



Wisconsin Alzheimer's Institute

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



Home Health Guide

Information for Caregivers

A comprehensive guide for caregivers to prevent, identify, and manage the medical issues commonly associated with moderate to severe dementia

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Dementia Basics

Information for Caregivers

Dementia Basics

The education materials provided to you by the home health agency were designed for caregivers of people with moderate to severe dementia. Dementia means a loss of memory and other cognitive abilities, to the extent that a person's daily life and functioning are affected¹. Dementia is a general term. There are many different causes of dementia. The most common cause of dementia is Alzheimer's disease. Dementia can also be caused by blocked or reduced blood flow to the brain, such as a stroke. This is called vascular dementia. Some other causes of dementia include Parkinson's dementia, and dementia with Lewy bodies. All causes of dementia result in damage to the brain. This damage can result in memory problems, personality changes, and problems with mobility, speech, or judgment.

People with dementia decline over time. Memory becomes more impaired and the person may have other problems that make caregiving challenging. People with dementia need more care as their condition advances. Things that once came easily become a struggle, such as turning on the television, making a sandwich, getting dressed, or using the bathroom. In addition, people with dementia often develop changes in their behavior, such as agitation, anxiety, wandering, or repetitive speech. How quickly a person will decline depends on many factors including the cause of the dementia or other medical problems the person may have.

Dementia can be characterized by stages. These stages help professional caregivers and health care providers understand the needs of the person with dementia and their caregivers. We know that as dementia progresses to more severe stages, people become at risk for medical complications, such as trouble swallowing, eating, or drinking. This workbook addresses how to prevent, identify, and manage these complications to avoid pain, suffering, and trips to the hospital.

Moderate Stage Dementia

In the middle, or moderate stages of dementia, people have more trouble with language and completing regular daily activities, such as bathing and dressing². Other common concerns in the moderate stage include:

Communication – It may be more difficult for the person to understand others and express him or herself. The person may forget words, repeat questions, or lose a train of thought. The person may become very frustrated when trying to communicate or follow a conversation.

Behaviors – At this stage many people with dementia experience one of the following: depression, anxiety, irritability, repetitive behaviors, sleep changes, emotional outbursts or wandering. See the Behavior Changes module for more information on this topic.

Daily care – In the moderate stages the person will need more help with every day activities such as dressing and bathing.

Safety – At this stage, most people with dementia cannot safely operate a car or other motor vehicles such as a tractor or riding lawn mower. Many people at this stage can no longer be left alone, or can only be left alone for designated periods and with careful planning. Other safety concerns include how the person takes medications, firearms, and trip hazards.

Medical complications – In the moderate stage, people are more likely to have falls and may begin to lose weight, and have swallowing difficulties and incontinence, among other problems.

The goal in moderate dementia is to help a person maintain engagement with meaningful activities as much as possible. The person may begin to suffer from medical complications, but with attention to prevention, early identification, and home management, hospitalizations can often be avoided so the person can stay as healthy as possible.

TEACH BACK

What are two characteristics of the moderate stage of dementia?

1. _____
2. _____

Severe Stage Dementia

Late stage, also called severe stage dementia, is characterized by a big decline in all areas of memory, cognition, and physical abilities. Some characteristics of severe stage dementia include:

- Inability to recognize family members
- Delusions, anxiety, agitation
- Remembering few, if any, details of childhood or early life
- Inability to walk
- Inability to speak
- Incontinence of bowel and bladder

This stage can last a few weeks to several years². People with severe dementia usually need around-the-clock care and help with every aspect of everyday life, including eating and drinking. People at this stage are much more likely to have a medical complication, but also much less likely to benefit from hospitalization. Some medical complications common to severe dementia include pressure injuries, infection, urinary and fecal incontinence, swallowing problems, and dehydration. In the severe stages, the goals of care shift to maintaining dignity and preserving quality of life.

When the person you care for transitions into the severe stage of the disease, it is important to talk to the home health staff about goals of care. At this stage, it is often appropriate to consult with palliative and hospice care (see Hospice and Palliative Care module).

TEACH BACK

What are two characteristics of the severe stage of dementia?

1. _____

2. _____

Hospitalizations in Moderate to Severe Dementia

An emergency room visit or hospital stay can be very difficult for a person with moderate to severe dementia. As dementia progresses, it is very difficult to process new routines, people, or environments. A hospital trip can be disorienting and frightening. People with dementia may experience delirium in a hospital stay. Delirium is a sudden change in attention and cognitive abilities. In cooperation with the health care team, caregivers are instrumental in helping to prevent, identify, and manage medical complications of dementia to avoid hospitalizations for people with dementia.

Avoiding Hospitalizations and Emergency Room Visits

The key to avoiding hospitalizations is to identify medical problems early and seek help from home health staff or the primary care provider. Problems caught early can often be treated at home. A sudden change, or a two to three day worsening in thinking, function, or behavior, is not due to the dementia getting worse. Most often, this means there is a medical problem, such as an infection. The home health team or primary care provider will assess the person you care for to find out what is wrong, and start treatment so the person can stay at home.

TEACH BACK

What is the key to preventing hospitalization when a person with dementia begins to suffer a medical complication?

REFERENCES:

1. Alzheimer's Association (2016). Basics of Alzheimer's Disease: What it is and what you can do.
2. Alzheimer's Association (2017). Late-Stage Care: Providing care and comfort during the late stage of Alzheimer's Disease.



Caregiver Role Strain Information for Caregivers

What is Caregiver Role Strain?

Caregiver – A caregiver, care partner, or carer is an individual (paid or unpaid) who provides any type of assistance to another person who is ill, disabled, elderly, or needs help. Such assistance includes helping with shopping, organizing mail/bills, preparing meals, mowing the grass, housekeeping, laundry, or taking them to doctor appointments. The caregiver role for family members and friends tends to evolve naturally, with the individual not recognizing they are a caregiver, and that they also need support (Source: Jody Krainer, MSW, LCSW, MBA, Dementia Diagnostic Clinic Network Manager).

Source: UW Health Health Facts for You, “Caregiver Role Strain.” © 2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6921 (<https://patient.uwhealth.org/healthfacts/6921>)

What are signs of role strain?

Social withdrawal
Loss of interest of hobbies
Excessive anger
Health problems
Sleep problems (too much or not enough)
Feeling very tired
Thoughts of death or suicide
Irritability
Change in appetite
Trouble concentrating
Feeling worthless or guilty
Crying easily or for no reason
Loss of interest in sex
Moody

Caregiver role strain – When caregivers find it hard to perform their roles or feel stressed because of:

- Financial burdens
- Increased responsibility
- Change in family life
- Role change

Is What I am Feeling Normal?

Yes, it is normal. It is not easy to care for someone with an illness. As a caregiver of a loved one it is normal to feel lonely, angry, or guilty.

What Can I Do?

Do not ignore your own needs. Taking care of someone takes a lot of energy. It is important to care for your own health. Accept that there is a limit to what you can do.

Organize your life. Write down your daily routine. Put the list in the order of importance. It is okay to change your priorities when something out of your control happens. Have easy access to the person's health records and make sure they are in order. Have a list of phone numbers, medicines, and other important information. Know your limits. Know that there are things you cannot control.

Build a support team. These are people you can count on at any time. Do not be afraid to ask for help. Accept help if someone offers. Your support team may include family members, friend, chaplain, counselor, nurse, or doctor. Make sure to talk with your support team about your feelings. Keep a journal. Take time out for yourself. Spending time with family and friends is a great way to relax. We also suggest you use home health care, family, friends, or respite care. It is okay for you to take time to enjoy your favorite pastime at least once a week. The support from others is the key to your success.

Eat healthy meals everyday. Fruits, vegetables, whole grains, and plenty of water are a great way to start. Use your favorite foods during stressful times as a comfort food. Prepare extra portions and place them into containers to freeze for a quick meal. Consider Meals on Wheels and other programs that provide healthy meals at a small charge delivered right to your home.

Look at the positives. Take pride in what you know and what you can do. Although giving care can be hard, you are doing great things for your loved one. Use humor.

Find time together. You are a team. Talk about the care you provide and your relationship. Find time together to do things you enjoy. You could go for a picnic or on a date.

Take care of your own health. Allow yourself to take a break from care giving. It is healthy for you and your loved one. To care for someone you also need to care for yourself. To care for yourself:

- Get plenty of sleep
- Exercise often
- Do quick stretches to help reduce tension and maintain muscle tone
- Keep your faith
- Keep doing the things you enjoy
- Don't forget to laugh

Where Could I Go for More Help?

Talk with a member of your health care team if you are feeling any symptoms of strain. Below is a list of resources that may be helpful.

When your loved one's life changes, so does yours.

Support Group at UW-Hospital G5/142: To sign up call Penny at 608-263-8574 or email pandrews@uwhealth.org

Share the Care, book by Cappy Caposseia and Sheila Warnock, Fireside, 2004.
www.sharethecare.org

Area Agency on Aging of Dane County: <https://aaa.dcdhs.com/>

Today's Caregiver Magazine: www.caregiver.com

Family Caregiver Alliance: www.caregiver.org (Bilingual information in Spanish, Chinese, Korean and Vietnamese.)

Family Caregiving 101: www.familycaregiving101.org

National Caregivers Library: www.caregiverslibrary.org

Medicare Information and Resources: www.medicare.gov

Eldercare Locator: www.eldercare.acl.gov/Public/Index.aspx

You can also contact an organization specific to your diagnosis to see what they have to offer.

TEACH BACK

How would you describe caregiver role strain in your own words?

TEACH BACK

What are two ways to reduce caregiver role strain?

1. _____

2. _____

REFERENCES:

Rolland, J. S. (1994). In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy*, 20(4), 327.

Novielli, K.D., & Mockus Parks, S. (2000). A practical guide to caring for caregivers. *American Family Physician*, 62(12).



Falls

Falls can have devastating consequences for any person. Individuals with dementia are twice as likely to fall as older adults who do not have dementia. When someone with dementia falls, he or she is more likely to have a serious injury, become hospitalized, have a permanent disability, or require care in a nursing home.

There are many different causes for falls, and often when someone falls, there is more than one cause. Individuals with dementia are more likely to fall because they typically have problems such as:

- Difficulty with walking or balance
- Inability to recognize obstacles or move around them
- Decreased judgment
- Decreased vision
- Urinary incontinence
- Weakness due to lack of physical activity and/or damage to areas of the brain associated with movement
- Wandering
- Side effects from medications

Individuals with dementia may have other health problems that contribute to the risk of falling. For example, individuals with diabetes or serious back problems can lose feeling in their feet, making balance much more difficult. Individuals with heart disease or anemia might have low blood pressure, causing a person to be lightheaded or woozy. Dehydration can lead to low blood pressure. Individuals with diabetes might also fall due to low blood sugar if he/she is not eating enough.

Does the person you care for have other medical problems? Discuss them together with the home health clinician to see if any of these conditions might add to the risk of falls.

TEACH BACK

Consider the person who you care for; what are two things about that person that increase their risk for a fall?

1. _____
2. _____

Prevention

Sometimes individuals fall due to a health problem like dementia, diabetes, or arthritis. Sometimes individuals fall because of a hazard in the environment. There are things you can be alert to in preventing falls.

Mobility – How is the person moving? Does he/she hang on to the furniture to walk? Is walking more difficult? Does the person wear solid shoes in the home, rather than slippers or socks?

Bathroom – Is the person impulsive about going to the bathroom? If he/she has to wait, will that cause him/her to get up quickly without waiting for assistance? Could this be avoided by prompting the person to use the bathroom more frequently, before it is an emergency? Are there grab bars to hold onto in the bathroom?

Medications – When a new medication is prescribed, ask the provider if it might increase the risk for a fall or if there are other side effects to look out for. Do you notice any changes in mobility after the medication is given? If so, notify the provider's office.

Fatigue – When the person is tired, such as before bed, he/she might have more trouble with walking. Can you get extra help at this time or take more time to get ready for bed?

Trip hazards – Are there a lot of obstacles in the house? Are there rugs on the ground that might cause someone to trip? Are the floors slippery in any part of the house? Are any pets underfoot?

Lighting – Is there good lighting in the house during the day and at night for trips to the bathroom? Are stairwells and hallways well-lit?

Nutrition – Is the person drinking enough fluids and eating well? Is food offered at regular intervals, rather than at mealtimes that are far apart? Encourage the person to move slowly from lying to sitting and from sitting to standing to avoid lightheadedness.

Vision – Does the person wear glasses, especially multi-focal lenses, which can increase fall risk? Has their vision prescription been updated recently? Do you feel their visual awareness of their surroundings has decreased?

Your safety – If the person falls, do you have a plan to help them while staying safe from injury yourself? Are there other people nearby who can help? Do you have equipment to help you move them, such as a gait belt, bath tub bench, or a transport chair? Have you had a therapist teach you safe ways to help them move?

TEACH BACK

What are two changes you could make to the environment or to how you give care to your loved one with dementia that might prevent a fall?

1. _____
2. _____

Management

Despite our best efforts, falls cannot always be prevented. Falls among older adults with dementia are very common. Falls can have serious consequences for the person with dementia, but also the caregiver trying to help the person who has fallen. It is important to have a plan for who to call if the person you are caring for has a fall. Go to the **Resource Guide** and review who you would call in case there is a fall.

Who to call: _____

A health care provider should evaluate the person with dementia for any fall that results in injury, or if the person is suddenly falling a lot or seems more weak or confused. A fall or cluster of falls can be a sign of an illness. Falls rarely have just one cause. There may be ways to prevent a future fall if we understand why a fall happens. You might ask the health care provider to check blood work for anemia, vitamin deficiencies, or thyroid problems because these may be fixable causes of falls.

You can help the health care provider by writing down:

- What was happening when the fall occurred?
- What time of day did the fall happen?
- Where was the fall?
- What parts of the body hit the ground?
- Did the person lose consciousness before or after the fall?
- What happened earlier in the day? Did he/she eat or drink well? Had he/she been sick, more confused, or agitated?
- When were medications given and were there any new medications?
- Were there any new symptoms before or after the fall such as pain, palpitations, or shortness of breath?

TEACH BACK

Name two things you should tell the health care provider about the circumstance of a fall:

1. _____
2. _____



Pressure Injuries

Information for Caregivers

What is a Pressure Injury?

A pressure injury is damage to the skin and underlying soft tissue, usually over a bony area. Pressure injuries are also known as pressure ulcers or bed sores. They can occur when someone sits or lies in one position for too long causing a diminished blood supply and depriving the area of oxygen and nutrients. The skin is a reflection of the health of the whole body. When an individual has one or more chronic diseases, that person is more likely to have problems that show up on the skin. Individuals with dementia are at high risk for pressure injuries for a number of reasons, including:

- Limited movement
- Poor nutrition – loss of muscle mass and fat
- Loss of feeling – for example not noticing pressure from a button, zipper or even an item in the bed
- Incontinence – moisture on the skin leads to skin breakdown
- Poor communication – losing the ability to say if he/she is having pain
- Restlessness or agitation – repeated movements can cause friction or shear that contributes to the development of an ulcer

Prevention of Pressure Injuries

Pressure injuries can be prevented. A healthy person naturally changes position frequently, even when sleeping. People with dementia tend to move much less, so helping the person change positions about every two hours is key to preventing injury to the skin.

- Feel for seams or folds in bedding and clothes, and eliminate them
- Talk to the home health nurse or therapist or primary care provider about padding for the bed to prevent ulcers
- Have the person get out of bed and sit up as much as possible during the day
- When sitting, encourage the person to shift or move even a little every 30 minutes or so
- For individuals who sit in a wheelchair, talk to the home health nurse or therapist about a pad for the chair
- Encourage or assist with standing or walking every two hours if possible
- Talk to an occupational or physical therapist about assistive devices or techniques for helping the person to move or transfer positions safely
- Pat skin dry after bathing, rather than rubbing
- Talk to the home health nurse or therapist about a barrier cream if the person is incontinent of urine or stool
- Avoid tight fitting clothing and synthetic materials
- Have the person wear socks and talk to the nurse about extra padding for the heels
- Provide a healthy diet
- Ask a healthcare provider about a nutrition supplement if the person does not eat well

Pressure injuries are more likely to develop as dementia progresses and the person has more problems with mobility. In the severe stage of dementia, the person is likely to need more help with all their personal care. Nurses, physical therapists, and occupational therapists can be very helpful in providing tips on keeping skin healthy, pressure relieving padding, and assistance with how to move a person with limited mobility. If you notice changes in mobility bring it to the attention of the primary care provider.

TEACH BACK

What are two ways pressure injuries can be prevented?

1. _____

2. _____

Identifying Pressure Injuries

Whenever you help to bathe or dress a person with dementia, it is important to closely examine the skin. Pressure injuries can be present without a break in the skin. The first signs of a pressure injury is discoloration in the skin, usually over a bony area. In individuals with light skin, the skin will be red or pink. In people with dark skin, the area might have a blue or purple tint. The coloring does not go away if you lightly press on the area.

If you suspect the person has a pressure injury, notify your home health nurse or therapist or make an appointment to see the primary care provider. Pressure injuries can worsen very quickly and can be difficult to heal once the skin is broken. Catching the area early is key to prevent further complications.

TEACH BACK

Where on the body are pressure injuries most likely to develop?



TEACH BACK

Describe what an early pressure injury looks like:

Managing Pressure Injuries

When a pressure injury develops, it does not mean that the caregiver is doing something wrong. The caregiver and members of the health care team should work together to treat the area and try to prevent further damage. The plan for treatment will depend on the severity of the injury and where it is on the body.

The first step in treating all pressure injuries is to identify the cause. It is important that no further pressure is put on the area already affected. The health care team might suggest padding, positioning, mobility aids, or nutrition supplements. If there is a break in the skin, the health care provider or nurse will develop a wound care plan that involves cleaning and dressing the wound. This will involve measuring the wound and providing instructions for how and when to change the dressing. Although caregivers may be responsible for many of the dressing changes, a follow-up with a health care provider should be scheduled to monitor the progress. If you notice a change in the wound, be sure to alert a health care provider right away because it might be infected. Infected wounds may need special treatments or antibiotics.

Sometimes these signs are present even when the wound is being treated for infection. If there is a change in the wound, more draining, a foul odor, or more redness, the initial treatment may not be working and a health care provider should evaluate it right away.

A pressure ulcer is usually painful and the person living with dementia may not be able to express that pain. Talk to the healthcare provider about appropriate treatments for pain if a pressure ulcer is present, such as acetaminophen (Tylenol) given in regular intervals.

Potential Treatments:

- Barrier creams
- Positioning aids
- Padding
- Wound dressings
- Antibiotics
- Pain medication

Signs of an Infected Wound:

- Getting bigger
- Draining more
- Foul odor
- The skin around the wound is red
- The skin around the wound is hot to the touch

TEACH BACK

What are two ways pressure injuries are managed or treated?

1. _____
2. _____



Weight Loss Information for Caregivers

Preventing Weight Loss and Malnutrition

Malnutrition is a deficiency, excess, or imbalance in an individual's intake of energy and/or nutrients¹. Weight loss can have severe consequences, including:

- Worsening memory and judgment
- Delayed healing from infections
- Weakness
- Death

The most common sign of malnutrition in individuals with dementia is weight loss. Weight loss is very common in individuals with dementia, especially as the disease progresses. There is usually not just one reason for weight loss. Although it is not possible to prevent weight loss in the late stages of dementia, it is possible to prevent some complications that can lead to weight loss.

Mealtime can be stressful for both the person with dementia and the caregiver. Below are some tips for making mealtime more fruitful. Additional tips can be found on the "Fact Sheet: Eating" from the Alzheimer's Association, that can be found in this packet.

1. Allow plenty of time for a meal. It can take a person with dementia up to 45 minutes to eat a meal
2. Make meal time cheerful by putting on music, and setting the table, or inviting friends and family to enjoy meals
3. Offer appealing foods that are culturally appropriate or base meals on what the person likes
4. Serve food that is the appropriate temperature. If the meal is delayed, be prepared to reheat the food or start again with a new offering
5. Serve meals away from distractions such as the television
6. Serve one to two types of food at a time
7. Offer snacks between meals
8. Consider high calorie shakes or smoothies

In addition to improving mealtimes, weight loss can be helped by addressing swallowing problems early. This is very important because swallowing can lead to weight loss and also pneumonia. All of the following are signs of a swallowing problem:

- Coughing or gagging with solids or liquids
- Drooling
- “Pocketing” food (keeping some food in the mouth)
- Hoarse voice
- Vomiting or regurgitating

A health care provider should evaluate a person with dementia who is having swallowing problems. The health care provider may consult with a speech therapist who can assist with mealtime modifications to make eating safer.

TEACH BACK

What are two ways that weight loss can be prevented?

1. _____
2. _____

Managing Weight Loss

It may not be possible to weigh a person with dementia. A caregiver might notice weight loss through loose or ill-fitting clothing, or notice that the person is eating less. There are a number of strategies to manage weight loss. First of all, if weight loss is noted, the person living with dementia should be evaluated by a health care provider. Many of the reasons for weight loss are medical and may be reversible. In addition, weight loss can cause medical complications that should be addressed by a health care provider.

There are ways that caregivers can manage weight loss. The following are some suggestions, but strategies will need to be tailored to the person and will need to be adjusted over time as the disease progresses.

1. Make sure dentures are in and fit well, that individuals who wear glasses have them on, and that hearing aids are in and have working batteries for all mealtimes.
2. Food should be placed where it can be easily seen by the individual.
3. Offer favorite foods and over-flavor to account for loss of taste in individuals with advanced dementia.
4. Offer the most calories at breakfast when an individual with dementia is most likely to be alert.
5. Ensure good oral care – dentures care, teeth brushing and swabs as necessary.
6. Offer frequent meals and snacks throughout the day.
7. Cut food into small bites and offer textures that are easy to swallow.

TEACH BACK

What are two ways that weight loss can be managed?

1. _____
2. _____

REFERENCE:

1. World Health Organization (2016). “Malnutrition.” Retrieved from <http://www.who.int/mediacentre/factsheets/malnutrition/en/>



Swallowing Problems

Information for Caregivers

Swallowing Problems

Most people with dementia will experience problems with swallowing¹. Swallowing problems lead to serious complications such as weight loss, poor nutrition, dehydration, and pneumonia². Although swallowing is second nature to a healthy person, it is actually a complex process that starts in the brain. Because dementia is a progressive disease of the brain, swallowing is more likely to be affected in the moderate and severe stages. Nearly everyone in the late stages of dementia has a problem with swallowing. Although we expect there to be issues with swallowing, there are ways to prevent complications of swallowing problems such as pneumonia or dehydration. Intervening early can mean extending the period of time the person you care for is able to take in food and fluids.

Prevention

Swallowing complications may be avoided by setting the stage for successful mealtimes. Some strategies you may try include:

- Allow plenty of time for the meal.
- Eliminate or reduce distractions during meal times.
- Make the environment pleasant.

- Encourage the person to sit in a dining chair, facing forward. It is not safe to eat or drink while lying or reclining, because this opens the airway and increases the risk of aspiration.
- Simplify place settings and tableware. It may be appropriate to use a spoon and bowl alone, or try finger foods if utensils are difficult to handle.
- Serve foods that are appealing to the person, and that are easy to chew and swallow
- Allow the person to feed him or herself, if possible. It can be helpful to model the motion of bringing food to the mouth.
- Remind the person to chew and swallow, if needed.
- Alternate solids with liquids
- Present one food at a time.
- Be alert to signs of choking (coughing with eating or drinking may be a sign), especially with liquids
- Provide soft or pureed foods if needed, as these are easier to swallow for those who have problems chewing or forget to chew. Ask a speech therapist to recommend the safest texture for your loved one's foods.

TEACH BACK

What is one way to prevent swallowing problems?

Identify

Identifying a swallowing problem early can prevent complications. The most serious complications of swallowing problems include choking and pneumonia. When food goes down the airway into the lungs, it can result in an infection called aspiration pneumonia. Another serious problem is dehydration. People with dementia can forget to drink enough liquids or have more swallowing problems with liquids compared to solids, so they can gradually become dehydrated.

Notify a primary care provider if you notice signs of a swallowing problem. The primary care provider can evaluate potential causes and may request a speech therapy consultation. Modifications can be made to medications, food, liquids, and mealtime practices to prevent choking, aspiration pneumonia, and dehydration. Some signs of a swallowing problem are:

- Inability to swallow
- Gurgling or hoarse voice quality after food or drink
- “Pocketing food - Keeping food in the mouth (especially in the cheek) after eating.

- Pain with swallowing
- Sensation of food getting stuck in the throat
- Coughing with liquids or solids
- Drooling
- Vomiting during meals
- Gagging
- Complaining of heartburn
- Weight loss

TEACH BACK

What is one sign of a swallowing problem?

TEACH BACK

What should you do if you notice a problem with swallowing?

Manage

When a person with dementia develops a swallowing problem, the primary care provider or speech therapist can recommend certain strategies to reduce the risk of choking or aspiration. However, there is no way to completely eliminate the risk of choking or aspiration³. Some strategies include pureed foods, thickened liquids, encouraging the person to tuck their chin into the chest when swallowing, and crushing medications or serving them in applesauce. Presenting food and dishes that contrast in color to one another, and presenting finger foods, can make the meal easier for your loved one.

If a speech therapist recommends it and has taught you proper set-up, use a straw. Do not use a straw if a speech therapist has not recommended it, as it can move liquid into the mouth too fast.

Complete oral hygiene before and/or after the meal if the person with dementia can participate in this. It helps you to check for food left over in the mouth. It also helps control bacteria that can give them pneumonia.

What is one way to manage swallowing difficulties?

A key strategy to prevent choking or aspiration is posture during meals. Have the person eat sitting in a dining chair with their feet and back supported, allowing the person to face forward. When a person eats leaning back in a bed or chair, it makes it harder to keep the head forward and chin down. When the neck is extended and chin up, it makes the food and liquid much more likely to go in the lungs. Lying down also makes it harder to see the food, and to stay awake for the meal. If the person must be fed in bed, keep the head of the bed up as straight as possible and elevated to at least 30 degrees for 30 minutes after eating or drinking.

We know that people with severe dementia develop significant problems with eating and drinking. In the severe stage of dementia, people are approaching end of life. It is natural at this time for people with dementia to have less interest in food. Weight loss is common. One approach to take at this time is called comfort feeding⁴. Comfort feeding means frequently offering small bites of easily chewed food and sips of liquids. The person should only eat or drink as much as they wish. Often this will only be a small amount, which is okay. The feeding should stop if the person with dementia shows any signs of distress. This type of feeding can provide comfort both to the person with dementia and the caregiver, as connections at mealtime are an important part of our shared human experience.

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Pneumonia

Pneumonia is an inflammation of one or both lungs caused by infection in which the air sacks of the lungs fill with fluid or pus. The infection can be caused by a virus, such as the flu, or bacteria. If a person has trouble swallowing, food can go down the airway into the lungs and cause infection. This is called aspiration pneumonia.

People who have dementia are at a higher risk for getting pneumonia than people who do not have dementia. Some of the reasons for this are:

- Swallowing problems
- Weak cough
- Lying down a lot or poor posture from general weakness
- Less physical activity due to dementia
- Weak immune system

Prevention

Although pneumonia is common among older adults in general, and even more common in people who have dementia, there are ways to help prevent pneumonia.

Vaccines – Many infections, including pneumonia, are caused by one kind of bacteria called *S. Pneumonia*. There are vaccines to protect against this bacteria. Pneumonia can also be caused by viruses, like influenza.

Avoid smoking or cigarette smoke in the home – Pneumonia is more common in people who smoke or are exposed to cigarette smoke in the home.

Good positioning – The lungs work best when they can expand all the way, so having a person change positions, sit up, and be active is a good way to keep air moving through the lungs.

Safe swallowing – The person you care for should be sitting all the way up when eating. Mealtimes should not be rushed. Alert a healthcare provider if you notice coughing or choking with eating or drinking. These are signs of a swallowing problem that could be corrected with simple techniques.

Good nutrition – Any person in poor health is more likely to get an infection. People who eat healthy foods and drink enough water are less likely to get sick than someone who does not eat fruits or vegetables.

TEACH BACK

What are two things you can do to help prevent pneumonia in someone with dementia who you care for?

1. _____
2. _____

Recognizing Pneumonia

Common signs and symptoms of pneumonia are fever, cough (with or without phlegm), loss of appetite, weakness, and body aches. A person with dementia cannot always report symptoms of the condition. Also, people with dementia do not always show the same signs of having pneumonia as people without dementia. Some of these differences include:

Lack of cough or non-productive cough – Some people with dementia have a weak cough reflex, and if the individual is dehydrated the cough might not be productive of sputum.

Lack of fever – Older adults do not always have the strong immune response that causes fever, and in fact a low body temperature can be a sign of a serious infection.

Lack of complaints about weakness or body aches – People with advanced dementia cannot always express symptoms with language including aches, pain, weakness and shortness of breath.

Someone with dementia might have any of the typical signs of pneumonia as well as any of the following signs:

- Rapid breathing
- New or worse confusion
- Poor eating or drinking
- Increased weakness
- More sleepy or lethargic
- Suddenly not able to do things he/she could do previously (e.g., feeding oneself, dressing, using the walker)

TEACH BACK

What are two signs of pneumonia in someone who has dementia?

1. _____
2. _____

Treatment

Pneumonia is usually diagnosed with a chest xray. Sometimes primary care providers can be almost certain someone has pneumonia by listening to a person's lungs with a stethoscope, taking vital signs, and getting blood tests. If the overall goal of care is to keep the person with dementia at home in a familiar environment, the person might be treated without a chest xray.

If you think the person you care for might have pneumonia, it is important to alert the home health clinician or primary care provider as soon as possible. Early diagnosis is key to preventing a hospitalization. Pneumonia is treated with antibiotics. Antibiotic medication can be given orally or through an IV. Pneumonia is a very serious infection that can lead to death, even when diagnosed and treated early. Many older people who develop pneumonia may need to be treated in a hospital, but it is also safe to treat pneumonia at home with the appropriate support. Other treatments given to a person with pneumonia might include oxygen and breathing treatments, such as inhalers or nebulizers.

When a person with dementia has pneumonia and is cared for at home, it is important to make sure that person finishes all antibiotics as prescribed. It is also important to encourage good intake of food and fluids. Food and fluids may need to be given in small amounts more frequently, rather than in large, spaced out meals, because the person may be weaker from the infection. Make sure the person is sitting as upright as possible when eating, and encourage deep coughing. Even when someone is receiving treatment for pneumonia, he or she can take a turn for the worse and need to be evaluated again. Alert a primary care provider if you notice any of the following symptoms:

- Sudden increase in confusion
- Poor intake of fluids
- Diarrhea
- Lack of urine output
- More weakness
- Lethargy
- Shortness of breath
- A new fever

TEACH BACK

Name two ways pneumonia can be treated at home to avoid a hospitalization?

1. _____

2. _____



Incontinence

Urinary incontinence means an involuntary loss of urine that is bad enough that it causes problems. Many people living with dementia have problems with incontinence. Studies estimate that as many as 90% of individuals with dementia will experience incontinence¹. Incontinence can be embarrassing for the person who experiences it and stressful for caregivers.

Most people with dementia experience incontinence at some point due to infection, problems getting to the toilet, being unable to sense the need to void, or forgetting to use the toilet. Also, people with dementia may be more likely to experience side effects from medication that can cause or worsen incontinence.

Incontinence can cause other problems for a person with dementia. In fact, some caregivers name incontinence as a reason for seeking out long-term care for their loved one². Other consequences of incontinence include:

- Pressure injury and other skin irritation
- Bladder infections
- Falls
- Depression
- Anxiety
- Social isolation
- Problems with sleep

Prevention

People with dementia can have trouble communicating needs, sensing when they need to void, or remembering to tell someone when it is time for them to use the toilet. Any of the following may be helpful in avoiding accidents:

- Make sure the path to the toilet is clear
- Eliminate caffeinated beverages
- Keep the bathroom door open, so the bathroom is easily recognized
- Ensure the bathroom is well-lit and comfortable
- Consider a raised toilet seat or grab bars for safety and comfort
- Remove planters, waste-paper baskets, buckets, or any container that might resemble a toilet
- Ask the person if he or she needs to use the toilet
- Remind the person to use the toilet or assist the person to the toilet approximately two hours, if the person does not know to go on his or her own
- Consider a bedside commode that might be easier to access than the bathroom
- Make sure the person is not constipated

People with dementia are at risk for dehydration, so limiting fluids to prevent incontinence is not a good idea.

TEACH BACK

What are two things you can do to help prevent urinary incontinence in the person you care for?

1. _____
2. _____

Recognizing Urinary Incontinence

It can be difficult to treat incontinence experienced by a person with dementia, but it is important to know it can be treated. Many steps can be taken to manage the incontinence in order to lessen the burden of this problem for both the person with dementia and caregivers.

Notify a home health clinician if the person you care for experiences new incontinence. If incontinence problems are suddenly worse or unmanageable, that is also a reason to call or visit a the primary care provider. New or worsening incontinence can be a sign of a urinary tract

What are two signs of urinary incontinence that would cause you to notify the primary care provider?

1. _____

2. _____

infection. Other signs of a urinary tract infection include fever, frequent urination, abdominal pain, pain with urination, dark or foul smelling urine, blood in the urine, being very tired or fatigued, and sudden confusion or agitation. Besides infection, new incontinence can also be due to constipation.

Managing Urinary Incontinence

There are treatments for incontinence. Some treatments involve medications and some do not. The treatment of incontinence is dependent on the cause and the person's level of memory or functional loss.

Prompted voiding and scheduled toileting – These techniques may reduce incontinence, but they do not provide a cure for incontinence. These strategies should be used on a trial basis for two to three days. If there is not a noticeable reduction in incontinent episodes or an increase in the requests by the person to use the toilet, then another strategy of containment should be used.

Prompted voiding means asking a person at regular intervals if he or she needs to use the toilet. The person needs to be able to sense the need to use the toilet for prompted voiding to decrease the frequency of incontinent episodes.

Scheduled toileting, or timed toileting, requires the caregiver to assist the person with dementia to the bathroom at regular intervals, such as every two hours during the day.

Medications – The primary care provider may prescribe a medication to treat incontinence or nighttime voiding. Medications can be effective, but some medications to treat incontinence have the potential to cause increased confusion, constipation, or falls. The effects of the medication will depend on the individual and his/her health status, other medications, and type of incontinence. As a caregiver, it is important for you to note any new or worsening symptoms after the medications have started and report these to the home health clinician or primary care provider.

Managing Incontinence – Despite treatments, incontinence is often an inevitable part of living with dementia as the disease progresses to the severe stage.

There are steps that can be taken to better manage incontinence.

If the incontinence is only occasional:

- Choose clothing for the person that is dark in color and easy to put on, take off, and launder
- Change wet clothing in a timely manner to avoid skin irritation
- Use a waterproof mattress cover and seat covers
- Although limiting fluids throughout the day is not recommended, limiting fluids two hours before bed might help with nighttime incontinence

For the person who is always or nearly always incontinent, it is important to use incontinence aids such as:

- Briefs or diapers
- Pull-ons
- Underwear liners

Disposable products can be purchased at most pharmacies, online, or through other home delivery services. They offer security and help to protect clothing, linens, and furniture. There is an on-going cost associated with the products, and for some people, it may be embarrassing to wear them. However, for the person with significant incontinence, these products are crucial. It is still important to change them frequently. Even with a product designed for adult incontinence, moisture against the skin can lead to irritation, rashes, and pressure injuries. When changing a brief or diaper, wash the skin with mild, soapy water, and pat dry, rather than rubbing. It can be helpful to use a barrier cream or ointment to protect the skin.

TEACH BACK

Name two ways urinary incontinence can be managed.

1. _____
2. _____

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Constipation

Information for Caregivers

Constipation

Constipation is a common problem among older adults. Constipation can cause discomfort and distress, as well as complications such as hemorrhoids and anal tears. When stool blocks the bowel, it can result in hospitalization, surgery, or even death. Every person is different and there are a range of normal bowel patterns. Someone is typically considered constipated if he or she has fewer than 3 bowel movements a week, often has to strain to have bowel movements, or is not able to fully empty the bowels.

People living with dementia may be at higher risk for constipation due to:

- Less physical activity
- Eating fewer high fiber foods
- Not drinking enough water, juice, or other liquids
- Older age
- Hospitalizations
- Other medical conditions such as Parkinson's disease or hypothyroidism
- Less awareness of the need to have a bowel movement
- Medications that cause constipation

Prevention

It is important to keep track of how often a person with dementia has a bowel movement, especially as the dementia progresses. Keep a record of the frequency of bowel movements. If there are multiple people who toilet the person with dementia, keep a log in a common area so anyone who does toileting can mark when there has been a bowel movement. Everyone gets constipated at times, but if it happens frequently the home health clinician or primary care provider should be notified. Many older adults with chronic constipation need medications to keep the bowels moving regularly.

The following are some ways constipation can be prevented in addition to, or instead of, medications:

1. Provide a diet that includes lots of fiber or roughage. Some fiber rich foods are whole grain breads and crackers, bran cereals, brown rice, prunes, fruits, and vegetables.
2. Encourage the person to drink 6 to 8 glasses of water a day. You can also offer juices, soups, and broths to prevent dehydration.
3. Encourage the person with dementia to be physically active, to the extent that is possible and safe. Chair-based exercise is better than no exercise at all.
4. Make sure the person knows where the bathroom is and that the path is free of obstacles.
5. Offer toileting at regular intervals.
6. If possible, make the bathroom a warm, relaxing, and private place.
7. If possible, offer a walk after meals. This can stimulate the need to move the bowels.
8. Prepare and give “Power Pudding” in ¼-cup servings daily (mixture of applesauce, prune juice, bran, and unprocessed oat bran).

There are a number of medications that cause or contribute to constipation. People who take more than 5 medications are at the highest risk for side effects from medications, such as constipation. A common over-the-counter medication that causes constipation is diphenhydramine, or Benadryl. This medication is found in sleep aids, such as Tylenol PM, and in allergy medications. Have a nurse or primary care provider review the medication list to see if there are medications that could cause constipation. Under the direction of the nurse or primary care provider, it may be possible to stop the medication or change to one that is less likely to cause constipation.

TEACH BACK

What are two things you can do to help prevent constipation in the person you care for?

1. _____
2. _____

Recognizing Constipation

Constipation can cause discomfort and pain. People with dementia cannot always express their needs, or tell us when they are in pain. As a result, signs of constipation in someone who has dementia can include:

- Increased agitation
- Calling out
- Distress
- Irritability
- Wandering
- Falling
- Nausea
- Bloating abdomen
- Loss of appetite
- Abdominal pain, especially in the left lower part of the abdomen
- Confusion
- Inability to function normally
- Repeated trips to the bathroom

If you suspect constipation, try the prevention strategies listed above and talk to the nurse or primary care provider about what medications can be used to manage the constipation, such as fiber powders, laxatives, or enemas.

A serious complication of constipation is a fecal impaction. A fecal impaction occurs when a large amount of hard stool builds up in the colon. As the colon is stretched, it loses the ability to contract and force the stool out. Sometimes liquid stool will leak out around the compacted mass of stool. A fecal impaction is very uncomfortable, but someone with severe stage dementia may not be able to say that he or she is in pain and the fecal impaction may not be recognized. Fecal impactions can lead to increased confusion or extreme fatigue. Notify a nurse or primary care provider immediately if you think our loved one may have a fecal impaction. Taking steps early can prevent pain, a trip to the hospital, or surgery.

TEACH BACK

What are two signs of constipation in someone who has dementia?

1. _____
2. _____

Managing Constipation

Constipation can be managed by preventing dehydration, providing a diet rich in fiber, increasing physical activity, and toileting frequently. There are medications that cause or contribute to constipation which can be reduced or stopped. There are also a number of medications that treat constipation. It is important to discuss these medications with the nurse or primary care provider because, like all medications, they also can have unwanted side effects.

Medication for Constipation	How it Works	Examples
Bulking Agents	Absorb liquids in the intestines and swell to form a soft, bulky stool. Also known as fiber supplements, these agents must be taken with water.	Metamucil, Citrucel, Fibercon
Osmotic Laxatives	Draw water into the bowel, providing a soft stool mass.	Milk of Magnesia, Miralax, Chronulac, Xylitol
Stimulant Laxatives	Stimulate the intestine to move.	Ex-Lax, Senokot, Correctol, Dulcolax
Stool Softener	Help liquids mix into the stool and prevent dry, hard stool masses. Stool softeners are not laxatives, but can be used to help relieve excess straining or painful defecation due to a rectal tear.	Colace
Emollients	Coat the bowel and the stool mass with a waterproof film so stool remains soft.	Mineral oil

TEACH BACK

Name two ways constipation can be managed.

1. _____
2. _____



Prevention

Pain is an everyday part of life for up to 50% of all older adults. Untreated pain can have serious consequences for a person including depression, isolation, poor sleep, and losing the ability to do things for oneself. Individuals with dementia can have a hard time communicating and often cannot say when they are in pain or why.

Acute pain comes on suddenly from an illness or injury. Chronic pain lasts for more than a month. It is most common in older adults and can be difficult to detect and treat.

A caregiver may be able to prevent pain by being aware of some common causes for pain in older adults.

Cause of Pain	
Constipation	Serve diet high in fiber, monitor bowel patterns, talk to the nurse or doctor about medicine for constipation
Urinary Tract Infections	Encourage good drinking habits to avoid dehydration, encourage urinating every two hours while awake
Pressure injuries	Help the person to move every couple hours, avoid contact with hard surfaces, provide for adequate cushioning and good nutrition

Cause of Pain	
Arthritis	Encourage the individual to get up and walk every now and then if possible, use gentle range of motion for individuals who have limited mobility, consider warm compresses to achy joints or arthritis creams, talk to the nurse or doctor about pain medications, such as Tylenol to be given on a regular basis
Back problems	Use a lumbar support for chairs, help the person to shift positions
Foot problems	Make sure shoes have a wide toe box, are soft and allow good support if the person is still walking, use soft socks, such as diabetic socks
Dental problems	Take care with the temperature of foods – nothing too hot or too cold, give soft foods easily chewed and swallowed

TEACH BACK

What are two things you can do to help prevent pain in someone with dementia who you care for?

1. _____
2. _____

Recognizing Pain

It is very important to recognize pain in a person who has dementia. Pain can be a sign of a new illness or injury. Untreated chronic pain can lead to a loss of function or behaviors such as aggression, wandering, or calling out repeatedly. A person in pain is likely to move less and as a consequence can develop pressure injuries or lose the ability to stand or walk.

A person with dementia might not be able to tell you that he or she is experiencing pain. This makes it very difficult to recognize pain. Below is a chart that shows how people with dementia might show signs of pain. This chart was adapted from a chart developed by the American Geriatric Society (2002)¹.

Signs of Pain	
Facial Expressions	<ul style="list-style-type: none"> • Slight frown; sad, frightened face • Grimacing, wrinkled forehead • Closed or tightened eyes • Any distorted expression • Rapid blinking

Signs of Pain	
Sounds	<ul style="list-style-type: none"> • Sighing, moaning, groaning • Grunting, chanting, calling out • Noisy breathing • Asking for help • Verbally abusive
Body Movements	<ul style="list-style-type: none"> • Rigid, tense body posture • Guarding (protecting a part of the body) • Fidgeting • Increased pacing, rocking • Restricted movement • Changes in the ability to walk or move
Changes in how the person interacts with others	<ul style="list-style-type: none"> • Aggressive • Resisting care • Decreased social interactions • Socially inappropriate, disruptive • Withdrawn
Changes in routines	<ul style="list-style-type: none"> • Refusing food, appetite change • Sleeping more • Not sleeping enough • Suddenly stopping regular routines • Increase wandering
Changes in thinking or mood	<ul style="list-style-type: none"> • Crying or tears • Increased confusion • Irritability or distress

If you notice signs of pain in the person you provide care for, be sure to alert your home health clinician, a nurse, or the primary care provider. The reason for pain should be investigated as soon as possible. Making an appointment with the primary care provider if you notice signs of pain could prevent more pain, complications, even a trip to the emergency department or hospitalization.

TEACH BACK

What are two signs of pain in a person who has dementia.

1. _____

2. _____

Managing Pain

Pain can be treated with medications. Sometimes pain medications are given “as needed.” If you notice the person you are caring for needs the medication frequently, at the same times every day, or takes it regularly for many days in a row, talk to your home health nurse or primary care provider about scheduling the medication at regular intervals or giving a dose that lasts longer.

Many people who have dementia can safely take strong pain medication. However, if you notice that there are behavior changes when the person takes the pain medicine, such as becoming very sleepy or hard to wake, or very agitated or confused, be sure to communicate that to the nurse or primary care provider.

There are many ways to treat pain aside from medications. These treatments can be as effective or more effective than medication, or used in combination with medication. Not every treatment will work for every person. You may need to try trial and error to see what works best for the person you are caring for. Below are a few options for managing pain.

- Massage
- Application of heat or cold packs
- Gentle exercise and stretching
- Physical therapy
- Relaxation
- Aromatherapy
- Distraction
- Music
- Menthol rubs

TEACH BACK

Name two ways to manage pain in a person who has dementia.

1. _____
2. _____

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Prevent

When people living with dementia get infections, they get more sick and faster than younger or healthier people. Eliminating all infections isn't possible. However, there are things caregivers can do to help prevent infections.

Encourage activity – People are more likely to get infections, especially respiratory infections like pneumonia, if they are confined to a chair or a bed. Encourage the person you care for to move to the extent that he or she is able.

Skin care – Make sure skin is kept clean and dry to reduce the chances of rashes or wounds.

Eating and drinking – The person with dementia should sit upright when eating or drinking to prevent food going into the airway which can cause pneumonia. Drinking fluids helps prevent dehydration, which can lead to fever and urinary tract infections.

Mouth care – Help the person to brush their teeth twice a day if possible. Use a soft tooth brush. Remove dentures and clean them every night. Use oral swabs to clean the mouth after meals to prevent pneumonia.

What is one action you can take to help prevent an infection?

Identify

It can be difficult to tell when someone with dementia is sick with an infection. The signs that the person is sick might not seem related to an illness like a urinary tract infection or pneumonia. Most people with moderate to severe dementia have trouble communicating when they have pain or don't feel well, making it even more difficult to tell when they might be sick. For example, the person you care for could have pneumonia without coughing, feeling short of breath, or having a fever. However, if he or she is eating less, more tired, or more confused, those may be the signs of the illness.

The following are signs that a person with dementia might have an infection:

- Sudden change in thinking, behavior, or memory
- Needs more help sitting, standing, or walking
- Sleeping more than normal
- Worse appetite than usual
- New or worse incontinence of bladder or bowel
- Falling
- Fever
- Rapid breathing
- Redness, warmth, or swelling of the skin or joint
- Foul smelling wound or drainage from a wound

What are two signs that may mean the person you care for has an infection?

1. _____

2. _____

Manage

It's best to treat infections at home with oral antibiotics whenever possible. People with moderate to severe dementia are at risk in the hospital setting. They are more likely to get difficult-to-treat infections that are contracted in the hospital¹. In the hospital, people with dementia can get more confused and agitated and lose mobility. For this reason, it is important to notify the home health staff or primary care provider as soon as you suspect an infection. The sooner someone is evaluated and treated, the more likely the infection can be treated at home.

People with severe dementia are the least likely to have a positive outcome from a severe infection. Some studies suggest that treating people with severe dementia with antibiotics does not prolong life^{2,3}. In addition, the evaluation and treatment for an infection may cause distress or discomfort for the person with dementia. See the Hospice and Palliative Care modules for more information for taking a comfort focused approach to care in severe dementia. Discuss with the primary care provider what your wishes are for the care of the person with dementia.

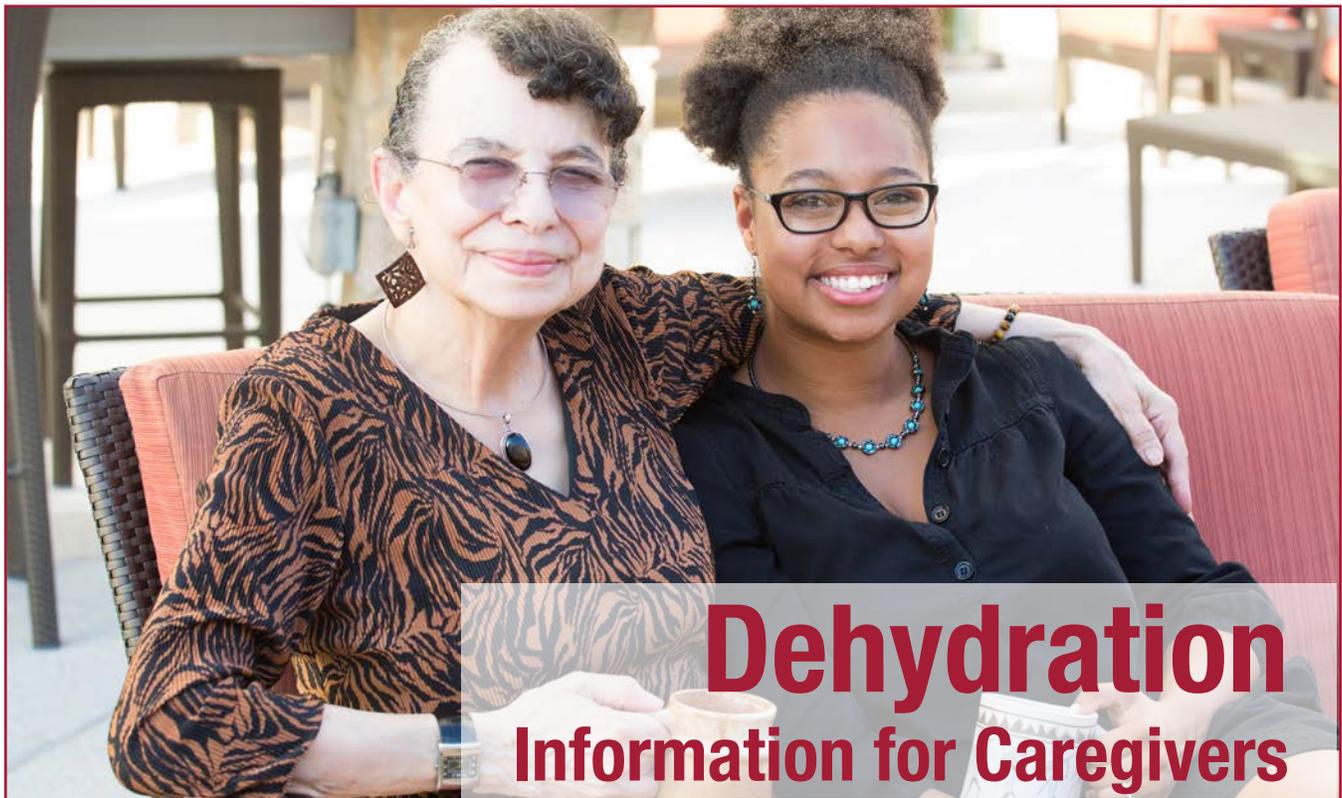
Regardless of the plan of care, the first step if you suspect infection is to notify the home health staff or primary care provider. At that time you can decide together the best course of action with the goal of keeping the person with dementia out of the hospital if at all possible. Because the signs of infection can be very subtle, reach out to the home health staff or primary care provider for any sudden change in thinking, mobility, ability to interact with others, energy level, or intake of food or fluids.

TEACH BACK

What should you do if you suspect the person you care for may have an infection?

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Dehydration Information for Caregivers

Prevention

Dehydration is a common and serious complication of dementia. Dehydration can cause falls, kidney failure, infections, and pressure injuries, and it is also linked to strokes. Dehydration can lead to emergency room visits and hospital stays. Many older adults both with and without dementia are mildly dehydrated. Individuals with dementia are particularly at risk for dehydration because of an inability to sense being thirsty, difficulty communicating being thirsty, forgetting to take a drink, being physically unable to get a drink, or an inability to swallow. An older adult who is mildly dehydrated can quickly become seriously dehydrated and it is not always easy to tell when this happens. The best treatment for dehydration is to prevent dehydration.

A caregiver may need to try different ways to get a person with dementia to drink more. Something that worked well last week might not work well this week. Often, when caring for someone with dementia, we discover what works best through trial and error. The following is a list of some strategies to prevent dehydration:

- Offer fluids frequently and keep lots of drinking containers around the house
- Offer a favorite drink or a variety of drinks
- Avoid liquids that are so hot they could cause injury if spilled
- Put the cup to the lips to trigger the reflex to drink
- If a cup is refused, try a mouth swab with a flavored drink to the lips, then offer the cup
- Serve drinks in a brightly colored cup that does not blend into the background

- Serve semi-solid foods or foods cooked in liquid to increase liquid intake
- Offer drinks when the person is sitting upright
- Use containers that are easy to drink from: two handles, one-way straws, water bottles

TEACH BACK

What are two things you can do to help prevent dehydration in the person you care for?

1. _____

2. _____

Recognizing Dehydration

Like many medical conditions, dehydration can be difficult to recognize in a person with dementia. The best way to know if someone might be dehydrated is if you notice a change in the amount of liquids he or she is drinking. Even a small change in the amount of liquid a person drinks can lead to dehydration. The caregiver is often the first person to notice signs of dehydration, because the caregiver knows what “normal” looks like. A sign of dehydration in one person might be normal for another person.

Signs and symptoms of dehydration can include:

- New or worse confusion
- Dry or papery skin
- Dry lips and mouth
- Dizzy or lightheaded when standing
- Dark and foul smelling urine
- Low blood pressure
- Change in mobility
- Fatigue

If you suspect the person you care for may be dehydrated, first try to give them more fluids or a cup of broth. Next, notify the home health staff or primary care provider right away. When dehydration is treated early, a trip to the emergency room can almost always be avoided. Someone with dehydration can get worse quickly. When a person is dehydrated, the medications that person takes may work differently. Dehydration can also be a sign that the person has a serious illness. It is good if you can get the person to drink more, but it is still important to notify the home health staff or primary care provider.

What are two signs of dehydration in someone who has dementia?

1. _____
2. _____

Managing Dehydration

As a caregiver, the ways you would manage dehydration are the same ways you can prevent dehydration. Offer fluids frequently, try different or more appealing liquids, incorporate more liquids into meals, and adjust the containers you use so they are easier for the person with dementia to use. Talk to the home health staff or primary care provider about involving speech therapy or occupational therapy. A speech therapist can help if there are swallowing problems. An occupational therapist can offer suggestions on how to provide fluids by looking at routines around eating and drinking and suggesting adaptive devices so the person can drink more easily.

If the person with dementia is ill, he or she may temporarily not eat or drink well. If that is the case, a decision might be made to give hydration through an infusion. Some infusions can be given at home with the assistance of a nurse. A severely dehydrated individual will need intravenous (IV) fluids and monitoring in a hospital setting. The best way to prevent hospitalization or a trip to the emergency room is to recognize signs of dehydration early and notify home health staff or the primary care provider.

Name two ways to manage dehydration in a person who has dementia.

1. _____
2. _____



Behavior Changes

Nearly every person with dementia will experience a behavioral or psychological symptom of the disease. These are sometimes referred to as “challenging behaviors”¹. Challenging behaviors are common in the moderate and severe stages of dementia. When behavioral and psychological symptoms are not treated, this can lead to increased stress and burden on caregivers, unplanned trips to the emergency room and hospital, long-term care admissions, and increased use of medications which can also cause harm.

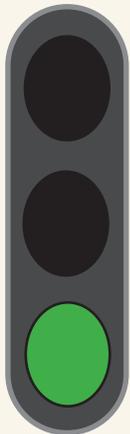
Some common behaviors associated with dementia include:

- **Delusions** – these might cause distress, or may be acceptable to the person. An example of a distressing delusion would be a belief someone has been stealing misplaced items.
- **Hallucinations** – these can be distressing or comforting. Some individuals see small children and it causes them no distress.
- **Agitation** – repeating questions, hoarding, arguing, complaining, calling out in a disruptive manner
- **Aggression** – physical or verbal

- **Socially inappropriate behavior** – swearing, removing clothes at inappropriate times, using vulgar language
- **Sleep disturbance** – days and nights mixed up, waking up frequently during the night
- **Wandering** - roaming, pacing with or without definite purpose, leaving/exiting the home

Although nearly all people with dementia will have a change in behavior, some behaviors require taking action and others do not. Some behaviors may be a sign of an emotional or medical problem. Some behaviors may cause harm to the person with dementia or others in the home. On the other hand, some behaviors are due to the disease progressing and do not cause harm.

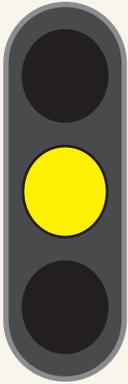
“GREEN LIGHT” BEHAVIORS



- Person living with dementia appears comfortable, even happy
- Behavior may be called annoying or irritating, but does not cause any harm
- You can re-direct or re-focus attention on a different activity
- Person is not exhausted or upset after showing the behavior
- There are no signs that the person might be ill
- There is no major change in everyday functioning

What to do: Roll with the changes. Meet the person where he/she is. For example, for someone having a pleasant hallucination, avoid pointing out that what they are seeing is not real. For instance, if they notice it is snowing and become nervous and say, “This is not right for July!,” you might say, “Yes, it is funny weather for July! What odd weather we’re having.” Make changes to the environment if needed. If the person likes to open and close drawers, move important or breakable items to another location. Report the change at the next visit with a healthcare provider.

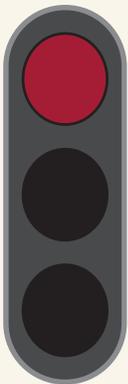
“YELLOW LIGHT” BEHAVIORS



- The behavior is not damaging or dangerous, but hard to tolerate by caregiver and others
- In addition to the behavior, there are some subtle changes in everyday function
- You are less able to re-direct the behavior or reassure the person if he/she is upset
- There are no signs that the person might be ill
- There is no major change in everyday functioning
- The behavior changes accompany a gradual decline in thinking, functioning, and memory

What to do: Example: The person with dementia is beginning to wander around the house and is more repetitive of questions. You’ve also noted the person is struggling more with hygiene and spends more time sleeping. In reflecting on these changes, each has developed slowly over the past few months, yet you are concerned that the wandering might escalate, and you feel irritated by the repetitive questions. Write down what you are noticing. Discuss the changes with a family member or other caregiver who knows the person well. Do they notice the changes as well? Try a different technique for re-direction. Take a caregiver break if you can, even if for an hour. Re-establish a routine if there have been changes. Get in touch with your local Alzheimer’s support agencies (see last page of Behavior Changes section).

“RED LIGHT” BEHAVIORS



- The behavior is causing harm to the person with dementia or others
- The behavior has the potential to cause an unsafe situation
- The behavior change is sudden
- The behavior causes distress to the person with dementia or others
- The behavior increases the burden of giving care
- There is a change in everyday functioning
- There was recently a change in medications
- There are signs the person could be ill

What to do: Example: The person with dementia is up 10 times a night and neither of you are getting any sleep; has begun hitting when you try to help with dressing; or is suddenly extremely tired and sleeping all day. Call the home health clinician or other health care provider. Describe what you have witnessed and any recent changes in routine, level of functioning, health, or medications.

When you think of your loved one, has that person experienced one or more of these challenging behaviors? What was it?

Manage

Behavioral and psychological symptoms of dementia can be difficult to manage. It can take a team of people to determine what caused the behavior and try to come up with a plan to manage the behavior. The behavior may be a way for the person with dementia to communicate an unmet need². Some possible causes of behavior changes are:

- Medical problem such as constipation or a urinary tract infection
- New medications, or a change in the dose of a medication
- Something new in the environment such as a new caregiver or routine
- Pain
- Lack of sleep
- An unmet need, such as loneliness, boredom, sadness
- Something irritating to the person about the way a routine is done

If you notice a new behavior in the person you care for that is distressing, sudden, persistent, or worsening, notify the home health clinician or primary care provider. A medical problem might be the cause and intervening early could prevent a hospitalization or emergency room visit. Getting early attention might also help prevent worsening behavioral challenges.

Before you call the home health clinician or primary care provider, take a few notes. What have you observed? How often does the behavior happen? What are the circumstances around the behavior? These details may help determine the cause and the treatment plan. Quite often, there is a cause and if the cause is removed, the problem goes away.

TEACH BACK

Think of the challenging behavior you have witnessed in the past. Can you think of any factors that may have contributed to the behavior of your loved one?

The management of behavioral and psychological symptoms of dementia depends on the cause. If the health care provider rules out a medical cause, the preferred method is to adapt the environment or care of the person with dementia to reduce the triggers for the behavior. This can be very challenging, but also rewarding once the cause is determined and removed. The important thing is to seek help. If one strategy or plan does not work, seek help again and try another. An occupational therapist can help assess and adapt the home environment to support BPSD. A clinic social worker or psychologist can help in figuring out strategies. An occupational therapist can help in changing routines to reduce distress. The following are some other resources available to caregivers:

- Alzheimer's Association 24/7 Hotline: 1-800-272-3900 or website www.alz.org
- A Caregiver Support group
- The Alzheimer's and Dementia Alliance of Wisconsin: www.alzwisc.org
- The Aging and Disability Resource Center for your county: www.dhs.wisconsin.gov/adrc/consumer/index.htm

TEACH BACK

What is one resource for managing the behavioral and psychological symptoms of dementia?

REFERENCES:

1. Karon, S., Gould, E., Hughes, S., Verrier Piersol, C., Maier, J., Leopold, J., & Wiener, J. (2015). Training family caregivers on skills for behavioral symptoms, *Administration on Aging*, retrieved on December 19, 2017 from <https://nadrc.acl.gov/documentation>.
2. Walaszek, A. (2020). *Behavioral and psychological symptoms of dementia*. Washington, DC: American Psychiatric Association Publishing.



Communication Changes

Information for Caregivers

Communication Changes

Dementia will gradually affect a person’s ability to communicate. Changes in communication are common in the moderate and severe stages of dementia. Communication changes include difficulty sharing thoughts and stories, making needs known, and understanding others. As dementia progresses, behaviors become a more frequent form of communication. Changes in tone, urgency, and speed of speech can indicate an unmet need, such as hunger or thirst, pain, or loneliness. Non-verbal behaviors, such as agitation, restlessness, aggression, and combativeness, can also indicate an unmet need¹. It is important not to dismiss these sounds and behaviors as symptoms of dementia, but rather try to determine the meaning behind them (see Behavior Changes module).

Here are some common communication changes experienced as dementia progresses, but keep in mind communication changes vary from person to person:

Early	<ul style="list-style-type: none"> • Difficulty with word finding when speaking or writing • Repeating oneself • Can still engage in meaningful conversation
Moderate	<ul style="list-style-type: none"> • Increased difficulty with word finding • Difficulty following conversations and stories • Difficulty following simple directions
Severe	<ul style="list-style-type: none"> • Difficulty understanding simple words • Talk or babble without meaning • Use of facial expressions, gestures, & pointing

When you think of the person you care for, has that person experienced a change in their ability to communicate? If so, what change(s) have they experienced?

What can I do?

The following tips can help improve communication with a person with dementia and reduce caregiver stress and burden. It is important to remember to be patient, gentle, and kind when talking with the person with dementia.

Make changes in the environment

- Reduce background noise (e.g. radios, TVs, hustle of busy environment, other's conversations)
- Adequate lighting

Listen closely

- Allow enough opportunities and time for the person to express themselves through verbal or non-verbal cues¹
- Demonstrate interest in what the person is communicating (e.g., maintain eye contact)
- Listen to find meaning in what the person is saying, and repeat to clarify
- Avoid correcting or criticizing
- Encourage the person to use gestures or pointing if having difficulty understanding what they are trying to say

Use simple language

- Use common or more frequently used words
- Think about the words the person with dementia might use themselves
- Speak slowly, clearly, and in direct presence of the person with dementia
- Use short words and sentences
- Avoid long sentences and multiple questions or instructions at once
- Consider using gestures, pictures, or written words if spoken words are confusing¹

Simple choices

- Allowing the person with dementia to make choices improves their sense of control; however, as dementia progresses, making choices becomes more difficult. Instead of making a choice for the person with dementia, give them fewer choices to pick from.
- Example: Instead of asking “What would you like to drink?” ask “Would you like water or milk?” or “Would you like coffee?”

Model tasks

- Give instructions one step at a time for a task the person is struggling with, such as brushing teeth, showering, or using a microwave. Example: 1) Get the toothpaste. 2) Unscrew the cap from the tube of toothpaste. 3) Pick up the toothbrush. 4) Place toothpaste on the toothbrush. 5) Open mouth. 6) Place toothbrush in mouth. 7) Rub toothpaste onto teeth. 8) Take toothbrush out of mouth. 9) Rinse mouth with water.
- If the person does not understand step-by-step instructions, show them how to do the task. Example: If the person is having difficulty brushing their hair, a caregiver may pick up the hairbrush, mime brushing their hair or actually brush their hair, then hand it to the person with dementia and say “you try.”

Reorient

- Reorientation is cuing your loved one to a person (themselves and those around them), place, time (day, year, season), and situation.
- Think ahead to how correcting your loved one will make them feel. Will it soothe, irritate, sadden, or lower self-esteem?
- If reorientation will sadden, anger, or diminish self-esteem, consider trying another communication method (see below).
- Examples:
 - Person with dementia: *How are my parents doing?*
 - Caregiver: *Your parents died a long time ago. You are 86, and your parents could not possibly be alive today.*
 - Person with dementia: *I want to go for a drive. Where is my car?*
 - Caregiver: *You sold your car years ago. You do not have a car anymore.*

Compassionate fibbing

- Compassionate fibbing is giving into your loved one’s belief.
- Think ahead to whether giving into their belief will reduce stress, anxiety, or agitation and provide a better sense of wellbeing.
- Examples:
 - Person with dementia: *How are my parents doing?*
 - Caregiver: *Your parents are fine. They are at church right now.*

What is one change you can make when you are talking to a person with dementia?

(Compassionate fibbing continued)

Person with dementia: *I want to go for a drive. Where is my car?*

Caregiver: *The car is in the shop. It will be ready next week.*

Acknowledge

- Understand your loved one's view of the world without entering into it (fibbing) or challenging it (reorienting).
- Acknowledge your loved one's feelings and memories associated with what they are talking about.

- Examples:

Person with dementia: *How are my parents doing?*

Caregiver: *It sounds like you are thinking about your parents.*

Can you tell me about them?

Person with dementia: *I want to go for a drive. Where is my car?*

Caregiver: *You must be thinking about your car today. Tell me about your car.*

What kind of car is it? Did you go for long trips in your car?

Reflection

- Ask yourself: What happened? What did I do? What would I do differently next time?

Resources available to caregivers:

Alzheimer's Association Handout

<https://www.alz.org/media/Documents/alzheimers-dementia-communication-all-stages-b.pdf>

Reference

1. Walaszek, A. (2020). *Behavioral and Psychological Symptoms of Dementia*. Washington, DC: American Psychiatric Association Publishing.



Hospice and Palliative Care Information for Caregivers

Hospice and Palliative Care

There is no cure for dementia. Sadly, this is true even for people who receive the best care possible from their families, caregivers, and their healthcare team. People diagnosed with dementia live, on average, 4.5 years¹. People who are older when they are diagnosed, or who have other serious illnesses, have a shorter life expectancy¹. Although the pace of disease progression is not always predictable, we know that when people enter the latest stage of the disease, severe dementia, they have severe memory problems and physical limitations, such as being:

- Unable to walk or sit up without assistance
- Unable to recognize family members
- Incontinent of bowel and bladder
- Unable to dress or bathe without assistance
- Unable to communicate verbally beyond a handful of words
- Unable to smile

Unfortunately, people with severe dementia often experience distressing symptoms such as pain, shortness of breath, or agitation². These symptoms are treatable, but can be hard to recognize in an individual who can no longer communicate effectively. As people with dementia enter into the severe stage, it is important to think about your loved ones wishes for the end of their life. At this point in the illness, families may choose to focus on comfort. That means treatment decisions are made based on whether the treatment would add to the person's comfort, rather than if it would cure their illness. Families can receive help in making these decisions through palliative and hospice care.

Palliative care:

Simply stated, palliative care is symptom management and support for people with a serious illness. Palliative care is usually provided by a team that includes a physician, nurse, and social worker. It is initiated at any time during the course of a serious illness such as dementia.

Hospice care:

Hospice care is a philosophy of care for people with a terminal diagnosis that shifts the focus of care away from curing the disease and onto the individual's symptoms, and addressing the emotional and spiritual needs of individuals and caregivers. Hospice care is a benefit provided under Medicare Part A. A physician or hospice medical director must certify that a person has a life expectancy of less than 6 months. It is difficult for health care providers to determine life expectancy for a person with dementia in the severe stages, so this estimation is based on symptoms. Some people live for a long time at the end stages of the disease. Once enrolled in hospice, individuals with severe dementia can be recertified for continued hospice care beyond the 6 month period if needed. The individual or the individual's primary decision maker must agree to hospice, thereby waiving the right for Medicare to pay for other medical services to treat the terminal illness³. Hospice is a comprehensive benefit. The following is a list of some of the benefits covered under hospice care with Medicare Part A:

- Doctor services
- Nursing services
- Medical equipment (such as wheelchairs, walkers, commodes, etc.)
- Medical supplies
- Occupational therapy
- Physical therapy
- Speech-language pathology services
- Medical social services
- Dietary counseling
- Home health aide and homemaker services
- Grief and loss counseling services
- Short-term inpatient care for pain and symptom management
- Prescription drugs for symptom control or pain relief³

Both palliative and hospice care teams include multiple specialists including doctors, nurses, therapists, social workers, and pastoral care. These teams are skilled at helping individuals and families navigate a difficult time, and optimize quality of life and comfort. People can receive palliative and hospice care in the hospital, at home, or in a long-term care facility. When people with severe dementia receive hospice care, their families report greater satisfaction with patient care, and the individual with dementia was more likely to receive treatment for distressing symptoms².

TEACH BACK

What are two benefits of hospice care?

1. _____
2. _____

Enrolling in Hospice Care

It is appropriate for individuals and family members to ask about hospice care at any time. Even before the person with dementia enters into the severe stage of the disease, it is helpful to talk about hospice care to plan ahead, which can help ensure the focus of care is reducing suffering as the disease progresses. This can be a discussion with the nurse, primary care provider, or social worker. An informational session with a member of the hospice team can also be arranged.

Hospice care is appropriate when a person enters the severe stage of dementia. Hospice care begins when the primary care provider makes a referral to hospice care. The hospice team will send out a team member for an initial visit within a day or two of the referral. The appointment is usually scheduled so any family members who wish to be there can be involved in the meeting. If the patient qualifies for hospice care based on a life expectancy of less than 6 months and the primary decision-maker chooses to enroll in hospice services, a schedule will be developed based on the patient's and family members' needs.

Usually nurses and other members of the hospice team set a schedule for regular visits. In addition, nurses and aides may visit as needed, if there is a change in condition. Hospice services are available on-call 24 hours a day.

If you are interested in hospice services for the person you provide care for, talk to your home health staff, primary care provider, or social worker.

How is a person enrolled in hospice care?

REFERENCES:

1. Xie, J., Brayne, C., Matthews, F. E., & Medical Research Council Cognitive Function and Aging Study collaborators (2008). Survival times in people with dementia: Analysis from population based cohort study with 14 year follow-up. *British Medical Journal*, 336(7638), 258-262.
2. Mitchell, S. L. (2015). Advanced dementia. *The New England Journal of Medicine*, 372(26), 2533-2544.
3. Centers for Medicare & Medicaid Services (2017). Medicare hospice benefits. Retrieved from <https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>.



Resources-Getting Help

There are rewards from providing care for a person with dementia. There are also challenges, and caregivers can face emotional, physical, and logistical challenges of caregiving at some point in that journey. The purpose of this section is to think and talk through who your resources are currently and identify other sources of support.

Fill out this section as completely as possible and keep it in a handy place.

Who are the other non-paid or family caregivers who take care of the person with dementia?				
Name	Relationship to the person with dementia	Schedule (M, W, F, afternoon)	Tasks or support provided (showers, meals, light housekeeping)	Contact information (email and phone number)

Who are the paid caregivers who take care of the person with dementia?

Name	Relationship to the person with dementia	Schedule (M, W, F, afternoon)	Tasks or support provided (showers, meals, light housekeeping)	Contact information (email and phone number)

As a caregiver, who do you turn to when you need emotional support? List friends, family, co-workers, neighbors, support groups, counselors, faith-based leaders.

Name	Describe how that person supports you	Contact information (email and phone number)

Who would you call if you needed help with the physical tasks of caregiving, such as lifting or transferring the individual off the ground or up from a bed or chair? List friends, family, neighbors or emergency medical services.

Name	Contact information (email and phone number)

Who are the members of the medical team for the person with dementia? List primary care provider(s).

Name of physician, nurse practitioner or PA	Clinic	Office location	Contact information (email and phone number)

How do you typically contact the primary care office?

Any medical office is comprised of several team members including one or more providers, such as a doctor, physician assistant or nurse practitioner, nurses, medical assistants, and office staff. It is rare to be able to contact a provider directly. Most communication will go through office staff and medical support staff, such as nurses and medical assistants, before getting to the provider. It is important to know that the individuals who answer the phone at an office usually do not have any medical training and are not able to assess the urgency of the need to see the provider. If you think the person you are caring for might be sick, it is a good idea to ask to speak to a nurse. The nurse can gather all the information and help set up an appointment with a provider, possibly much sooner than the office staff who answer the phones. The nurse can also troubleshoot or help you decide when and where is the best place for the person living with dementia to be seen and cared for.

Is there someone else at the office who you routinely talk to, such as a nurse or social worker?

Name: _____

Phone: _____

Are there any specialty providers who the person with dementia routinely sees, such as a cardiologist, pulmonologist, dermatologist, neurologist or palliative care specialist? List specialty care provider(s).

Name of physician, nurse practitioner or PA	Clinic	Office location	Contact information (email and phone number)

Respite providers or agencies

Agency contact person	Agency	Location	Contact information (email and phone number)

If there was a change in the caregiving needs for the person with dementia, who would you call for extra support? For example, if the person with dementia was sick and had more trouble getting out of bed, or was much more confused and needed extra supervision, who would you contact for more help?

Name	Relationship	Contact information (email and phone number)