists are experts in symptom management and advise the team, making suggestions on how comfort can be improved, and how side-effects of medication can be reduced.

Spiritual Counselors
Iowa City Hospice spiritual counselors specialize in helping individuals and families with spiritual issues they may face. They support individuals’ and families’ beliefs and practices, and offer rituals such as prayer or readings that provide comfort. They assist in memorial service or funeral planning, and sometimes lead a service when requested.
Hospice Aides
Iowa City Hospice aides assist with personal care, such as bathing, showering and getting dressed. They can help transfer patients, provide light massage, do basic nail care, and apply lotions. They teach caregivers how to provide personal care safely.

Music Therapists
Iowa City Hospice music therapists are professionals who use music in various ways to work toward a non-musical goal. Common goal areas include reducing pain and agitation, and exploring and expressing emotional, spiritual, and social themes through music.

Volunteers
Iowa City Hospice volunteers are specially trained people who visit patients for companionship, provide household assistance, lend an empathetic ear or a hand to hold, and provide respite for the family.
- Creating a Low-Stimulus Milieu (CALM™) Volunteers have received additional training to help meet the needs of patients with dementia and their families.
- Final Days Volunteers provide daily respite for families during the last days of a patient’s life.
- 11th Hour Volunteers sit with patients and families in the last 24-48 hours of life, providing support and comfort while a patient is actively dying.

Bereavement Counselors
Iowa City Hospice grief counselors specialize in providing education and support to families, friends, and caregivers after the death of a loved one. They also facilitate support groups for the community.

Education and Outreach Social Workers offer education and support to all community members whether or not they are receiving or have received hospice services.
- In collaboration with Pathways Adult Day Health Center, Iowa City Hospice offers a Caregiver Support Group the first and third Wednesdays of the month from 1:00-2:30 p.m.

Grief Support Groups for Adults:
- A group for those whose spouse or partner has died meets the first and third Wednesdays from 5:00-6:00 p.m.
- A group for those who have experienced a significant loss by death meets the last Wednesday of each month from 6:30-8:00 p.m.
- Understanding Your Grief is a six-week support group for those who have experienced the loss of a loved one. It is offered in the summer and winter.

Grief Support Groups for Children and Youth meet on the second Tuesday of the month from September through May from 6:00-7:30 p.m. A pizza supper is provided.
- KUL (Kids Understanding Loss), a group for children ages 5-10
- ROLL (Respect Our Life Losses), a group for youth ages 11-15
- Parents and caregivers meet separately in their own support group

For updated information on groups and educational offerings, please refer to the Iowa City Hospice website (www.IowaCityHospice.org).
Eligibility for Hospice

It is not unusual for individuals with advanced dementia to fluctuate in health. They may experience periods of seemingly better symptom control and overall increased well-being, as well as periods of seemingly drastic decline. Iowa City Hospice follows Medicare guidelines for admission into hospice as well as recertification. Cases are regularly reviewed to ensure that patients continue to meet hospice criteria for participation.

A person with dementia may be discharged if he or she stabilizes or improves in health over a period of time. If this occurs, we celebrate the patient’s improvement in health and do our best to connect people with resources to maintain the highest level of support for the individual and family.

Persons may be reassessed for admission to Iowa City Hospice at any time. Signs that a person with dementia may qualify for hospice include difficulty swallowing; loss of bladder and bowel control; inability to speak or speaks less than six words; progressive weight loss; and infections. Please call Iowa City Hospice if you believe that your loved one qualifies for hospice admission.

Conclusion

We hope that you have found this document to be helpful to you in learning more about dementia and how to care for a loved one affected by dementia. All individuals and families deserve to receive the highest quality of care throughout this disease process. Care is always guided by the patient’s and family’s goals and wishes. We strive to provide the highest quality end-of-life care to everyone regardless of age, background or insurance coverage.

Iowa City Hospice is honored to provide care during your journey with dementia. Please call us at 1-800-897-3052, or visit our website at www.IowaCityHospice.org for more information on our services and how we can be of assistance to you and your loved one.

“It had been years since someone just asked what Mom liked and did before her dementia. You made her a person again, and I will never know how to thank you for your unending support. You were, most times, the only people I could lean on.

Thank you, thank you, thank you.”
- An Iowa City Hospice Family Caregiver
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Centers for Disease Control (CDC) and Prevention, National Center for Health Statistics. (2010). *Mortality data from the national vital statistics system*, accessible at www.cdc.gov/nchs/deaths.htm


Rural Iowa Alzheimer’s Demonstration Grant; AoA Grant #90AZ2774. (2004-2007). *Enhancing capacity for dementia specific adult day care and respite for rural and emerging minority populations*. Iowa Department of Elder Affairs with the University of Iowa College of Nursing.


**Additional Resources**

*The 36-Hour Day*
– by Nancy L. Mace and Peter V. Rabins
A Family Guide to Caring for People with Alzheimer’s Disease, Other Dementias, and Memory Loss in Later Life.
Publication: November 2006

*Ambiguous Loss: Learning to Live with Unresolved Grief*
– by Pauline Boss
Boss explains that those confronted with ambiguous loss fluctuate between hope and hopelessness. Readers will relate to the provocative examples and stories included.
Publication: October 2000

*What If It’s Not Alzheimer’s? A caregiver’s guide to dementia*
– by Lisa Radin and Gary Radin
This guide for caregivers covers the medical aspects of frontotemporal dementia (FTD), which is one of the largest groups of non-Alzheimer’s dementias.
Publication: April 2008

*Alzheimer’s Dementia and Memory Loss: Straight talk for families and caregivers*
– by Monica Vest Wheeler
Wheeler interviews caregivers and families on how to overcome frustration, loneliness, and grief experienced when caring for loved ones with Alzheimer’s, dementia or memory loss.
Publication: January 2008
**Still Alice**
– by Lisa Genova
A fictional account of a 50-year-old woman’s descent into Alzheimer’s disease.
Publication: January 2009

**Final Journeys: A Practical Guide for Bringing Care and Comfort at the End of Life**
– by Maggie Callanan
This book was written by a hospice nurse and is designed to be used as a companion, resource, and advocate from diagnosis through the final hours of life. There is useful information designed to help families keep the lines of communication open, get the help they need, and create the peaceful end we all hope for.
Publication: March 2008

**Alzheimer’s from the Inside Out**
– by Richard Taylor
The author shares his personal account of the early stages of Alzheimer’s disease and the slow transformation and deterioration, along with the growing division between his world and the world of others.
Publication: December 2006

**The Alzheimer’s Project: Momentum in Science**
– by John Hoffman
A four-part documentary series changing the way America thinks about Alzheimer’s Disease by looking at the groundbreaking discoveries made by top scientists in the field of Alzheimer’s research.
Publication: March 2010
A Dignified Life: The Best Friend’s Approach to Alzheimer’s Care
– by Virginia Bell and David Troxel
This book offers an enlightened approach to Alzheimer’s care for anyone faced with the responsibility of caring for someone with Alzheimer’s, either at home or a medical facility.
Publication: September 2002

Sometimes Ya Gotta Laugh: Caregiving, Laughter, Stress and Alzheimer’s Disease
– by Karen Stobbe
Written by a caregiver, this book offers facts and insights on the topic of Alzheimer’s disease. Stobbe tells stories about ways to find humor in successful caregiving.
www.in-themoment.com/director-sometimesyagottalaugh.asp

Alzheimer’s Disease: Unraveling the Mystery
– by the National Institute on Aging of the National Institutes of Health
Explains what Alzheimer’s disease is. Describes what has been learned to date about the disease. Provides a glimpse into future directions for research.
Publication: September 2008

Learning to Speak Alzheimer’s
– by Joanne Koenig Coste
A groundbreaking approach for everyone dealing with the disease, this guide for families presents an approach to caring for people with Alzheimer’s disease that emphasizes the importance of communicating with patients by focusing on their emotional language.
Publication: September 2004
**Marwit-Meuser Caregiver Grief Inventory (MM-CGI)—Short Form**

**Samuel J. Marwit, Ph.D., University of Missouri, St. Louis**  
**Thomas M. Meuser, Ph.D., Washington University, St. Louis**

**Instructions:** This inventory is designed to measure the grief experience of family caregivers of persons living with a progressive dementia, such as Alzheimer’s disease. Read each statement carefully, and then decide how much you agree or disagree. Circle the number 1-5 that reflects your response using the answer key below. It is important that you respond to all items so that scores are accurate.

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I’ve had to give up a great deal to be a caregiver.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>I feel I am losing my freedom.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>I have nobody to communicate with.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>I have this empty, sick feeling knowing that my loved one is “gone.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>I spend a lot of time worrying about the bad things to come.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>Dementia is like a double loss…I’ve lost the closeness with my loved one and connectedness with my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>My friends simply don’t understand what I’m going through.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>I long for what was, what we had and shared in the past.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>I could deal with other serious disabilities better than with this.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>I will be tied up with this for who knows how long.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>It hurts to put her/him to bed at night and realize that she/he is “gone.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>I feel very sad about what this disease has done.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>I lay awake most nights worrying about what’s happening and how I’ll manage tomorrow.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>The people closest to me do not understand what I’m going through.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>I’ve lost other people close to me, but the losses I’m experiencing now are much more troubling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>Independence is what I’ve lost…I don’t have the freedom to go and do what I want.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>I wish I had an hour or two to myself each day to pursue personal interests.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>I’m stuck in this caregiving world and there’s nothing I can do about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Scoring Procedure:** Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you.

- **Personal Sacrifice Burden** (*six A Items*)  
  (High score is greater than 25)

- **Heartfelt Sadness & Longing** (*six B Items*)  
  (High score is greater than 25)

- **Worry & Felt Isolation** (*six C Items*)  
  (High score is greater than 23)

- **Total Grief Level** (Sum A + B + C)  
  (High score is greater than 70)

**Plot your scores** using the grid at right. Make an “X” nearest to your numeric score for each sub-scale heading. Connect the X’s. This is your grief profile. Discuss this with your support group leader or counselor.

**Authors’ Note:** This scale may be copied and freely used for clinical or supportive purposes. Those wishing to use the scale for research are asked to email for permission: meusert@abraxas.wustl.edu (5/04).
Suggestions for Coping and Healing
Based on MM-CGI Subscale Scores

High scores in two or more areas may indicate symptoms of depression in addition to high levels of grief. Further evaluation from a medical and/or behavioral health professional is recommended.

Low scores in two or more areas may indicate adaptive coping or denial of grief-related issues.

Below are some suggestions for coping and healing in each of the three CGI subscales:

<table>
<thead>
<tr>
<th>MM-CGI Subscales</th>
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<tbody>
<tr>
<td>Personal Sacrifice Burden (PSB)</td>
<td>Addresses what the caregiver must give up to function in the care giving role</td>
<td></td>
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<tr>
<td>· Use respite services on a regular basis</td>
<td></td>
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<tr>
<td>· Involve other family members and/or friends in person’s care</td>
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<tr>
<td>· Consider use of long-term care services such as:</td>
<td></td>
<td></td>
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<tr>
<td>· Home care</td>
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<td></td>
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<tr>
<td>· Adult day health care</td>
<td></td>
<td></td>
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<tr>
<td>· Assisted living/nursing facility</td>
<td></td>
<td></td>
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<tr>
<td>· Hospice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heartfelt Sadness &amp; Longing (HSL)</td>
<td>Refers to personal sadness and separation pain, traditionally understood as grief in our society.</td>
<td></td>
</tr>
<tr>
<td>· Learn new ways to adjust the relationship while remaining connected to the person through:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>· Music</td>
<td></td>
<td></td>
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<tr>
<td>· Massage/Touch</td>
<td></td>
<td></td>
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<tr>
<td>· Spiritual/Religious practices</td>
<td></td>
<td></td>
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<tr>
<td>· Humor/laughter</td>
<td></td>
<td></td>
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<tr>
<td>· Food</td>
<td></td>
<td></td>
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<tr>
<td>· Celebrations/Ceremonies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>· Other</td>
<td></td>
<td></td>
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<tr>
<td>Process feelings of loss through:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>· Peer/group support</td>
<td></td>
<td></td>
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<tr>
<td>· Journaling</td>
<td></td>
<td></td>
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<tr>
<td>· Memory books</td>
<td></td>
<td></td>
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<tr>
<td>Worry &amp; Felt Isolation (WFI)</td>
<td>Represents a more pervasive depression-like sense of uncertainty and feelings of social isolation</td>
<td></td>
</tr>
<tr>
<td>· Learn about and plan for progression of dementia</td>
<td></td>
<td></td>
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<tr>
<td>· Develop and maintain social connections through:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>· Family and friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>· Social and recreational activities/interests</td>
<td></td>
<td></td>
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<tr>
<td>· Peer/group support</td>
<td></td>
<td></td>
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<tr>
<td>· Telephone support services</td>
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</tbody>
</table>

Please note: Support groups and other forms of emotional support that offer education, open discussion, and nonjudgmental listening can be helpful in all the above areas.
My name is _______________________________. My nickname is _______________________________.

I was born on ____________ [date] in ________________________________ [city, state, country].

I have lived in ________________________________________________________________ (places, countries, etc).

I (am/am not) married/partnered and (have/do not have) children. Their names are ________________________________________________________________.

I (have/do not have) ______ grandchildren and ______ great-grandchildren. Their names are ________________________________________________________________.

Other significant people in my life include ________________________________________________________________.

I have/had ____ brothers and sisters. Their names are ________________________________________________________________.

My first language is ________________________________________________________________.

My spiritual/religious affiliation is ________________________________________________________________.

My occupation is/was ________________________________________________________________.

My favorite activities include ________________________________________________________________.

I do not like to participate in ________________________________________________________________.

My favorite food is ________________________________________________________________.

My favorite music is ________________________________________________________________.

My favorite photos/art/books are ________________________________________________________________.

I (do/do not) like animals (Specify) ________________________________________________________________.

I do/do not like touch (Specify) ________________________________________________________________.

It is normal for me to be ________________________________ during personal care activities. Activities that make personal care better for me include:

_______________________________________________________________________________________

_______________________________________________________________________________________

Other things that are important for my care (routines, rituals, etc.):

_______________________________________________________________________________________

_______________________________________________________________________________________

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