University of California San Francisco

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Tips for Daily Life

The regular tasks of day-to-day life can become more challenging for a person as their disease gets more advanced.

Activities of daily living are divided into two major categories. The first, often called *instrumental activities*, includes more complex types of activities such as paying bills, shopping, managing medications, preparing meals and driving. The second category involves *activities related to personal care needs* and includes eating, bathing, dressing, getting in or out of bed or a chair, and using the toilet.

In the beginning of the disease, the person with dementia will have trouble with the complex instrumental activities. They may have changes in personality or behavior that impair their judgment or ability to complete multi-step tasks. The person will likely start to need some supervision and support to help maintain function and safety. As the disease progresses, the person will have more difficulty with basic functions and will need more hands-on help and support from caregivers.

General Tips for Supporting a Person with Dementia with Daily Tasks

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Things to do include:

- Creating a predictable and stable routine
- Providing regular opportunities for rest and activity
- Arranging the environment to help the person do as much as they can while staying safe
- Facilitating enjoyable activities that match the person's current strengths, interests and abilities
- Learning when and how to ask others for help as needed

People with dementia often lose the ability to plan and organize their day on their own. Establishing a routine can help the person remain as active and independent as possible. Here is one suggested (and detailed) example of how you might help them keep a routine:

MORNING

7 to 8

1 A / I							
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8 to 8:30

Get dressed

9 to 10

Cook and eat breakfast, help with the dishes afterwards

10 to 10:30

Look at pictures or a magazine or listen to the radio

10:30 to 11

Take a walk or do an exercise video like Sit and Be Fit

11 to 11:30

Do some stretches and balancing exercises from Go4Life

11:30 to 12:30

Help prepare and eat lunch, help with dishes afterwards

AFTERNOON

12:30 to 1

Sort the mail or sort playing cards by color, play a matching game like bingo, or make greeting cards

1 to 1:30

Rest with feet up or take a nap

1:30 to 2:30

Help with chores like folding laundry, sweeping or arranging things in the kitchen

2:30 to 3

Take a walk or do an exercise video like Sit and Be Fit

3 to 3:30

Have some decaf tea and a piece of fruit or snack

3:30 to 4

Call a friend or family member on the phone, or write a letter

4 to 5

Help with errands or chores around the house, tend to plants, shop for groceries

5 to 6:30

Help prepare and eat dinner, help with dishes afterwards

6:30 to 7

Help plan the menu for the next day (breakfast, lunch, and dinner), look at pictures of food, talk about recipes, watch a cooking show

EVENING

7 to 8

Take a shower or do grooming tasks like a manicure or pedicure, pick out clothes for the next day

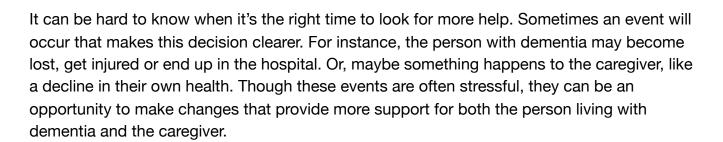
8 to 9

Sit on the porch or somewhere comfortable and talk about the day, old times, family updates, etc.

9 to 10

Begin bedtime routine, brush teeth, wash face, change clothes, go to bed

When to Seek Outside Help



Here are some signs that the person living with dementia may need more help or supervision:

- They get anxious when left alone
- They make mistakes with their medications
- They are unsafe when cooking, using tools or appliances
- They neglect their appearance or resist personal hygiene, such as not showering, wearing soiled clothing or have poor oral care
- They lose weight because they forget to eat, they are no longer able to prepare food for themselves or they cannot shop for groceries on their own
- They have difficulty getting around on their own without getting lost or falling, or being at risk for injury due to poor judgement
- They make mistakes with money such as spending more money than they have in their bank account or getting late notices for forgetting to pay bills
- They are drinking alcohol or smoking in an unsafe manner
- They behave in socially inappropriate ways that place them at risk for altercations with others or criminal action

Here are some signs that you, as a caregiver, may need more help:

- You can't find the time or energy to take care of your own health and wellbeing
- You have difficulty concentrating on what you are doing

Communication

Communication allows people to share information, feelings and ideas. People with dementia experience many challenges with communication. They may have trouble remembering what someone said to them, or they may have trouble following a conversation. They may not understand the words being said, and they may have trouble expressing themselves. A common challenge is finding the right word to use, so they sometimes substitute words that don't make sense. People with dementia often become quieter over time and don't take part in conversations. Older people with dementia may also have hearing loss that can affect their ability to follow a conversation.

It can be difficult for families to adjust to these changes

- It is hard to accept that the person with dementia cannot follow conversations the way they
 once did.
- It can feel lonely to lose the ability to have meaningful conversations with someone you have been close to.
- The ability to follow logic and reasoning often declines in dementia.
- It can be hard to adjust to speaking in simpler terms.
- It can be difficult to figure out what the person needs or wants.
- People with dementia may feel frustrated and self-conscious about their difficulty with language and comprehension, and this can be hard for families to observe.

How you can help

- Sometimes families find other ways to feel connected to the person with dementia, even in its advanced stages. Activities, such as listening to music, holding hands, or just sitting quietly together can feel meaningful.
- In many cases, the emotions being communicated are more important and more helpful
 than the content of what is being said. This is true for both the person with dementia and
 the caregiver. Pay attention to feelings rather than words. If you show feelings of being calm
 and comfortable, the message to the person with dementia is that they don't have to be
 worried.
- A person's behavior can be a good way to gauge how well they understand what is going on.
- For example, if the person is becoming irritated or anxious, that may be a sign that the conversation is too difficult or overwhelming.
- Do not use reasoning and logic if it leads to frustration and irritability.

 Tips for managing caregiver frustration include: counting to 10, taking a deep breath, taking a break, getting some help, attending a support group, and finding out how other caregivers are dealing with these same concerns.

Common Problems and Strategies

Trouble with Speech and Language

Result

- · Mixing up words
- Frustration with trying to express themselves
- · Difficulty understanding what is being said

Strategy

- Help the person find the word by guessing, asking them to describe it, or saying what they do with it
- · Apologize for not understanding
- Be patient and give the person time to say what they need to say

Trouble with Speech and Language

Result

· Avoiding conversations

Strategy

If they don't understand what you have said, repeat it using the same words

Offer limited choices and more time for the person to respond

- · Ask "yes" or "no" questions rather than open-ended questions
- Tell the person what you want them to do instead of telling them what you don't want them to do
- · Pay attention to the underlying emotion the person is expressing
- Go along with nonsensical speech—show interest and use the tone of voice and the rhythm that mimics a typical conversation

Visual Problems

Result

· Difficulty reading notes, calendars or written signs

Strategy

- · When giving instructions, use simple sentences
- Try using commonly recognized icons; for example, place a stop sign on doors that you don't want the person to open
- Show the person where to go or what you want them to do with gesture and gentle touch; for example, use gentle pressure on the lower back to offer guidance on where to walk

Forgetfulness

Result

- Forgetting what was said
- Repeating themselves frequently
- Forgetting names and relationships
- · Worrying about forgetting something important

Denying being forgetful

Strategy

- Greet the person by name and introduce yourself in case they cannot remember who you are
- · Do not give the person information too far in advance if they might worry about it
- Do not test their memory or remind them that they forgot
- Offer a reassuring response to frequently asked questions
- · Redirect the person to something pleasant
- Apologize even if it's not your fault

Inattention

Result

- Difficulty following conversations
- Getting distracted easily

Strategy

- Try to engage the person in one-on-one conversation instead of group discussion
- · Make sure the environment is quiet; turn off the TV, radio, phone or computer
- Keep eye contact and respond with enthusiasm

Poor Judgment

Result

- Saying rude or offensive things
- Not noticing or not responding to other people's feelings

Strategy

- Try to understand that the behavior is caused by the disease, not the person
- Try not to take things personally
- Try to find other ways to feel connected such as through humor
- In public, you may want to apologize to others for the person's inappropriate comments
- Avoid opportunities for trouble; plan public outings carefully
- Try using distraction with a snack or activity

Loss of Reasoning Skills

Result

- Inability to follow complex explanations
- Inability to understand "why" like the person used to
- · Difficulty making good decisions

Strategy

- Note that this can be difficult for both of you
- Try to let go of being right
- · Honor the person's grief over loss of independence

Offer alternatives when available

Inability to Problem Solve

Result

Overreacting or worrying about little things

Strategy

- Respond to the feelings, not the words
- Increase support to meet the person's needs without taking over
- · Limit information if sharing it will only cause worry
- · Apologize even if it's not your fault

Slowed Thinking

Result

- · Difficulty understanding what was said
- · Difficulty coming up with an answer to an open-ended question

Strategy

- Speak slowly and use simple sentences
- · Give the person time to process what you are saying

· Repeat yourself as needed using the same words you used the first time

Types of Conversations

Person with Dementia

"I don't know why that doctor took away my driver's license. I am a good driver."

Less helpful response

"Don't you remember? The doctor says you can't drive with a diagnosis of dementia."

Strategy

Avoid defending the decision that the person needs to stop driving; it may lead to an argument between the two of you. It's okay to acknowledge their frustration and anger about not being able to drive.

Better response

"You have always been a good driver. I know this is difficult. Shall we go have lunch now?"

Person with Dementia

"This is not my home. I want to go home."

Less helpful response

"Of course this is your home. We have lived here for 30 years. Don't you remember?

Strategy

Pay attention to the emotion and the feeling being expressed. The person isn't recognizing their home. Try to elicit positive memories.

Better response

"You have a lovely home. Tell me something you love about your home."

"Tell me something about the town you grew up in."

Person with Dementia

"You didn't tell me I have a doctor's appointment today."

Less helpful response

"I told you this morning, but you don't remember."

Strategy

While difficult to do, it's sometimes easier to accept blame, even when you know you are right.

Better response

"I'm sorry, it must have slipped my mind. I thought we could have lunch after the doctor's appointment."

Person with Dementia

"What are we doing today? Where are we going?"

Less helpful response

"I just told you that we are having lunch with our friends."
"What do you want to do today?"

Strategy

The person isn't deliberately forgetting: they really cannot remember. Yes/no questions may be easier to answer than open-ended questions.

Better response

"It is time for breakfast now. Let's listen to the birds and drink our coffee. Would you like eggs or yogurt?"

"Shall we go to the park or to our friend's house?"

Person with Dementia

"Where am I? Why am I here?"

Less helpful response

"Why do you keep asking me? You come to this day program every day."

Strategy

Dementia often affects visual perception, so places may not seem familiar.

Better response

"This is the Senior Club. I am glad you came for class. Can you help us move those chairs over here?"

Person with Dementia

"Leave me alone – get out of here! I don't need your help!"

Less helpful response

But you can't do this by yourself."

Strategy

Avoid arguing. Maybe take a break and try again later. With some distraction, the person may be willing to accept assistance.

Better response

"I am sorry, this is a tough time. Let's make the best of it together. Did you see the blossoms on the trees out front? They made me sneeze all morning! Would you please get me a tissue?"

Person with Dementia

"I don't want to go to that program!"

Less helpful response

"You always go on Wednesdays, and they are expecting you."

"I need you to go to your program, so please hurry and get ready."

Strategy

Avoid arguing or reasoning. Distraction may help. Check with the program staff and make sure the person is enjoying the program once they get there.

Better response

"I am sorry, this is a tough time. Let's make the best of it together. Did you see the blossoms on the trees out front? They made me sneeze all morning! Would you please get me a tissue?"

Person with Dementia

"I don't care what you want! I'm getting away from here!"

Less helpful response

"Don't go out the door! It's a busy street and it's not safe!"

Strategy

Telling a person to not do something when they are agitated can make them even more upset. Tell the person what you want them to do instead of telling them what you don't want them to do.

Better response

"I'm getting a snack. Let's go to the kitchen."
"I'll walk with you."

Balancing Safety & Independence

Families often struggle with trying to support the person with dementia be as independent as possible while protecting safety. Common risks that lead to hospitalizations in dementia include falls and infections such as urinary tract infections and pneumonia. Persons with movement problems like parkinsonism (including Parkinson's disease, Lewy body dementia [LBD] or progressive supranuclear palsy [PSP]) often have a higher risk for falls and may benefit from assistive devices like walkers, raised toilet seats and grab bars.

In addition to reducing risks, there are ways to support persons with dementia to help them maintain their independence for as long as possible. For example, people with visual spatial deficits (that often occur with Alzheimer's disease [AD] and posterior cortical atrophy [PCA])

may benefit from home modifications that improve lighting, reduce clutter and increase color contrast to enhance function.

This section offers tips that are generally helpful for people with dementia of all types. It includes ideas for making changes to the environment and other practical strategies to promote the person's safety and independence.

IF

THEN

The person is stumbling and falling at night

- Keep a light on in the bathroom. Consider using nightlights to enhance visibility
- Make sure the pathway to the bathroom is clear of rugs and clutter
- · Consider keeping a urinal or commode near the bedside
- Limit fluid intake after dinner and make sure the person uses the bathroom before going to bed
- Consider using a partial bedrail at the head of the bed to help the person get out of bed.
 Full-length bedrails can be dangerous because people injure themselves trying to climb over them
- Consider getting a low hospital bed or lowering the mattress close to the floor to make it
 more difficult for the person to get out of bed on their own. Use a baby monitor or bed
 alarm to alert the caregiver that the person needs assistance. Remote alarms that alert the
 caregiver without startling the patient are preferred
- · Consider hiring overnight help to reduce disruption of the caregiver's sleep
- Provide verbal cues to remind the person to get out of bed slowly, especially if they take blood pressure medication

The person is tripping or falling during the day

- Clear pathways of papers, electrical cords, and anything else the person might slip on or trip over. Try putting things in baskets or storage containers to reduce clutter
- Consult with the person's doctor to see if medications, pain/numbness, dizziness, urinary urgency, vision problems or hearing problems may be contributing to falls
- Request a referral for physical therapy if weakness or balance issues may be contributing to falls
- Ask the doctor or physical therapist about using a four-wheeled walker (the kind with a seat)
- Avoid wearing slip-on shoes or slippers, heavy boots or high heels. Do not walk around the home barefoot or wearing socks
- Wear well-fitting shoes that have a thin, hard-rubber, non-skid soles, with firm heel support, and Velcro straps
- · Remove or secure rugs on the floor with double-sided tape
- Avoid rugs or flooring with busy patterns or high contrast designs. The person with dementia may perceive that a dark rug is hole or that a design is an object on the floor
- · Avoid shiny floors and surfaces that produce glare
- Use lighting to reduce shadows on the walls and floor
- Standby and observe the person in public areas like parking lots or restaurants so that you can easily offer assistance if they stumble
- Avoid distracting the person by talking when they are walking—try to help them concentrate
 on what they are doing
- · Limit alcohol intake
- Increase exercise to improve strength and balance
- Try an exercise, tai chi, or fall prevention class at the local senior center
- Consider joining a gym with the Silver Sneakers program
- Consider home exercise videos like Sit and Be Fit or home exercises like these

The person's home is not accessible for people with frailty or mobility problems

- Consider hiring a professional care manager or occupational therapist to do a home safety visit to make recommendations
- Have grab bars installed in the bathroom
- Here is a placement guide
- Here is a do-it-yourself instructional video

- Programs like <u>Safe at Home at Rebuilding Together</u> may be able to make home modifications for you
- Apply non-skid tape to shower or tub floor or consider using a non-skid mat. Consider a bench or shower chair. <u>Transfer benches</u> are helpful for bathtubs
- · Use a commode chair to elevate the toilet seat
- In California, used adaptive equipment is available through organizations like Ability Tools
- Purchase a sturdy chair with arm rests and open space under the seat. Consider a motorized lift-up chair if the person needs assistance to transfer from a chair.
- Consider partial bedrails and transfer poles to assist the person with transfers from the bed
- Place handrails in hallways and along both sides of a staircase. Apply bright reflective tape
 to the edge of stairs to improve visibility. Install a ramp or chair lift to enable entrance and
 exit from home
- Consider getting an adapted phone or medical alert response system the person can use to call for help in an emergency
- Observe for signs that the person may need more help and supervision such as: poor hygiene, weight loss, unexplained bruises, burns, or other injuries

The person gets disoriented or has difficulty processing visual information

- People with visual spatial problems are especially at risk for wandering and getting lost.
 They should wear a medical alert bracelet with the caregiver's contact information on it or enroll in the Alzheimer's Association Safe Return program
- Observe the way the person figures out how to do daily tasks and adapt the environment to support their function. For example, make sure that things the person uses regularly are visible to them by storing them in the same place and removing any surrounding clutter. See ideas from real caregivers in this <u>Conversations with Caregivers video</u>: <u>Balancing Safety and Independence</u>
- Use color contrast to help the person see things.
- · Optimize lighting to reduce glare.
- Apply bright reflective tape to the edge of stairs to improve visibility
- It may be difficult for the person with visual spatial deficits to tell the difference between safe items and those that are hazardous:
 - Look for and throw away any spoiled food in the refrigerator on a weekly basis to avoid food poisoning or stomach upset
 - Remove or lock up hazardous household chemicals and cleaning products
 - Remove or lock up potentially hazardous tools and appliances

Remove guns from the home. If they cannot be removed from the home, remove
ammunition and store it separately from the gun. Apply gun locks and secure guns in a
locked cabinet. For more information on gun safety, see here

The person with dementia is left home alone or has minimal supervision for any period of time

- Help the person keep a predictable daily routine. Attending a day program can be helpful to give the person activity and structure to their day. See here for more ideas
- Consider getting an <u>adapted phone or medical alert response system</u> that the person can demonstrate they can use to call for help in an emergency
- Observe for signs that the person may need more help and supervision such as: poor hygiene, weight loss, unexplained bruises, burns or other injuries
- Observe for signs of paranoia or unrealistic beliefs that someone is out to get them. For
 example, the person might try to tape the window coverings shut, hide their valuables, or
 barricade the doorway. This may be a sign they are no longer safe to be left alone and may
 need more supervision and support.
- Look for and throw away any spoiled food in the refrigerator on a weekly basis to avoid food poisoning or stomach upset.
- · Remove or lock up hazardous household chemicals and cleaning products
- · Remove or lock up potentially hazardous tools and appliances
- Remove guns from the home. If they cannot be removed from the home, remove ammunition and store it separately from the guns. Apply gun locks and secure guns in a locked cabinet
- Consider using a "nanny camera" or home security camera to observe the person's behavior when no one is around

The person with dementia wants to drive even though their license was revoked

- · Get rid of the car or park it out of sight
- Get a steering wheel lock or another safety device that prevents someone with the ignition keys to take the car
- · Disable the car
- Empathize with the person's anger or frustration about losing their independence

- Let the doctor or the DMV be the "bad guy" for taking away their driver's license
- Arrange for alternate transportation such as taxis or ridesharing apps (Uber, Lyft) or paratransit
- Ask the person to help navigate when they are in the passenger seat
- Change routines so the person has other things to do and isn't bothered by not driving

Being in Public or Social Situations

People with dementia often say and do things that are considered inappropriate for their age. This can be confusing for those who don't know they have dementia. Discomfort and conflict can often be avoided by simply saying the person has dementia. You can also discreetly hand out business cards that explain that the situation. These cards can be made on a home computer and can say something like: "My companion has a brain disorder; thank you for your patience" (click here to download cards you can print).

People with dementia may become easily overstimulated by crowds, noise or too much activity. They may get tired and irritable and act out. Plan ahead to avoid busy shopping or dining times. Make sure the person has an area they can escape to for rest and quiet if needed.

On the other hand, some people with dementia have lots of energy and get bored easily. If this is the case, bring an "activity bag" with you when you leave with house. Pack the bag with things to help distract the person such as coloring supplies, magazines, tactile/fidget toys, music with headphones and a snack. Keep a close eye on the person when in public as they may do something impulsive in a second!

Helping with Bathing & Grooming

Accepting help with bathing and grooming is one of the biggest challenges for people with dementia. It is often uncomfortable and stressful for caregivers too. Here are some ideas for making bathing and grooming a little easier.

Find a way to start from a calm place. Plan to allow plenty of time so that you don't have to rush. Before introducing any bathing or grooming tasks, try to connect with the person by talking about something pleasant or funny. Avoid drawing attention to the fact that the person needs help to preserve their sense of dignity. Use a respectful, matter-of-fact tone of voice to help you both feel more at ease. Keep a predictable schedule or routine for bathing and grooming. Support the person to do as much as they can without getting frustrated. Apologize when things get especially difficult or frustrating even though you may be doing your best. Celebrate once the hard part is over: laugh, congratulate yourselves, or enjoy an activity or treat together. This will help the person forget any unpleasantness.

Here are more ideas for responding to specific problems:

IF

THEN

The person is upset or irritable

Try using the following strategies to help them feel calm before you start personal care:

- Decrease sensory input
 - Reduce noise level (close the door, turn off the television, etc.)
 - Dim lights and lower blinds (but make sure there is enough light for the task at hand)
- · Apologize and offer reassurance
 - "It's okay, we can handle this."
 - "I am sorry, I know this is uncomfortable. I will be gentle."
 - "You will feel so much better when we are done."
 - "I don't like this part either, let's try to get through it together!"
- Provide distractions
 - Talk about something pleasant, for example, the weather, a fun fact, a humorous story or a fond memory
 - Give them something comforting to hold, like a soft blanket, a stuffed animal or other preferred item
 - Sing or hum a favorite song or play background music
- Follow familiar habits around bathing and grooming
 - For example, if they usually brush their teeth or shave before bathing, help them keep that routine

The person refuses help with bathing or grooming

Try different ways to introduce the task:

- Find opportunities to ease into the task discreetly; for instance, if there is a spill or they get dirty, or when they have an outing or an appointment
- Make it part of a regular routine; try using a calendar and writing the shower schedule down
- · Try first thing in the morning before they are fully oriented to their own agenda
- · Cheerfully offer limited options
 - "Today is shower day! Would you like to shower now or after breakfast?"
 - "How about wearing this lovely green sweater today?"
 - "Let's wash up before we go to the movies."
- Set up the environment to prompt the person to do the activity themselves
 - Turn on the shower and set up a change of clothes in the bathroom and say, "Your bath is ready, it's nice and warm, just the way you like it!"
 - Set out pajamas in the evening and say, "Time to put on your cozy, soft pajamas!"

Find out if the person might be refusing help because the task is physically painful:

- · Observe for signs of pain (moaning, bracing, wincing)
- · Ask, "Does it hurt?" when the person resists something
- If you think you see signs of pain, talk to the person's doctor about it to see if medication would help

The person has difficulty following directions or doing grooming tasks

Set up the environment

- Clear any unneeded items away from the work area to avoid confusion
- Arrange needed items in the order they will be used
- Consider using a chair so the person can sit at the sink or in the shower
- Watch these videos to learn about supplies and equipment that can help
 - Family Caregiver Alliance Caregiver College Video Series: Bathing and Dressing
 - Conversations with Caregivers: Helping with Dental Hygiene
- Keep some extra supplies nearby just in case the process gets messy, such as disposable gloves, a plastic garbage bag and a towel

- Show the person what you want them to do; for example, pretend to brush your own teeth, pull up your pants or comb your hair
- Give the person simple 1–2 step directions, pause after each instruction and talk them gently through the whole task (verbal cues)
 - "Stand up."
 - · "Hold this."
 - · "Wash your face."

The person is uncomfortable with the intimacy of allowing someone to help with bathing and grooming

- Use a matter-of-fact approach; avoid drawing attention to the fact that the person needs help
- Support the person to do as much as they can for themselves
- Pay attention to privacy; keep the person covered as much as possible: close curtains, window coverings and doors
- Talk the person through the process to help them feel safe, or distract them with small talk
- Thank the person for helping

Incontinence

Incontinence is defined as a partial or total loss of control over bladder or bowel function that results in wetting or soiling oneself. Many things can cause incontinence, including medications, food or drink, infections or other medical problems. It is a good idea to tell a doctor about any new incontinence to <u>see if treatment is available</u>. Dementia can also cause incontinence. The sequence below shows how symptoms of dementia can lead to incontinence. It also includes strategies to help caregivers manage each symptom.

IF

THEN

The person is apathetic or has lost interest in going to the bathroom or lost the ability

to notice or care if their clothes get wet or soiled

- Set a routine toileting schedule to assist the person to the bathroom every 3–4 hours, such as before/after meals and before/after sleeping
- Provide respectful reminders and cues as needed
- · Use pads or pull-up briefs for occasional accidents

The person has memory problems and they forget to go to the bathroom, forget *how* to go to the bathroom or get distracted on their way there

- Set a routine toileting schedule to assist the person to the bathroom every 3–4 hours, such as before/after meals and before/after sleeping
- · Provide respectful reminders and cues as needed
- · Give the person simple instructions; ask them to do one thing at a time
- · Use pads or pull-up briefs for occasional accidents

The person has visual/spatial problems and has difficulty finding the bathroom or they go to the bathroom in the wrong place (such as a trashcan, houseplant or sink)

- Make sure the pathway to bathroom is clear of clutter
- Keep a light on in the bathroom or use motion sensor nightlights
- Place a picture or sign on the door to the bathroom
- Use a colored toilet seat or toilet bowl light

The person has mobility problems that make it difficult for them to get to the bathroom in time, hard to get on and off the toilet, or difficult to use zippers and belts

 Set a routine toileting schedule to assist the person to the bathroom every 3–4 hours, such as before/after meals and before/after sleeping

- Give the person enough time to get to the toilet
- Ask their doctor for a referral to a physical or occupational therapist
- Try using a commode, grab bars, raised toilet seat, or urinal
- Use pants that are easy to remove (e.g., those with an elastic waist or Velcro fly)
- Use pull-up briefs if the person can walk to the toilet but has occasional accidents
- · Use more absorbent tabbed briefs if the person is unable to walk to the toilet

The person has sensory impairment and they no longer feel like they have to go to the bathroom or sense when their clothes are wet or soiled, or they're no longer able to control their bladder or bowel function

- Set a routine toileting schedule to assist the person to the bathroom every 3–4 hours, such as before/after meals and before/after sleeping
- Use absorbent briefs and protective skin products (barrier creams or zinc ointments)
- Inspect the skin for redness, irritation or open sores

The person has nighttime bladder problems such as wetting the bed or going to the bathroom many times during the night

- · Consult with the person's doctor to see if there is a medication that might help
- Limit fluid intake in the evening
- Avoid caffeinated and alcoholic beverages
- Use the bathroom before going to bed
- · Use a urinal or bedside commode
- Use a waterproof mattress cover, absorbent underpads and super absorbent briefs
- Consider using a hospital bed to help protect the caregiver's back during care

The person seems embarrassed about their incontinence and refuses or denies the need for help. They get angry or frustrated, hide soiled clothing or avoid public places and social events.

- Use a respectful, matter-of-fact approach to offer help (do not use baby talk)
- Only offer as much help as the person needs, sometimes people just need patient verbal instructions
- Avoid reacting negatively or drawing attention when the person has an accident
- Try distracting the person with pleasant conversation, music, or something to hold
- Plan ahead for public or social events, locate the bathroom and bring incontinence supplies and extra underwear just in case

The person has skin problems like red irritated skin, blisters, open sores or purplish discoloration.

- Help the person stay clean and dry; use absorbent pull-ups or briefs and help change them regularly
- Use no-rinse cleansing lotions, foams, creams, or wipes (i.e., Tena, Coloplast, Medline Remedy, Convatec Aloe Vesta, or Comfort Shield brands)
- Some people prefer to use a bidet to rinse the perianal area after using the bathroom
- Apply barrier ointment to the groin area
- For skin that is already tender, red, and irritated, use an ointment that includes zinc and menthol; zinc helps with healing and menthol soothes skin (i.e., Calmoseptine, Desitin, Lantiseptic, Medline Remedy, or Coloplast brands)
- See a doctor if skin irritation does not improve or appears purplish, as this may be a sign of fungal infection or deep tissue damage

The person has pain that makes it difficult for them to get to the bathroom in time, causes them to avoid or delay going to the bathroom, causes them to physically refuse or resist help, or causes grimacing, moaning, or bracing during incontinence care.

- Tell a doctor about signs of pain during incontinence care
- Try using a raised toilet seat or commode, consider a cushioned toilet seat
- Be careful, slow, and gentle when providing incontinence care
- Talk the person through the process by telling them what you are going to do before you do
 it
- Consider offering the person a treat after a difficult episode of care

Dealing with incontinence is often stressful for people with dementia and their families. The person with dementia may feel embarrassed and ashamed about needing help. An adult child may feel uncomfortable helping their older parent with such an intimate task. A spouse or partner may feel sad or angry watching their loved one lose control over a basic function. It is normal to feel this kind of grief. With time, people often get used to these changes. They may even find it is not as bad as they thought it would be.

Incontinence care can be tiring and painful for caregivers. Using a commode or hospital bed can help prevent injury. No-rinse soap can make it easier to keep the person clean. Families often need respite by this stage and may hire paid caregivers to help in the home. In some areas, the person with dementia may go to an adult day center where they can participate in activities and get help with incontinence care. Sometimes, the person with dementia needs more help than families can provide at home, and the best option is for the person to move into a long-term care facility.

Additional Resources on incontinence:

- NationalIncontinence.com website
- Adapt a Home Bathroom En Suite illustrated info sheet
- ThisCaringHome.org website

Videos about how to help with incontinence care:

- Toileting & Incontinence (Caregiver College Video Series)
- Transfer Skills (Caregiver College Video Series)

Eating Changes & Challenges

When a person has dementia, their eating habits and abilities change. They might forget to eat or try to eat non-food items like lotion or cleaning products. They might forget that they already ate and ask to eat again just after finishing a meal. They might crave sweets, have trouble seeing the food on their plate or have difficulty using spoons and forks. Eventually the person with dementia will lose the ability to say when they feel hungry or thirsty, and they will have trouble swallowing regular food and drinks. Weight loss and choking become a concern. It is important to keep track of the person's weight and look for signs of difficulty swallowing such as coughing, gagging and drooling. Other things that may affect eating and drinking include tooth pain or mouth sores, breathing problems, illness, medication changes, depression, drowsiness or lack of exercise. It is important to talk to the person's provider about any weight loss or signs of choking.

IF.

THEN

The person forgets to eat

- Set up a routine for meals to help them remember
- Try a written schedule if the person can read
- Set out food with simple instructions (i.e., a bowl, a box of cereal, a spoon and a note that says the milk is in the refrigerator)
- Try an alarm or telephone reminders
- Eat together or arrange friendly visits around mealtimes
- Try meal delivery or communal meals at a senior center or day program
- · Place snacks they like near their favorite place to sit

The person eats too much because they forget they already ate or have developed compulsions that lead to frequent food intake

- Set up a routine that includes meals, socializing, exercise and other activities to prevent too much focus on food
- Offer low calorie snacks if they insist on eating again (i.e., fruit, veggies, popcorn without butter, soup broth, cottage cheese, sardines)
- Encourage fluid intake when they request food after just eating. Try saying in a matter-of-fact tone of voice, "Oh! We just ate eggs and toast. Now it is time to drink this glass of water/tea/lemonade" or try holding up a drink and simply saying, "Cheers!"
- Redirect them to another activity when they request food after just eating. Try saying, "Let's go for a walk and enjoy the sunshine/fall leaves/fresh air."
- Consider whether this is a problem worth trying to fix or if limiting food intake causes conflict or distress

If the person tries to eat non-food items

- · Set up a routine for meals to make sure the person is getting enough to eat
- Hide or secure toxic cleaning products
- · Label liquid soap, lotion, toothpaste and other toiletries if the person is able to read
- Remove clutter from kitchen and dining areas to make food more visible
- Place snacks near the person's favorite place to sit

If the person does not eat enough

- Discuss any weight loss or signs of choking with the person's doctor
- Check the person's mouth for redness, swollen gums, tooth problems or mouth sores
- Help the person clean their teeth and mouth twice a day
- Offer one or two foods at a time so the person is not overwhelmed by a full plate
- · Serve finger foods or food in a bowl to make eating easier
- Use a solid colored plate or bowl to make the food more visible or try placing a colored placemat under a white plate or bowl
- Serve colorful foods that look appealing
- Try soft, moist foods if the person eats slowly or takes a long time to chew their food (cooked vegetables, canned fruit, pasta with sauce, hot cereal, mashed potatoes with gravy, creamy casserole, meatloaf, etc.)
- · Reduce clutter, noise and other distractions during mealtime
- Eat with the person and provide visual, verbal and tactile cues to help them stay on task
- Use hand-over-hand assistance to get them started
- Honor their food preferences; many people with dementia prefer sweet flavors
- Offer foods high in fat and protein to maintain calorie intake (ice cream, cheese, nuts, butter, avocado, eggs, bacon, etc.)

More Information About Eating:

- Conversations with Caregivers: Meals video
- Better Mealtimes: Tips for meal set up and useful product ideas to make eating easier

- Meal set-up for someone with Parkinson's disease or progressive supranuclear palsy (PSP)
- Eating tipsheet
- Helping someone with advanced dementia eat and drink
- Dementia friendly assistive tableware
- Adaptive spoons
- · Budget friendly recipe ideas

Simple Finger Food Ideas:

- Peanut butter, tuna, avocado or grilled cheese sandwich squares
- · Hummus and tomato stuffed in pita triangles
- Muffins
- Veggie sticks (cucumber, carrot, bell pepper)
- Fruit slices
- · Cheese cubes or slices
- Quesadilla or English muffin pizza
- · Hardboiled egg
- · Bagel or toast
- · Granola or breakfast bar
- · Dried fruit
- Nuts

Sleeping Changes & Challenges

When a person has dementia, their sleeping habits often change. They might lose the ability to initiate or carry out the steps necessary to get ready for bed on their own. Falling asleep initially or falling back to sleep if they awake in the night may become difficult. Continuing to use equipment for sleep disorders such as sleep apnea may become more confusing and disruptive to their sleep. They may interrupt your sleep due to excessive movements when sleeping, or restlessness trying to fall asleep. They may become active in the middle of the night and wake you with noise/commotion. Managing the person's sleep problems will better ensure both of you get more rest.

- Try to keep a consistent schedule of wake/sleep times.
- Provide at least a little exercise each day even if it is just a walk around the yard.
- Give the person tasks to compete during the day to keep them active, e.g., folding laundry or sorting items.

- Avoid a lot of TV watching during the day this usually leads to napping.
- Keep the person hydrated during the day but avoid giving them a lot of liquids (especially caffeinated) before bedtime to decrease the likelihood of accidents and/or the need to get up during the night.
- Engage them in a quiet and calming activity before bedtime.
- · Assist the person in the tasks of getting ready for bed.
- Consider asking someone to sleep over a couple nights a week to relieve you of nighttime duty.

Everyday Advice
Caregiving Resources
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