Caring For A Loved One With Dementia

a practical **guide**for family
caregivers

Personal Care and Safety





Introduction

With dementia comes a decline in one's ability to take care of oneself and a greater risk to injure oneself.

As the disease progresses, you may notice a change in your loved one's hygiene and grooming. For example, they may forget about bathing, dental care or how to get dressed. As a caregiver, it will be helpful being comfortable in aiding with personal care for your loved one.

This book's objectives are to help you assist with personal care and overall hygiene in order avoid infections and skin conditions, as well as to explain how to improve your loved one's general safety.







Bathing and Showering

Bathing and showering require a lot of patience and diligence from caregivers. It can be a strenuous job, but with the right tools, it can turn into a smooth process. When trying to encourage bathing, be aware of the tone that you're using. Moods are contagious, and your frustration could make your loved one more hesitant to take a shower. Bathing is a very private and personal manner so loved ones may feel self-conscious about needing assistance. Provide a comfortable, non-threatening experience, so they don't feel shamed into bathing.

The shower itself should be equipped with multiple safety protocols such as a spray attachment, safety handles/rails, and a shower chair (if possible). Such devices are useful to help wash your loved one in an effective and safe manner. Water temperature should be warm and not too hot or cool, allowing your loved one to sit or stand in the shower without risk of burning or discomfort. Use a spray attachment to clean the peri area with water only (though it is okay to use soap on the pubic hair). After showering, pat down the skin with a towel to dry, apply lotion immediately to your loved one's skin to lock in moisture.

Ideally, people with Alzheimer's should bathe 2 to 3 days a week. In between washing days, you can use baby wipes to clean the face and body.



Incontinence care

When dementia advances, people may lose the ability to recognize when to use the restroom. It's common for people with dementia to experience incontinence. Certain medications may also contribute to incontinence. For caregivers, it can be difficult to determine when their loved one must go to the bathroom.

Protective Products

There are many different products to protect from leakage and soiling problems for your loved ones. There are different advantages for each product depending on your loved one's needs.

• Incontinence Pads:

These are typically used for patients in the early stages of dementia or Alzheimer's. They're useful for minor leakage problems and are popular among women because of their resemblance to the feminine product. Incontinence pads conform to the body and are discreet so no one will notice that your loved one is wearing one. They feature a special material that wicks urine away from the skin, keeping the user dry, comfortable, and odor-free. Worn on the person's underwear, incontinence pads are used for daytime protection, although some pads are absorbent enough to use during the night. There are also pads designed for men with a cup impression in front of the pad.

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• Tab Briefs:

Designed with tape tabs or hook and loop taps, these briefs are replacing the person's underwear and can be donned or removed while standing up, laying down or sitting on a wheelchair. These undergarments are especially useful for later stage patients who might have a harder time getting to the restroom. Tab briefs have adjustable tabs for patients of all shapes and sizes. It also has wetness indicator lines to signal when it's time to change.

• Maximum Strength Underwear Diapers:

These diapers hold a lot more liquid than regular briefs and can be kept for longer periods of time without needing to be changed. They are not recommended for patients in a wheel chair or bed ridden.



Bathroom

Finding the Way to the Bathroom

You may notice that your loved one may have more difficulty finding the restrooms or distinguishing it from other rooms. This fact may be problematic when it comes to using the bathroom at night.

Persuading Your Loved One to Use the Bathroom

To prevent accidents, it's useful to keep a bathroom schedule for your loved one. Every 2 to 3 hours, ask them if they would like to try to use the restroom. If it's been longer than that, be insistent and encourage them to follow you into the bathroom.

"When it comes to taking your loved one to the bathroom when they don't want to, try to remain very calm. The trick is to make it fun for them. Don't tell them you are going to the bathroom, distract them with another topic or sing a song they really like. If it does not work now, try again in 30 minutes."

When guiding your loved one into the restroom, make sure your pathway and space is free of clutter. You want to provide a nonthreatening, spacious experience that keeps your loved one calm and unafraid. If your loved one is having trouble urinating, try offering them a cup of water or turn on the faucet beforehand. To help accidents at night, consider lighting up a pathway to the restroom. You could install little night lights with signs pointing towards the correct way. If your loved one is unable to walk very far, place a chamber pot next to the bed.

Cleaning Up

Take time to properly clean your loved one to avoid infections or unpleasant odors. Urinary Tract Infections (UTIs) are common in dementia patients can be difficult to detect early as and they may be unable to decipher and communicate where the pain is coming from. To prevent UTIs in your female loved one, make sure to wipe from front to back. To keep your loved one from getting scared or stressed, be sure to vocalize each step of the cleaning up process.

"I always tell my mom what we are going to do first. 'We are going to the bathroom. Now I am going to pull your pants.' Singing while they are in the bathroom is a great way to quiet her anxiety too. There are a few songs that work particularly for her, such as 'You are my sunshine' or 'Show me the way to go home'."

Having an accident

If your loved one does have an accident, confront it in a nurturing way. Instead of saying, "You wet yourself," ask, "Did you have an accident?" That way, it doesn't make your loved one feel ashamed. When your loved one denies incontinence, express that they must have sat on something and that their clothes need to be changed. Don't reason or argue. Be sure to follow up with your Doctor to report any changes of incontinence as they may be a sign of a Urinary Tracy Infection or another medical condition.

Dressing

Helping your loved one maintain their appearance can help promote positive self-esteem. However, for a person with dementia, having a plethora of clothing options can not only take a long time to choose but also cause confusion and stress in the process. To help prevent agitation, consider choosing outfits in advance for each day of the week. If your loved one has a favorite shirt, feel free to incorporate it into the lineup, but be sure to offer simple and comfortable clothing as well. Shirts that open in the back, elastic waist pants, socks without seams, and shoes with Velcro straps are popular clothing suggestions.

If your loved one wants to wear the same outfit daily, consider buying multiples of the same clothing. Even though you are limiting his/her choices in outfits, you still want to applaud them for dressing themselves every day.

Safety

One of the most frequent questions a caregiver has is: "How can I keep my loved one safe?" It sounds like a tough question, especially since there are so many situations for them to get hurt. With flexibility and imagination, you can make your home a both safe and supportive place for your loved one and their needs.

The first step to providing a safe environment is to "dementia-proof" your home. Pay special attention to all rooms that may have sharp items or electrical outlets such as the kitchen, garage, bathrooms, backyard and workrooms. To prevent any accidents with stoves or other appliances, consider unplugging them or removing the knobs so your loved one cannot turn them on.

Preventing Falls

Current research shows that seniors with dementia are three times more likely to suffer from a fall or hip injury than seniors without dementia¹. Additionally, about half of all falls take place in an individual's home. Therefore, it's important that certain measures are taken to reduce the chance of falls and injury in the household.

- Be sure to keep the house as clean as possible by picking up items that you can trip over such as books, papers, and shoes.
- Install support bars on the staircases and in the restroom.
- Use nonslip mats in tubs and showers.
- Keep necessary items such as a glass of water, eyeglasses, and a lamp on their bed stand in case they are needed at night.
- Be mindful that rugs create a trip hazard and provide your loved one with comfortable supportive shoes.

Wandering

A study from the Alzheimer's Association found that 6 out of 10 people with dementia will wander². For even the most diligent caregivers, it can be a very scary moment not knowing where your loved one has gone off to. Fortunately, there are practices that you can adopt to help reduce the risk of wandering.

If a person experiences memory loss or is diagnosed with dementia, chances are he/she will wander at least once. To prepare for these occurrences, or if you are unsure whether your loved one will start to wander, look out for these risk factors:

- Forgets how to get to familiar places
- Acts nervous or anxious in crowded places
- Says they will go do a chore or hobby and is unable to follow through
- Talks about going to past jobs

To help prevent wandering from taking place, try to fill up your loved one's day with activities as much as possible. When he/she is preoccupied, they'll focus more on the task at hand.

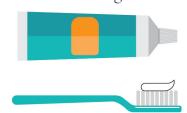
If wandering does occur, the first step is not to panic. Call the authorities right away and set up a party to search the surrounding area. Studies have shown that dementia patients get up to 1.5 miles away from home.

There are additional resources to help caregivers monitor their loved ones. Durable medical equipment stores offer a variety of locks, alarms, and other devices designed to keep your loved one from wandering. The Safe Return program is an emergency response service that activates a community network when a person with dementia is reported lost. The alert goes out to local law enforcement and Alzheimer's Association chapters to help locate the missing person.

Oral Hygiene

Once the dementia starts to progress, individuals with dementia may forget when or how to brush their teeth. To prevent dental problems, it's important to be persistent in assisting your loved one with brushing and flossing daily. Don't try to force them to open their mouth or pry their lips open. If the individual insists on not brushing their

teeth at that moment, try at different time. Tooth brushing doesn't have to necessarily happen in the morning or before bedtime. Find a time when you and the individual are calm and have extra time to perform the task.



While it's instinctive to know how to brush and floss, it's difficult for individuals with dementia to learn.

Depending on the stage, simply saying, "brush your teeth," may just confuse the individual. To encourage your loved one to brush, we suggest brushing along with them and provide step by step instructions. While fluoride toothpaste is preferable for dental health, the taste may be displeasing for some. Using children's dental products with pleasing flavors (such as bubblegum or cherry) may encourage individuals to brush more often -especially if they swallow the toothpaste in the process.

Oral Discomfort

When individuals with dementia start to lose their ability to form words, it becomes difficult for them to convey their pain. Oral discomfort may stem from lack of brushing or flossing or dentures not fitting correctly.

Some signs of mouth pain include:

- Refusal to eat
- Pulling at the face or mouth
- Aggressive behavior including moaning and shouting
- Leaving dentures out of their mouth

Be on the lookout for any symptoms and signs of oral discomfort so that it can be treated immediately. The longer the problem stays, the higher risk of tooth decay or infections.

Finding a Dentist

To find a dentist that will suit your loved one's needs, we suggest to call your insurance to find providers that have experience working with dementia patients. Notify the dentist of your loved one's condition and provide a list of his/her doctors and medications. Depending on the stage of dementia, there will be different procedures that your loved one will be able to handle, but be sure to schedule regular appointments for bi-annual cleanings.

Sleep Hygiene

Many people will experience a change in their sleep as they age, however, it is even more prevalent in persons with Alzheimer's disease or another dementia. Sleep disturbance, change in sleep cycle, waking during the night, and the need for less sleep may occur. Other sleep changes may include hypersomnia; excessive sleeping during the day or at night, or insomnia; difficulty falling asleep and not feeling well-rested. Some sleep changes occur due to depression, anxiety, or a medical problem that keeps the person from regulating their sleep, so it is always advised to talk with your Doctor if you have noticed change in your or your loved one's sleep.

Our bodies have an internal "clock" that helps tell us when to go to sleep and when to wake up. It is regulated by a hormone called melatonin. This hormone keeps our clock on time. It is also very sensitive to dark and light, meaning we make more of it when it becomes dark outside at night, and production slows down when we are exposed to more light. Many research studies suggest that as we age, we produce less melatonin, and therefore are less regulated in our sleep.

In people with dementia, sleep disturbances are frequent, and often the result of deterioration of brain neurons and decreased

hormones that we depend on to regulate sleep. This may lead to increased confusion, agitation, and wandering. Waking up during the night can happen at any stage of Alzheimer's disease. They may be disoriented and believe that it is morning, time to wake up, or time to get ready to leave for work or another appointment.

1. Get active.

It's important to be active during the day. Being exposed to enough light, sunshine, and proper stimulation will keep melatonin production low and keep us active and alert. About 15 minutes of sunshine per day will also contribute to necessary Vitamin D production.

2. Wind down.

Exposure to bright lights at night may interfere with our melatonin production and slow down our natural processes that encourage sleep. This includes blue screens of televisions, iPads, and computers. Use these earlier in the day and wind down your evening with soft lights.

3. Practice good sleep hygiene.

Have a consistent routine of going to sleep and waking each day. Avoid major shifts in sleeping hours, and skip taking a nap if you have difficulty going to sleep at night. Avoid exercise, alcohol, caffeine, and nicotine before bed as these can be stimulating. When it is time for bed, make sure the room is at a comfortable temperature with the proper safety measures in place such as night lights and window locks.

4. Caregivers need sleep.

If your loved one wakes during the night, stay calm. Gently guide them back to bed if they wander and remind them that it is bedtime. Keep them active and stimulated during the day and avoid daytime naps. If sleep disturbances are frequent and interfering with your ability to have regular, restful sleep, reach out to others for help and utilize respite services to allow you to rest. Sleep deprivation and exhaustion is not a sustainable plan, and increases the health risks for caregivers.

5. Prepare and secure.

Remember that night time waking is a possibility at any stage of the disease. Sleep better by taking steps in advance to secure doors and windows with locking mechanisms designed to keep your loved one safe inside. Visit a durable medical supply company to learn about door locks, bed alarms, and other devices that can be used to wake you up if your loved one leaves their bed or attempts to leave the house.

6. Talk to your doctor.

Talk with your doctor about any medications that might be interfering with sleep, or medications that may help your loved one sleep better. Remember to check with your doctor before getting a melatonin supplement. Even though melatonin can be purchased as an over the counter supplement, it may interact with other medications and may not be right for everyone.

Good sleep is critical to our health, functioning, thinking and immune system. Making it a priority will lead to feeling better, looking better, and improving your health.

Sundowning

Sundowning is a symptom of Alzheimer's disease and is often referred to as "late-day confusion." Sundowning may occur in up to 20% of patients with Alzheimer's disease, and most frequently occurs in the middle to late stages of the disease.

Individuals experiencing sundowning may have increased agitation, confusion, and behaviors starting in the late afternoon and evening- as the sun is going down. These late-day increases of behavioral problems can disturb the sleep cycle.

Try the following tips to help manage sundowning and keep the sleep cycle on schedule:

- 1. Stay active during the day to promote good sleep habits at night.
- 2. Brighten the lights when your loved one feels confused or agitated in the early afternoon or evening.
- 3. Avoid stressful activities and noisy or overstimulating environments during Sundowning episodes.
- 4. Use familiar items to comfort them- a familiar keepsake, blanket, or other item.
- 5. Keep a routine. A regular schedule of waking up, activities, and going to sleep will help promote a regulated sleep schedule for both caregivers and their loved ones.

Conclusion

Helping a loved one with dementia to stay healthy, clean and safe is an important task. The ability of a person with dementia to bathe, use the toilet, dress or recognize safety hazards will diminish over time. By using the information in this book, caregivers can help preserve the quality of life for their loved one, better manage their hygiene and safety, and know what to expect as dementia progresses.

Resources

Incontinence care

www.tena.com www.abena.com www.tranquilityproducts.com

• Clothing for undressing issues

www.buckandbuck.com www.silverts.com

Door locks for wandering

www.alzstore.com www.mindcarestore.com

• Safe return bracelets

MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a

medical emergency. They provide 24-hour assistance, no matter when or where the person is reported missing. More information at www.alz.org.

Studies mentioned in this book:

¹National Council on Aging ²Alzheimer's Association

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