

# *Caring for Someone with Memory Loss*





Caring for someone with memory loss is tough work — both physically and mentally. It requires your knowledge, creativity and patience, as well as the help of many people to do this special work effectively.

This booklet is intended to provide basic information to help those who are caring for a loved one with memory loss and related challenges. The Rainbow Hospice and Palliative Care team is trained in brain disorders and are available to assist you when you need us. We are committed to helping everyone in our care – the individuals who are seriously ill as well as their family members and friends.

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# Memory Loss and Related Challenges

Forgetfulness is a normal human condition, but it can become a serious problem due to a medical illness known as dementia. This refers to a slow, progressive loss of different brain functions including memory, thinking, language and self-care skills. There are many types of dementia, with Alzheimer's disease as the leading type. Large and small strokes can cause dementia too.

Unfortunately, there are no medications or other treatments to reverse or stop the progression of dementia. There are a few prescription drugs that may slow it down, but they are not effective in most cases. Dementia usually unfolds over many years and can be categorized by four stages: early, middle, late and final. These stages are described here so you can understand the changes in your loved one and adjust your expectations to suit his or her special needs. Keep in mind that at any stage, much can be done to provide comfort and maximize quality of life for someone with dementia.

Some people with dementia remain in the early to middle stages for many years and may have other chronic or terminal illnesses. They may die as a result of these other medical conditions. However, their care is often complicated by their symptoms of dementia. For example, in addition to forgetfulness about recent events, they may lack insight into their limitations or use poor judgment, making it difficult to gain their cooperation or to reason with them. It is important to remain calm in the face of irrational behavior and to accept it as part of the medical condition. If they become upset, it is important to consider their perspective.

Perhaps they are experiencing distress because of physical pain or feeling overwhelmed by sights and sounds.

People with dementia who survive to the late and final stages are severely impaired. They require full-time care and are often moved from their home into a residential care facility such as a nursing home. Just as brain functions slowly diminish over time, personal awareness about their limitations diminishes too. Their sense of time is lost and they no longer compare their current life to their past life. They may be content in the “here and now.” They may not recall their current loved ones but may recall relatives and friends from the distant past. Their confusion may lead them to believe that deceased relatives are still living. It is important to honor their own personal timeline instead of forcing them into our reality.

By the final stage of dementia, people lose their ability to recall any recent and past memories. They also lose other abilities such as eating, walking and talking. Swallowing problems may occur too. Death is often triggered by pneumonia or another infection but the actual cause of death is the underlying dementia.



These charts summarize the typical course of dementia in the early, middle, late and final stages, as shown by several affected brain functions. These stages and symptoms often overlap and the rate of progression varies from person to person. Since everyone is a unique individual, this chart may not exactly fit your situation.

	Early Stage	Middle Stage
<b>Memory</b>	Loss of short-term memory much of the time; repeats oneself.	More consistent loss of short-term memory and some long-term memory.
<b>Language</b>	Trouble finding words and keeping track of conversations.	More trouble completing sentences and understanding others.
<b>Orientation to Place and Time</b>	May get lost in unfamiliar places and lose track of time and dates.	May get lost in familiar places and lose track of months and years.
<b>Movement and Muscle Control</b>	Trouble writing and using familiar objects.	Difficulty coordinating movements of hands and feet.
<b>Mood or Behavior</b>	May appear withdrawn, apathetic, depressed or irritable. Less interest in hobbies or new activities.	May appear more withdrawn, depressed, irritable or agitated.
<b>Self-Care Skills</b>	Needs reminders with household tasks such as cooking, shopping, managing money and taking medications.	Needs additional reminders and help with personal care tasks such as dressing and bathing.

	Late Stage	Final Stage
<b>Memory</b>	Mixes up the past and the present. May “time travel” to an earlier period of life.	No apparent awareness of the past or present.
<b>Language</b>	Severe difficulty expressing and understanding words; reverts to first language.	Uses few words or is mute.
<b>Orientation to Place and Time</b>	Has trouble identifying familiar people and places.	Seemingly unaware of surroundings.
<b>Movement and Muscle Control</b>	May have trouble walking, develop tremors or rigidity.	Little purposeful movement; difficulty swallowing and breathing.
<b>Mood or Behavior</b>	May experience agitation, hallucinations or delusions.	Completely passive and may sleep more often.
<b>Self-Care Skills</b>	Needs help with nearly all tasks such as dressing, eating, bathing and toileting.	Requires help with all tasks.

# What do People with Dementia Need?

At any stage of dementia, it is important to focus on the comfort and well-being of the person who is experiencing changes in memory, thinking, language and so forth. A good quality of life is still possible but loved ones may need to make adjustments in how they relate to the individual whose brain is no longer functioning normally. You and others can learn new and creative ways of doing things and communicating with someone with dementia.

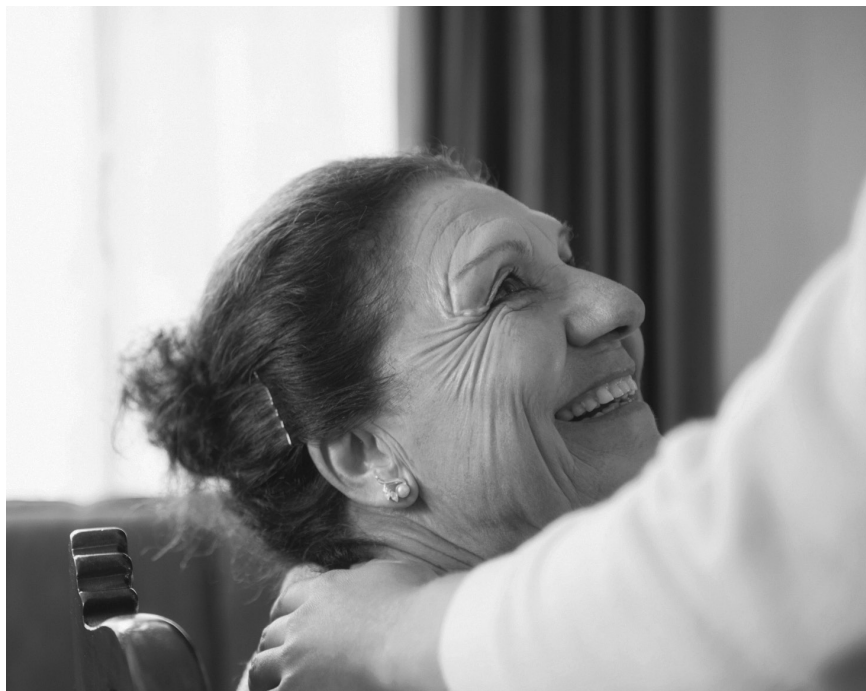
In the early to middle stages, people with dementia may be aware of their difficulties with memory and thinking. Some are disturbed by the changes in their abilities but most are not — they manage to adapt or simply forget that they are forgetful. They need reminders to keep track of their activities and conversations. They need reassurance that they are still valued in spite of their limitations. They need encouragement to continue using their remaining abilities. They need practical help doing things they are struggling to do on their own.

*Above all, they need patient and compassionate partners in their care.*

In short, they need a best friend who will remind them that they are loved and respected. With such support and assistance, they may cope surprisingly well with dementia symptoms.

In the late and final stages, people with dementia are often unaware of their difficulties. Although you and other loved ones know how they once managed independently, people





with dementia seldom complain about their disabilities. They tend to live quietly in the “here and now” and are sensitive to their immediate surroundings.

As a result, they respond positively to people who speak and act kindly and react negatively to people who are insensitive. They no longer can rely primarily upon words for communication. They need people who will engage them using all five senses — touch, taste, sound, sight and smell. This requires care partners to develop new and creative ways to make meaningful connections.

*We are eager to help you find new ways of communicating with your loved one.*

People with dementia may sometimes become irritable, angry or withdrawn. It is important to look for reasons for such changes in behavior or mood. Changes are often reactions to actual or perceived threats to their wellbeing. For example, a noisy or busy environment may increase their confusion. Also, fear or worry may trigger unpleasant reactions.

Hurrying or coercing people with dementia is likely to result in negative reactions on their part. Depression may lead to social isolation, sleep disturbances and loss of appetite. Physical problems, such as constipation and pain, may be expressed in unpleasant behaviors such as agitation or resistance to care.

Sudden changes in behavior such as aggressiveness and fatigue may result from infection or dehydration and need to be medically evaluated and treated. Likewise, hallucinations (seeing or hearing imaginary things) and delusions (such as paranoid thoughts) may be upsetting and require medical attention too. By anticipating the physical and emotional needs of people with dementia, such problems and unpleasant reactions may be avoided or minimized.

Again, we are eager to problem solve with you and find creative solutions.

## **Communication is Key**

It is important for you to communicate in ways that match the needs and abilities of your loved one with dementia. The following tips may be useful:

### ***Identify yourself.***

Approach from the front, make eye contact and introduce yourself. Such cueing will help orient the person. If your loved one no longer recognizes you, it's fine to just say that you are an old friend who has come to visit.

### ***Limit distractions.***

Find a place that is quiet, so you both can focus on the visit or interaction.

### ***Set a positive tone.***

Your attitude and body language communicate your feelings and thoughts more strongly than your words. Speak to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show affection.

### ***Use short sentences and be patient.***

Don't overwhelm the person with information or lengthy stories. Speak slowly and get to the point. Wait patiently for a reply. If you get no response, wait a moment and ask again. Use the same phrasing or simplify what you've just said.

### ***Offer comfort and reassurance.***

If the person is having difficulty expressing themselves, let them know it's okay. Encourage words and thoughts, no matter how jumbled. The content is not as important as the feelings being expressed.

### ***Offer a guess.***

If the person appears frustrated, try helping out. Listen to the tone of voice. As long as you understand, the right words may not be necessary.

*Avoid criticizing or correcting.*

Don't tell the person that what he or she said may be incorrect or untrue. Rather, listen and try to find the meaning in what is being communicated. If something is said that you don't agree with, let it be. Don't argue, it simply does not help.

*Avoid quizzing.*

Reminiscing can be fine, but avoid asking, "Do you remember when...?" or "Do you know my name?" Provide facts or photos to help trigger fond memories of the past.

*Give simple directions.*

Break tasks and instructions into simple steps, one step at a time.

*Turn questions into answers.*

Try providing the solutions, rather than the question. For example, say "The bathroom is right here" instead of asking, "Do you need to use the bathroom?"

*Use sensory items.*

If words are no longer effective, gather some items to make meaningful connections using the five senses.

For example, hand lotion may be used to give and receive a hand massage or peppermint patties may be shared to stimulate taste. Life-like dolls, stuffed animals or pets may also be sources of comfort. Music and song can be very powerful in triggering pleasant feelings. We can suggest other things that may be effective in creating a bond with your loved one.

## Care for the Caregiver

It is well documented that caring for someone with dementia is extremely challenging. It can be taxing emotionally, physically, financially and spiritually. It is normal to experience grief in light of the series of changes and losses that you experience due to your loved one's dementia.

Denial, anger and sadness are common reactions when someone dies but are also common when a loved one is living with dementia. If such feelings of grief are not confronted or managed properly, health problems including depression and anxiety may develop. We are here to help you manage these feelings.

It is important that you take active steps to take care of yourself in order to prevent or minimize such fallout. Give yourself permission to care for yourself. If you do not



practice self-care, your loved one with dementia may suffer the consequences. On the other hand, if you take care of yourself, your loved one will benefit from having someone whose life is balanced. The question is: How to achieve this balance? By definition, self-care is an individualized endeavor. What may be helpful to you may not “work” for another person. Nevertheless, the following practices have been known to promote personal wellbeing:

***Listen to your body.***

Be sure to eat and drink properly, exercise regularly and get plenty of rest. Take time out daily for quiet reflection, prayer or meditation. You may need the help of others to accomplish these goals. Do not hesitate to ask for help or hire someone to help so you can get a well-deserved break. Enlisting help may be beneficial to both you and your loved one. If you do not pay attention to these basic needs, you run the risk of becoming worn down.

***Listen to your mind and spirit.***

It is normal to feel upset by the changes in your life due to dementia. Thoughts and feelings of frustration, loneliness and sadness can be overwhelming. You may feel cut off from friends and family as a result of your care responsibilities. Again, do not hesitate to get help. But you may also need others to help you manage your feelings. Talk to someone, such as a confidante, minister or a professional counselor.

Consider taking part in a local support group sponsored by the Alzheimer’s Association (800–272–3900) where you can be with other people who are also coping with a loved one’s dementia. Remember, Rainbow is here to listen and respond to you, both before and after the death of your loved one.



Caring for a loved one with dementia is challenging but may be rewarding too. You are in a unique position to enhance the quality of life of someone who needs care due to declining abilities. Your loving presence and practical help may empower someone to feel valued and loved in spite of limitations with memory, thinking and language. At the same time, maintaining your wellbeing is essential too.

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We are here to help both you and your loved one to be as comfortable as possible. Do not hesitate to ask how we might assist. Someone is always on hand to speak to you:

**(847) 685-9900**

*Caring for Someone with Memory Loss* is published by Rainbow Hospice and Palliative Care as part of our *Dementia with Dignity* program. We provide highly skilled professionals in many disciplines as well as experienced volunteers who are specially trained in caring for individuals and families affected by dementia.

Rainbow Hospice and Palliative Care empowers our community to live with hope and resilience throughout the journey with illness and loss.

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