



PATIENT AND
CAREGIVER
RESOURCE GUIDE



Dementia Care Resources

*A guide for people living
with dementia*

Provided by:



*This NPHI resource has been adapted and edited to suit the needs of Hospice of Cincinnati patients.



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Dear Persons living with Dementia and their Caregivers,

The National Partnership for Healthcare and Hospice Innovation (NPHI), along with the Center to Advance Palliative Care (CAPC) and Aliviado Health, has developed a special Dementia Care Program to support the home care of people living with dementia. Our mission is to ensure you and your family are well supported and informed so symptoms can be managed under our care, with you safely at home.

This guide represents the best standards of care for mid, to advanced, to end-stage dementia with the collective input of 100+ not-for-profit hospice, palliative, and advanced illness care organizations.



Many people living with end-stage dementia frequently visit the doctor's office, emergency room and hospital due to worsening symptoms. These conditions can be prevented or managed with hospice and palliative care. With our program, you can expect:

- To receive regular visits by a nurse with specialized training in the evaluation of dementia, to evaluate and manage your dementia, and to control the symptoms at home. The nurse will follow the direct orders of your physician or care team.
- To receive patient education specifically designed for you and your family. If you have any questions about the contents of this booklet, please ask your care team.
- To be part of a team overseen by our physician who is board certified in Hospice and Palliative Medicine and who works directly with your primary care physician or care team.
- To have medications ordered by your physician or care team to help control symptoms. Your healthcare team will review your medications with you and order those medications that are essential for your symptom management.
- To receive additional supportive care in the form of visits provided by a social worker, a nurse assistant, a chaplain, a counselor, and/or another member of your care team, as might be helpful to you.
- The management of your dementia takes a team effort, and YOU are the KEY member of the team. The rest of your team members depend on you to call your care team if you have any concerns.



We are pleased to share this Dementia Care Guide, which includes valuable information to address your questions and concerns and ensures high-quality dementia care from the safety and comfort of your home. All of our members embrace the visible and invisible qualities housed within each person we encounter. Not only do we respect the unique and individual journey of life, but we also understand that listening and engaging fosters empowerment. Every decision we make is driven by what we value. We believe the values housed within integrity, compassion, care, commitment, and creativity unleash belonging, making safe space for diversity, equity, and inclusion.

Please reach out to us 24/7 to find a care provider in your area at 1-844-GET-NPHI (438-6744) or visit us at www.hospiceinnovations.org.

On behalf of The NPHI, CAPC, and Aliviado, we wish you the best, knowing you have access to the best in dementia care.

Sincerely,

Tom Koutsoumpas

CEO

National Partnership for Healthcare and Hospice Innovation

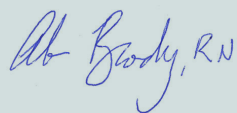


Dear Persons living with dementia, care partners, and members of the healthcare team,

It is such a pleasure to partner with NPHI and CAPC on this handbook in hopes that it helps you to receive or provide care that improves quality of life for persons living with dementia and their care partners. Aliviado Health is an implementation program of the Hartford Institute for Geriatric Nursing at the New York University Rory Meyers College of Nursing. Our mission is to build expert teams who can then provide expert care and an extra layer of support to persons living with dementia and their care partners. In our long-standing partnership with NPHI and its members, we have helped to improve care for tens of thousands of persons living with dementia and their care partners through providing training, care plans, care partner education materials, treatment algorithms and other tools. This manual builds on that partnership.

As a registered nurses and geriatric and palliative nurse practitioner who has both provided care for over 20 years, and cared for multiple family members living with dementia, I know the toll this set of illness can take on individuals and their families. It can also bring families together and strengthen them in the face of adversity. I have also seen how the right intervention, tailored specifically for a person living with dementia and their care partner, can radically improve the experience of caregiving and quality of life. I, and our whole team at Aliviado Health hope that this handbook provides you with some key tips that can help you to use evidence-based interventions to improve the care you receive or give. We also stand ready to work with clinical organizations across the country to help them build expert teams to provide effective, evidence-based care. Please reach out to us at aliviado-support@nyu.edu if we can be of service.

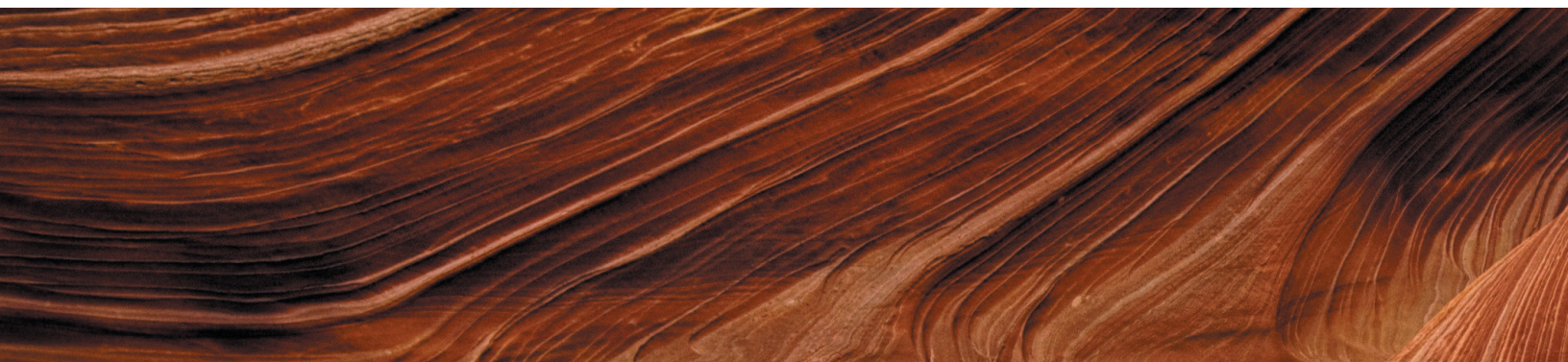
Sincerely,



Ab Brody, PhD, RN, FAAN
Mathy Mezey Professor of Geriatric Nursing and Professor of Medicine



Associate Director, Hartford Institute for Geriatric Nursing
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Dear reader,

We hope that this guide is helpful to you and your family. Our goal is to provide you with the information you need to ask your care team questions about what matters most to you, understand what to expect in the future, and navigate your journey with dementia.

You deserve the best possible care that your team can provide, and the sections of this guide describe the issues that your doctors and clinicians can help with.

Many people living with dementia – and their families – work with palliative care teams as an added layer of support, to help relieve stress and improve quality of life. For more information about how palliative care teams might support you, including blog posts and podcasts with patients and families, go to www.GetPalliativeCare.org.

Sincerely,

Brynn Bowman
CEO
Center to Advance Palliative Care



Acknowledgements

The National Partnership for Healthcare and Hospice Innovation's (NPHI) Innovation Lab would like to thank the following individuals and member programs for their leadership in developing the Dementia Care Resources Guide, and CAPC and Aliviado for their contributions in reviewing the content contained in this guide:

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Understanding Dementia

What Is Dementia?

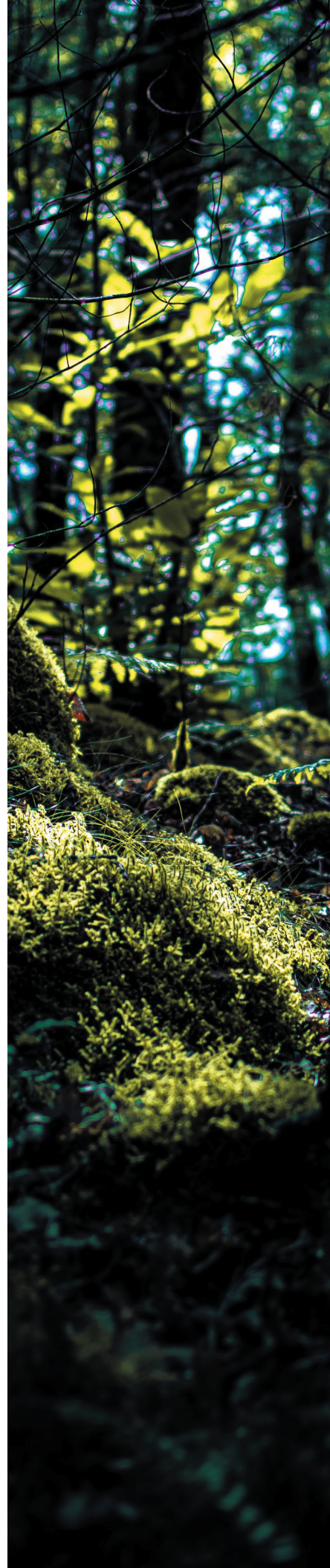
Dementia is a general term used to describe a decline in a person's cognitive abilities that affects their ability to perform work or everyday tasks. People use their cognitive abilities to solve problems, make plans, and remember things that happened in the past. Alzheimer's disease is the most common form of dementia.

A dementia or Alzheimer's disease diagnosis can be overwhelming, whether it affects you or someone you love. Not only do you have to think about the physical and psychological effects of dementia, but you also need to consider how to find quality dementia care, how to pay for that care, and how to share the responsibility with other family members.

If you're supporting a loved one who's living with dementia, you already know how challenging being a family caregiver can be. However, you might not know what to expect in the upcoming weeks, months, and years, particularly if you plan to keep your family member at home for as long as possible. Unfortunately, dementia is a progressive degenerative disease with no known cure, which can make being a dementia caregiver an especially difficult journey.

What are the Types of Dementia?

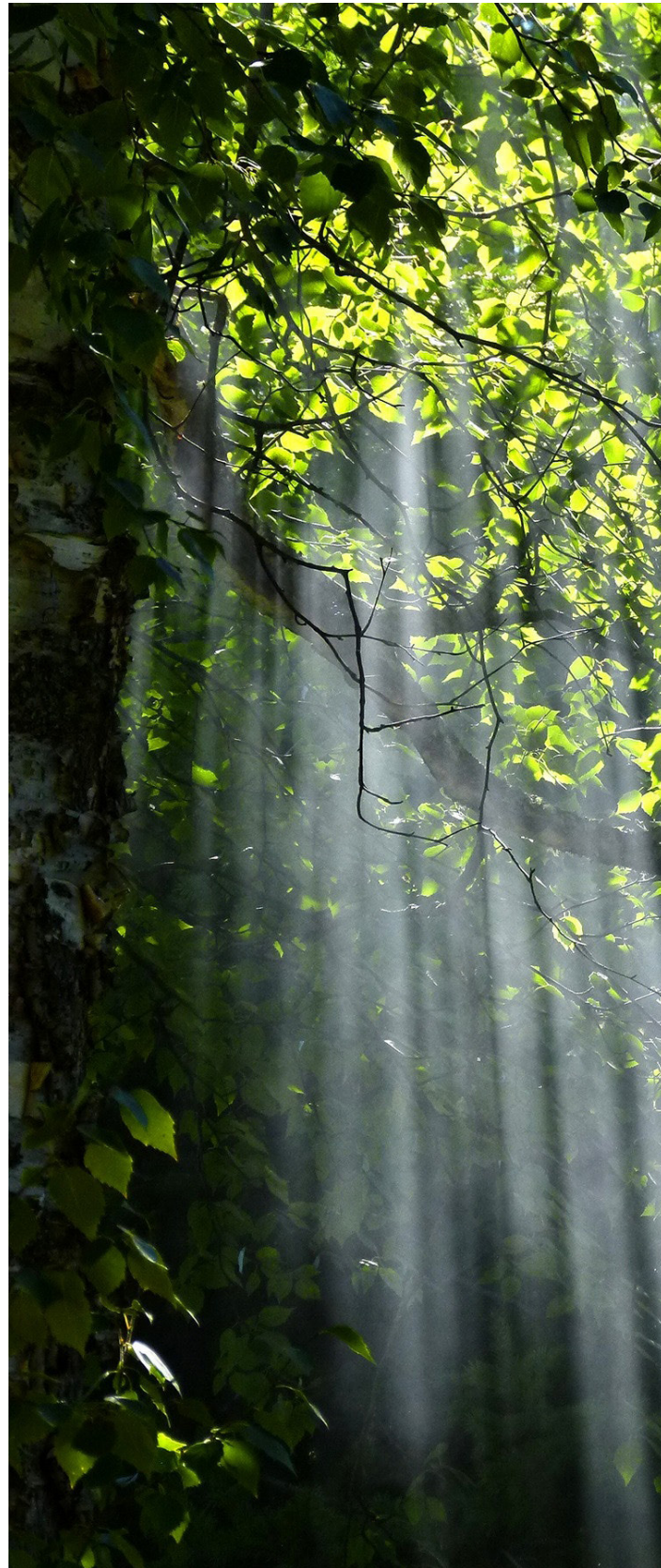
- **Alzheimer's Disease:** Alzheimer's is a progressive type of dementia caused by changes in the brain. These changes occur due to abnormal protein deposits that damage nerve cells, leading to a decline in the ability to think, reason, plan, and remember.
- **Vascular Dementia:** Vascular dementia refers to cognitive decline associated with a stroke or some other type of vascular problem within the brain. These problems reduce the amount of blood flowing to the brain, depriving the brain tissue of the oxygen it needs to work properly.
- **Lewy Body Dementia:** Lewy body dementia develops when alpha-synuclein, a protein, builds up in the brain. These protein deposits are known as Lewy bodies.
- **Other:** If you've been diagnosed with another form of dementia, talk to your healthcare team for more details.



Common Symptoms of Dementia

- Memory Lapses
- Confusion Over Words
- Marked Changes in Mood or Personality
- Trouble with Abstract Thinking
- Difficulty Completing Familiar Tasks
- Changes in Sensory/Perception of the Environment
- Misplacing Items
- Impaired Judgement

Many of the above symptoms can be managed or controlled with proper approach, medication, and self-care techniques in the comfort of your own home.



What Are the Stages of Dementia?

First Stage

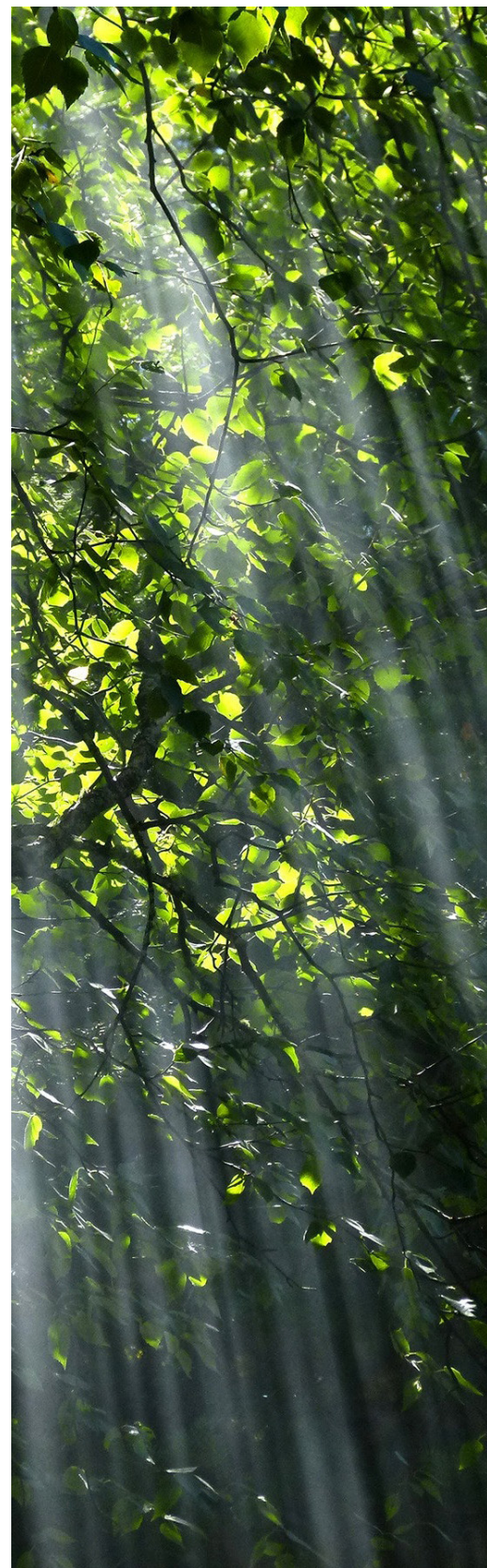
- Gradual onset
- Forgetfulness
- Word-finding difficulties
- Problems with memory and concentration
- Misplacing things
- Trouble organizing and planning
- Difficulty remembering to take medications

Middle Stage

- More obvious problems with memory
- Gets lost in familiar places
- May have difficulty recognizing family members
- Needing extra help with eating, bathing, dressing, toileting, etc.
- Increased difficulties with communication
- Potential behavior and personality changes

Late Stage

- More dependent on care for daily activities (see middle stage)
- Difficulty walking
- May no longer be able to verbally communicate
- Memory gets worse
- Personality may change
- Swallowing and eating problems
- May lose ability to control going to the bathroom
- May have recurrent infections



Symptom Management & Care Tips

Care Techniques to Help the Person Living with Dementia

If you're caring for someone who has dementia, there are some things you can do to help support their strengths, assist with their overall health and wellness, and delay the onset of further symptoms.

- **Keep Their Mind Stimulated:** One of the best things you can do for the person living with dementia is to keep them mentally active.
 - Continue to involve them in conversations
 - Include them in family dinners and events
 - Chat with them about their hobbies and interests
 - Take the time to find activities they enjoy (a game of cards, watching a television show, or going for a relaxing walk); focus on enjoyment, not achievement
 - Reduce your expectations
 - Avoid the urge to correct any misplaced words or memory errors
 - Play their favorite music
 - Try a robotic pet to help reduce feelings of isolation and loneliness
- **Simplify Their Daily Tasks:** Look for ways to reduce the demands on your loved one.
 - Offer to manage their household finances
 - Set up a meal delivery service so they don't need to cook or shop for groceries
 - Hire a housekeeper to do daily chores
- **Maintain Some Routine:** People with dementia tend to do best when they follow a predictable routine.
 - Try to set a daily schedule and stick to it
 - Eat meals at the same time every day
 - Perform daily physical activity such as walking, riding a stationary bike, or gardening.
 - Minimize disruptions to their schedule

Other Tips to Help with Caregiving



Plan Ahead for Care: There are several options for ensuring that your loved one's care needs are met. In the early stages, the home environment may be modified and you can develop a plan for family or paid caregiving help at home. As the disease progresses, some individuals may need to transition to a facility depending on the situation and/or resources available. Now is the time to have a plan in place.



Get organized: Getting organized will help you take on challenges and remain in control.



Record-Keeping: Develop your own system of keeping records and notes, such as using binders or folders to organize medical and financial records. Do this early so the person living with dementia can participate.



Dates: Set up a calendar in the home of the person living with dementia to help them remember appointments and planned visits with friends and family. You can also suggest they keep a journal or list to help their memory.



Money: Early-stage dementia is the best time to start protecting the assets of the person living with dementia. If you haven't been involved in helping them manage their finances, then it's important to start with a discussion about their financial situation, including monthly income, options for funding their care, and any debt or loans they may have.



Legal: An elder law attorney can serve as an objective third party in helping families navigate difficult decisions related to managing the assets of the person living with dementia and deciding who should make decisions on their behalf. They can help draft legal documents outlining who should make financial, legal, and medical decisions on behalf of your loved one when they're no longer able to do so themselves.

Home Safety

Everyday objects in the home can become hazardous for a person living with dementia because of sensory changes and disease progression. With adjustments, many people living with dementia can stay safe in their homes.

- **Evaluate the home for potential hazards:**

- Look around for cleaning supplies, chemicals, medications, and poisonous plants (contact the National Poison Control Center at 1-800-222-1222 for more information).
- Check the home for any potential slip, trip, and fall hazards such as throw rugs, small pieces of furniture, extension cords, and clutter.
- Be sure to keep the home well-lit.

- **Stairs:**

- Eliminate the need to use by installing door locks or safety gates
- Install railings
- Put colored electrical tape on the edge of the steps
- Consider adding safety grip steps

- **Cooking:** Turn off the gas when the stove is not in use and/or remove knobs from the stovetop.

- **Bathrooms:**

- Install grab bars in the shower, tub, and toilet area
- Consider installing a walk-in shower and a handheld showerhead

- **Water heater:**

- Set the temperature to 120 degrees to prevent burns
- Label hot and cold faucets

Safety Tips



- **Install locks:** Childproof locks work well for cabinets, drawers, doors, cupboards, or anywhere that may have potentially unsafe items.
- **Consider using cameras:** There are many great monitoring systems and security cameras that can be used to keep an eye on the person living with dementia throughout the day and night.
- **Lock or remove weapons.** Guns, knives, scissors, or other weapons can quickly become dangerous.
- **Enroll in a wandering response service:** Those enrolled in a program wear a small tracking device in case they go missing. The personal tracker/transmitter tracks the person's location and direction in which they are moving to help emergency personnel locate them as soon as possible. Personal tracking devices that link to a cellphone can also be helpful. These devices may not be reliable in areas with poor cellphone connectivity.
- **Be prepared for emergencies:**
 - Make sure smoke detectors and carbon monoxide detectors are in working order
 - Gather a list of phone numbers and addresses for local police departments, fire departments, hospitals, and poison control helplines
 - See Appendix E for more information
- **Use signs:** Use simple instructions and pictures to remind them of danger and help show them where to go. For example, "Keep Closed" or "Bathroom" with a picture of a toilet and an arrow.
- **Evaluate footwear:** Buy and wear shoes and slippers with good traction and that fit well to lower the chance of a slip or fall.
- **Consider mirrors:** If the person living with dementia no longer recognizes themselves, mirrors can become a concern. Remove mirrors or cover them with curtains.
- **Monitor food:** Check food in the refrigerator regularly and throw out any that has gone bad. Keep salt and sugar out of sight if this becomes a concern.



Tips for communicating with people living with dementia

While each person living with dementia has unique needs and preferences, the following guidelines can help put the person at ease, to ensure their attention and understanding.

Proximity: Explain what you are going to do before moving into an individual's personal space.

Eye Contact: Move to eye level to ensure that you establish and maintain eye contact with the person.

Voice Tone: Use a calm, reassuring tone of voice, and project positive energy. A friendly and positive affect can help the person feel calmer.

Simplicity: Keep communication simple, making one request or suggestion at a time.

Positivity: Ask requests in a positive manner, avoiding the use of the words 'don't' or 'no'. For example, try "let's go here" instead of "don't go there".

Attitude: Reframe your perceptions and attitude toward the person's behavior. They may not understand the task or directions.

Validation: Do not confront delusions or false beliefs. Rather, validate, reassure, or redirect the behavior.

Redirection: Use redirection or distraction if the person is repeating a question or retelling a story.

How Can We Help with Eating?

- Encourage food and drink if they accept it.
- Meal preparation or helping them eat may be required.
- Offer foods that have a more sweet, spicy, or sour flavor.
- Offer finger foods.
- Provide alternate sources of nutrition, such as ice cream or high-calorie shakes (example: Ensure).
- Make sure food and drinks are a consistency they can swallow easily. (Food consistencies include soft, ground, or pureed. Drink consistencies include thin, nectar, or honey).
- Make sure that food selection aligns with cultural and personal preferences.
- Monitor for coughing with intake (dysphagia) or food staying in mouth or cheeks (pocketing). This may indicate a need to change the consistency of food or drink. If food or drink get into the lungs, a person is at risk of developing pneumonia.
- Maintain good oral and dental hygiene.
- Eliminate distractions such as background noise (TV, music, etc.)

Oral
Care
Tips



When to use
feeding tubes
for people
with dementia



What If These Things Do Not Help?

- Contact your healthcare team about other options for improving appetite or increasing weight.

Can a Feeding Tube Help?

- A feeding tube may be temporary (down the throat) or permanent (surgically placed into the stomach) for people with severe swallowing difficulties. They then receive liquid feedings through this tube, instead of eating or drinking by mouth.
- **Feeding tubes are not helpful or recommended for people with advanced dementia.** There is no evidence that they help people live longer, gain more weight, or become stronger. They do come with discomfort and the risk of the person living with dementia pulling out the feeding tube. Other risks include pneumonia; please discuss the use of feeding tubes with the healthcare team.

Pain

As an individual's dementia gets worse, it may be harder for them to know when they are in pain and tell you about it. As the caregiver, it is important for you to manage their pain as fast as possible. If left untreated, it may cause more problems in the future for you and the person living with dementia, including unnecessary suffering and agitation.

What Is Physical Pain? Why Is It Important to Be Aware of Pain?

- Pain is different for everyone; some are more sensitive than others.
- Pain can be difficult to check in a person living with dementia, as they may feel it differently or they cannot clearly tell you what they are feeling.
- If pain is left untreated, it may cause depression, frustration, agitation, limited moving, social isolation, and aggression.

What Are Some Causes?

- Arthritis or Gout
- Diabetes
- Bone fractures from Osteoporosis
- Cancer
- Shingles
- Lower back strain
- Sciatica
- Physical trauma
- Sitting or lying for long periods of time without moving
- Urinary Tract Infection (UTI)

What Are Some Ways a Person Living with Dementia Might Communicate Pain?

- Hitting (especially the area that hurts)
- Crying or yelling
- Being restless
- Frowning or tensing up their body
- Withdrawing
- Pain is often more than just physical. It can be emotional, mental, or spiritual. Some of the tips below may help with this type of pain as well.

How Can It Be Recognized and How Can We Help with Pain?

- Ask if they have any pain or are uncomfortable throughout the day, try to make them feel comfortable as soon as possible. Make sure to ask about pain both when the person is resting and when the person is moving.
- Look for any physical signs of pain like:
 - Frowning or grimacing
 - Crying
 - Not moving a certain body part
 - A change in their tone of voice
- Try some at home treatments like:
 - Ice and heat packs
 - Massages
 - Music
 - Meditation
 - Aromatherapy
 - Compression
- It is important to remember that even though the person with dementia may not be able to verbalize pain, they still experience pain.

What If These Things Do Not Help?

- Speak with your healthcare team about taking over-the-counter or prescribed pain medicine.



Sleep Disturbances

We all have patterns to our awake and our sleep time each day. Dementia often changes these sleep/wake cycles. Problems with sleeping are common for people living with dementia. They may not get enough sleep or sleep too much, both of which can affect their mood and energy levels.

What Are Sleep Disturbances?

- Waking up many times during the night.
- Staying awake during the night.
- Sleeping for long periods of time during the day.

What Are Some Causes?

- Other health problems like depression, restless leg syndrome, and obstructive sleep apnea disorder.
- An uncomfortable bed or feeling pain during the night.
- Changes in the brain caused by dementia.
- Having the feeling to use the bathroom during the night.



How Can We Help with Sleep?

Sleep Routine	Environment
<ul style="list-style-type: none"> • Encourage a regular daily routine with activities to keep them busy • Keep set meal times • Avoid heavy meals 2 hours before bedtime. These may cause reflux or interfere with sleep (especially proteins) • Engage individuals with physical movement during the day (moving arms and legs) • Minimize daytime napping (90 minutes or less) • Set a regular wake/sleep schedule • Limit reading, watching TV, or staying awake in bed for long periods of time • Minimize fluids 2 hours before bedtime • Avoid nicotine, caffeine, and alcohol at least 4 hours before bedtime • Treat any pain, especially before sleep hours • Do not take dementia drugs at bedtime unless specifically instructed by healthcare team • Use bathroom immediately before going to bed 	<ul style="list-style-type: none"> • Keep the room dark during the night and bright during the day (consider blackout curtains) • Reduce noise at night (consider a sound machine) • Eliminate interruptions during sleep. Work with healthcare team to create medicine schedules that minimize waking person unnecessarily to take medicine • Play soothing or relaxing music before bedtime • Consider use of lavender aromatherapy oils or pillow sprays • Evaluate the temperature of the bedroom - is it too hot/cold (consider adding/removing blankets) • Consider a fan for white noise or temperature control • Exposure to sunlight or a light box in the morning may help lessen sleep/wake cycle disturbances • Combine light therapy with exercise during the day

What If These Things Do Not Help?

- If they continue to have sleep problems after trying all these things, let your healthcare team know and they may change current medications or prescribe a short acting sleep medication.

Medications

The person living with dementia may be taking one or more medications daily to manage their symptoms, or slow the progression of the disease. Never stop taking medications or change your dose unless instructed by the healthcare team. It is also important to note that with disease progression, the healthcare team may modify your medications.

Deprescribing (Stopping) Medications





The healthcare team will regularly check in with you regarding the medication routine for the person living with dementia, including the names, doses, and therapeutic goal of medications. The care team will monitor for any changes that may indicate a medication is no longer providing the benefit that was originally intended and may recommend stopping medications, including those intended to slow the progression of dementia.




You may notice that the person living with dementia has more difficulty taking their medications. It's important to tell your healthcare team if you are noticing any of the following changes:

- Difficulty swallowing
- Not opening their mouth
- Spitting medications out
- Becoming more sleepy or groggy (sometimes when these medications are stopped people become more alert and interactive)



Medications that may help:

	Concern	Medication types that may help	How will I know the medication is working?
	Sleep problems Prescribed medication name, if any: _____ _____ _____	Trazodone	This medication may help the person living with dementia feel calm, drowsy or sleepy. It may help them sleep longer.
	Aggression or Agitation Prescribed medication name, if any: _____ _____ _____	Citaprolam (SSRI), THC (limited evidence)	SSRIs may reduce, but not stop, episodes of aggression or agitation.
	Anxiety or restlessness Prescribed medication name, if any: _____ _____ _____	Donepezil, Memantine	Benzodiazepines may help the person living with dementia feel calm. SSRIs may help manage feelings of anxiety or restlessness.
	Depression or sad mood Prescribed medication name, if any: _____ _____ _____	Citaprolam, Escitaprolam, Sertraline, Paroxetine, Venlafaxine, Duloxetine	It may take several weeks for the medication to be effective. SSRIs may help the person living with dementia feel calm and in a better mood.

	<p>Hallucinations Prescribed medication name, if any:</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>Quetiapine, Donepezil, Memantine</p>	<p>There may be a decrease in the number of bothersome hallucinations someone experiences.</p>
	<p>Apathy Prescribed medication name, if any:</p> <p>_____</p> <p>_____</p>	<p>Donepezil, Methylphenidate</p>	<p>There may be a increase in interest/passion.</p>
	<p>Sexual Disinhibition Prescribed medication name, if any:</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>SSRI (1st line): Escitalopram</p> <p>Antiandrogen (2nd line): Medroxyprogesterone, Quetiapine</p>	<p>There may be a decrease in inappropriate sexual activities.</p>

Your care team will prescribe the most effective and simplest for you to take medication. Depending on the progression of the dementia, the care team may change the medications or prescriptions.

Understanding Terms of Care

Understanding Terms Used by Your Care Team

- **Understanding “Baseline”:** Baseline is a word that a healthcare team uses to describe how a person usually thinks and acts. When someone has dementia, his/her thinking and behavior can change, but it is usually a slow change.
- **What is “USUAL”:** Everyone is different, but you know what the person you are caring for is usually like. When someone has dementia, they have some days that are better than others, but overall, they act and think a certain way.
- **When to call a member of your care team:** People with dementia may not be able to tell you with words or full sentences that something is wrong. They may not be able to say they are not feeling well.
 - You should call the healthcare team if you see that the person has had a **sudden or unusual change in the way he/she is acting, thinking**, or has a **medical condition that is getting worse**. These changes can happen over a period of several days.
- Be prepared to tell the healthcare team what the person is usually like (before he/she had the sudden and unusual change). Please see Appendix A for specific guidance on when to call the healthcare team.

Understanding Delirium

- Delirium is **usually caused by an illness or reaction to medication**.
- Delirium looks like **severe confusion** and can develop over hours or days. The person may seem “out of it” and then become alert again. The person may also have changes in sleeping patterns, with vivid/intense dreams.
- **It is important to call your healthcare team so a member of the care team can make a visit and perform an assessment. The healthcare team may adjust medications. If the symptoms do not improve after medication adjustments, then the patient may need a higher level of care until symptoms are under control.**

Tips for the Caregiver to Thrive

Caring for a person living with dementia can be rewarding and also challenging. Too much stress can be harmful for both you and the person you are caring for. Taking care of yourself can help you not only survive caregiving, but also learn to thrive as a caregiver. Self care is not selfish.

Signs of Caregiver Stress?

- Feeling irritable, angry, and frustrated
- Feeling alone, hopeless, anxious, or depressed about the future
- Not engaging with people or activities that you enjoy
- Inability to concentrate ("brain fog") that makes it difficult to do familiar tasks
- Experiencing health problems, sleeplessness, or exhaustion

What Causes Caregiver Stress?

- Lack of acceptance about the disease and its effects on you and the family
- Taking on more tasks than what is healthy or what you can comfortably handle.
- Blaming yourself for things you cannot control or change.
- Focusing on negative thought or bad times
- Not making time in your schedule for yourself and to let out any stress/frustration.



Stay Healthy and Positive	Ask for Help
<ul style="list-style-type: none"> • Schedule breaks and relaxation time • Eat a healthy diet • Engage in regular movement/exercise • Prioritize healthy sleep habits • Identify activities that leave you feeling refreshed or motivated. Make time for those activities • Learn to accept your feelings. It is ok to feel guilt, anger, stress, and resentment • Remember the positive aspects of being a caregiver. You may become closer to the person living with dementia, you may gain a sense of personal accomplishment, or you may develop stronger family bonds 	<ul style="list-style-type: none"> • Have family meetings to negotiate sharing of tasks and to help resolve disagreements (a member of your care team can help facilitate a family meeting or see tips in Appendix F) • Make a list of tasks you are willing to give up and a list of people who have offered to help. Offer people the gift of helping you • Consider joining a caregiver support group or work with a counselor to help cope with this significant life change
Look for Resources	Be Realistic
<ul style="list-style-type: none"> • Talk to your healthcare team, or the care team of the person living with dementia, to see if there are additional resources available to you • See Appendix D for additional resources for respite options, such as adult day care, PACE programs, etc. 	<ul style="list-style-type: none"> • Learn about the disease and what to expect for the person living with dementia • Set reasonable goals and know your limits • Accept how things are in your life and the person living with dementia's life for what it is (accept their diagnosis) • Focus on what you can change • Understand that this is a difficult responsibility • Create a game plan for the future – See page 24 for more info on Advance Care Planning

Caregiver Grief & Loss

We begin to grieve the loss of the person living with dementia when we begin to notice decline or they receive a diagnosis. Anticipatory grief is grief that happens before death. Most of us assume we will feel grief after a death, but may be surprised by grief that occurs while the person living with dementia is still with us. Many dementia caregivers are grieving several losses all at once. The caregiver may face the loss of a companion, financial insecurity, lifestyle changes, loss of employment, loss of identity, loss of sleep, shifts in normal routine, loss of future hopes and dreams, less time with friends, family, and/or “alone time”. The caregiver role is dynamic - changing and evolving over time as care needs increase. The caregiver may experience grief as their role changes from spouse/partner or son/daughter to caregiver.

Ambiguous loss refers to the type of loss you feel when the person is physically present but may not be mentally or emotionally present in the same way as before. It is a unique loss that is not often recognized or understood by others. Acknowledging ambiguous loss can help you realize that your feelings are normal and a valid response to a disease that changes the person over time. You can both love the person with dementia as they are now and miss how they used to be. Understanding ambiguous loss can help you process your experience, grieve losses, and stay connected to the person with dementia.

Common Caregiver Grief Experiences	Ways to Cope with Caregiver Grief
<p>Denial</p> <ul style="list-style-type: none"> You may expect that the person living with dementia is going to get better, that he/she has not changed, or that their challenging behaviors are just a typical part of their personalities. You may believe that there was something you could have done to have prevented the disease and start to blame yourself. You may avoid discussions with others surrounding the decline of the person living with dementia, which can lead to emotional distress and isolation. 	<p>Face Your Feelings</p> <ul style="list-style-type: none"> Let yourself feel and process your feelings and try to embrace the time you have with your loved one. Recognize that it is common to have feelings of both letting go and holding on all at once. Writing in a journal can help you express your feelings. It is normal to feel mixed emotions at different times and more than once. Know that there is no right or wrong way to grieve.

Common Caregiver Grief Experiences	Ways to Cope with Caregiver Grief
<p>Anger</p> <ul style="list-style-type: none"> You may feel resentful of others who are not willing or not able to help provide care. You may feel bitterness surrounding the strains of providing care. You may feel frustration toward the person living with dementia. 	<p>Talk with Someone</p> <ul style="list-style-type: none"> Talk with someone you trust about your grief and the emotions surrounding that grief. It could be a family member, a friend, a trusted coworker, or someone who has had a similar experience as you. Talk to the grief counselor at your hospice agency, a therapist, or join a caregiver support group.
<p>Guilt</p> <ul style="list-style-type: none"> You may feel that you have failed if you are unable to care for the person at home or if you require outside assistance. You may have unrealistic expectations of yourself, which could lead to exhaustion and burnout. You may have negative thoughts about the person living with dementia or you may regret aspects of your relationship prior to the diagnosis. 	<p>Self-Care</p> <ul style="list-style-type: none"> It can be difficult to make time for ourselves when so much of our time is devoted to providing to caring for others. Caring for yourself is equally as important. Take breaks when you can. Stay active in hobbies that you enjoy. Ask for help when you need it. Reach out to friends or family to chat, meet for lunch, or take a walk together. These actions may help reduce feelings of isolation and loneliness. Consider joining a caregiver support group to connect with others who understand and are also experiencing grief.

Common Caregiver Grief Experiences	Ways to Cope with Caregiver Grief
<p>Sadness</p> <ul style="list-style-type: none"> • You may feel overwhelmed, cry frequently, feel anxious or depressed, or withdraw from social activities. • You may experience difficulty in performing everyday tasks, have outbursts, or thoughts of self-harm. • You may experience loneliness, isolation, or numbness. 	<p>Alternate Ways to Express Love</p> <p>Find new ways to connect with the person living with dementia:</p> <ul style="list-style-type: none"> • Hold hands • Massage the hands of the person living with dementia • Enjoy music together • Take a walk together (if able) • Look at photos together • Tell stories about the past
<p>Acceptance/Surrender</p> <ul style="list-style-type: none"> • Acceptance/surrender occurs when we are able to find personal meaning in caring for the person living with dementia and ask for help from others when needed. • You may begin to understand how the anticipatory grief process is affecting your life and others around you. • You may begin to find your sense of humor and see the person you care for in a different light. 	

Appendix A: Dementia in Persons with Intellectual and Developmental Disabilities

Agitation & Aggression

Agitation and aggression can be expressed verbally or physically. They may occur suddenly with no obvious cause, or from frustration/anxiety. This can make your job as caregiver more difficult. It is important to understand that the person living with dementia is not acting like this on purpose.

What Are Agitation & Aggression?

- Frustration and anxiety may cause the person to act out angrily towards other by hitting, pushing, shouting at, or arguing with them.

What Are Some Causes?

- The person feels uncomfortable.
- Large crowds, or the presence of certain people.
- Annoying sounds.
- The person feels unable to talk about their needs and feelings.
- Fear or confusion about who they are, who the people around them are, and where they are.

How Can We Help with Agitation & Aggression?

- Check if they have any pain or are uncomfortable throughout the day and try to make them feel as comfortable as can be.
- Let the person do as much on their own as possible.
- Use a caring tone to calm the person down.
- Remind them of where they are, who you are, or who they are if they become confused and anxious.
- Try music. Consider having the person living with dementia listen to 30 minutes of their favorite type of music at the same time every day. If they like dancing, you can try dancing with them.
- Try to exercise with the person living with dementia.
- Aromatherapy.
- Try a robotic pet to help calm the person.

What If These Things Do Not Help?

- Give the person some space if it is not a safety issue and try again later.
- If other treatments have not worked, you can talk to your healthcare team about starting them on a medication to treat symptoms and behaviors associated with dementia.

Aggression When Performing Bathing/Personal Care

Helping with bathing and personal care, like changing incontinence pads or clothing, can be difficult. Since it is such an intimate interaction, people with dementia may see your help as uncomfortable and disrespecting their personal space. This can lead to frustration, causing them to become aggressive towards you.

What Is It?

- Yelling, insulting, cursing, hitting, spitting, or kicking because they are frustrated and angry.

What Are Some Causes?

- The person may become frustrated doing certain tasks because they may have forgotten how to do them correctly.
- Frustration over losing their independence and not wanting to accept any help.
- The person does not want to be told what to do.

How Can We Help with Aggression?

- Make bathing and getting ready simple and easy for them to do.
- Respect their need to do things on their own and have their own space.
- Give them hints if you notice them having trouble with bathing or dressing.
- Lay out their outfits and the items they need to shower beforehand so that they know they must put on/use each item.
- Avoid becoming frustrated or angry yourself, as this could make them even more agitated.
- Place an object in their hand to hold during care to help distract from feelings of aggression and to help focus on present activity.

What If These Things Do Not Help?

- Try walking away and coming back again to help them later if it is not an immediate need.
- If all other treatments have not worked, you can talk to your healthcare team about starting them on medication.

Constipation

Constipation can be a serious issue if left untreated. Many people with dementia are at risk for long-lasting constipation, which can make them uncomfortable and agitated.

What Is Constipation?

- Uncomfortable or infrequent bowel movements.

What Are Some Causes?

- Not drinking enough water or liquid.
- Not going to the bathroom enough times during the day/week.
- Not eating enough fiber.
- Eating too much dairy.
- Stress.
- Not getting enough exercise.
- Taking certain medications.

How Can We Help with Constipation?

- Have them eat foods that are high in fiber, like vegetables, whole grains (brown rice, whole grain bread), and beans.
- Offer foods high in water content such as prune juice, gelatin, decaffeinated coffee/tea, and broth-based soups.
- Encourage enough water each day, about 8 or more glasses, unless their healthcare team has said they have to drink less because of another health problem they may have.
- Encourage them to exercise (move/walk) for at least 30 minutes a day, at least 3 times a week.
- Ask the healthcare team if the person living with dementia can take over-the-counter fiber supplements, stool softeners, or laxatives.
- Keep a record of when the person has a bowel movement.
- Alert the healthcare team if the person living with dementia goes more than two days without a bowel movement.

What If These Things Do Not Help?

- Ask your healthcare team if they have other prescription medications they can suggest for constipation.

Depression

Depression is a common problem in people who have dementia. It can make dealing with the disease harder for both the person living with dementia and caregivers.

What Is Depression?

- Feeling sad for long periods of time.
- Little energy or motivation to do enjoyable/everyday activities.
- A lack of interest and concentration.
- Trouble sleeping at night or sleeping too much.
- Not wanting to eat as much or at all or wanting to eat too much.

What Are Some Causes?

- Physical disabilities, loss of independence, pain, sleeping problems, and other health problems may lead to depression.
- The person may begin feeling depressed because they feel alone or separated from certain people or activities because of their dementia.
- Changes in the brain from dementia, alcohol abuse, drug abuse, injury, or taking certain medications.

How Can We Help with Depression?

- Let them know that you are there to help them as much as they need, and always talk to them in a positive and caring voice.
- Create a daily schedule that includes fun activities, going outside, and spending time with other people.
- Encourage them to exercise (move/walk) for 30 minutes a day.
- Try different activities such as:
 - Spend time with a pet or get a robotic pet for the person
 - Aromatherapy
 - Music
 - Light Therapy
 - Vitamin D
 - Spend time outdoors

What If These Things Do Not Help?

- If these tips do not seem to work, let the healthcare team know and they may prescribe a medication for the depression.

Hallucinations & Delusions

Many people with dementia experience hallucinations or delusions. They may be frightening for you and them, but also may just involve people or things from the person's past.

What Are Hallucinations & Delusions?

- Hallucinations are things the person may see, hear, smell, taste, or feel that are not actually there.
- Delusions are when the person has false or exaggerated beliefs like someone is out to hurt them.

What Are Some Causes?

- Changes in the brain from dementia.
- Some medications.
- Mental health problems like schizophrenia, alcohol abuse, or drug abuse.
- Hearing and vision problems.

How Can We Help with Hallucinations or Delusions?

- If the hallucinations or delusions are new, talk to the healthcare team as this could be caused by a new health problem or a recent change in medication.
- If the hallucinations and delusions do not cause harm to anyone, they do not need to be treated.
- If they have a lot of hallucinations throughout the day, make sure they are always in a place where they cannot hurt themselves.
- Try calming them down if they become frightened.
- Try distracting and/or redirecting them to divert their attention to something pleasant.
- Ensure adequate lighting to reduce the risk for sensory triggered hallucinations.

What If These Things Do Not Help?

- If the hallucinations or delusions become a concerning issue, talk to the healthcare team. Some medications have many side effects including an increased risk of heart attack and stroke.

Incontinence

People with dementia often become incontinent (unable to control how their bladder or bowels empty). They may have frequent accidents (urinating or soiling themselves). This can happen both at home and when out in public.

What Is Incontinence?

- The person cannot control their need to use the bathroom.

What Are Some Causes?

- They forget or cannot feel that they need to go to the bathroom.
- They forget where the bathroom is located (in their home or elsewhere).
- Some medications may make it easier for the urine to accidentally leak out.
- Stress, constipation, urinary tract infections (UTI), or prostate issues can worsen incontinence.
- Drinking too much soda, coffee, tea, or alcohol.
- They cannot get to the bathroom in time because:
 - They walk more slowly.
 - They do not get out of bed fast enough.
 - Their clothes are hard to unfasten (belts, buttons buckles, or pantyhose).

How Can We Help with Incontinence?

- Try taking the person living with dementia to the bathroom every two hours during the day.
- Make sure they are wearing clothing that is easy to take off (such as sweatpants).
- Try using absorbent underwear and bedding made for people with incontinence to make accidents easier to manage.
- Remind them to let you know when they feel the urge to use the bathroom.
- Be supportive if an accident happens.
- Make going to the bathroom at home easy. Make sure the bathroom is easy to find; the toilet and sink are easy to get to and use, and they can easily get to everything they need. Keep walker/ wheelchair close at hand. Bathroom lights should be left on or triggered by movement.
- If the person has trouble getting to the bathroom, talk to your healthcare team about getting a bedside urinal or commode.
- Do not let them drink too many fluids, two hours before bedtime

What If These Things Do Not Help?

- Make sure to clean the person living with dementia as soon as possible to prevent skin irritation. If they are starting to have redness in their groin or buttocks, tell your healthcare team as it could be a sign of infection and they may get you special lotions or powder to apply.
- If a person is aggressive when you are trying to change them, try again later.
- If the person is not urinating or not having bowel movements regularly, call your healthcare team. Infections or blockages may require medication or urine tests.

Pressure Ulcers

Pressure ulcers, also known as bedsores, can become a frequent problem if the person living with dementia does not move around a lot. Pressure ulcers can be painful and if left untreated, can become open wounds that may get infected.

What Are Pressure Ulcers?

- An area of skin that becomes red and starts to become weak when something keeps pressing against it for long periods of time.
- Over time, this pressure on the skin causes the skin to become so weak that the skin breaks and an open wound is made.
- Mostly this happens where the skin is very thin and over bone like the hip or bottom of one's back.

What Are Some Causes?

- Not getting enough proteins and nutrients in their food.
- Long-term pressure on areas of skin over bones.
- Sitting or lying in the same position for long periods of time without moving.
- Fragile, thin, sensitive skin is more at risk of becoming a pressure ulcer.
- Leaving the skin wet from incontinence (urine or bowel movements) for long periods of time.
- Weight loss and having less padding on bones
- Sliding down in chair, pulling the skin in a different direction

How Can We Help with Pressure Ulcers?

- Keep healthy skin moisturized by applying lotion after a bath or bed bath.
- Encourage and help the person living with dementia to get up and move every couple of hours.
- Always look for any patches of redness on the body that do not return to the usual skin color when you press on them in areas like the:
 - Ankles
 - Heels
 - Buttocks
 - Hips
- If the person living with dementia cannot move on their own:
 - Put pillows in between knees and ankles.
 - Make sure their bed/chair is soft and padded.
 - Try putting them in a different position every 2-4 hours.
- Always make sure their skin stays dry.
- Make sure they are eating enough and getting the right nutrients.

What If These Things Do Not Help?

- Talk to your healthcare team about how to best prevent and treat any forming pressure injuries. They will show you how best to turn someone, how to best position pillows, and how to change the bed without removing the person.

Sexual Disinhibition

Inappropriate sexual behavior may become a problem as their dementia progresses. This may occur due to physical changes in the brain which can cause increased sexual thoughts or feelings. It is not a reflection of the person living with dementia's character or morals. Dealing with this can be one of the most frustrating, embarrassing, or frightening moments for caregivers.

What Is Sexual Disinhibition?

Inappropriate sexual behavior like:

- Pleasuring themselves.
- Sexually touching others.
- Taking off their clothes in public.
- Sexual behavior directed towards children, family, friends, and caregivers.

What Are Some Causes?

- Tight clothing.
- Discomfort (from having movement restricted).
- Increased libido.
- Bladder infections or being constipated.
- Sexual frustration.

How Can We Help with Sexual Disinhibition?

- Offer a soft stuffed animal or a blanket.
- Try distracting them or guide them to what they should be doing when they begin to undress or act inappropriately.
- Keep them occupied with tasks and other activities.
- Have them wear clothes that are harder to take off if they are known to take their clothes off in public, such as suspenders or shirts that button in the back or slip over the head. Make sure clothes are not too tight.
- If they are known to have sexual disinhibition, make sure that they are not left alone in public.

What If These Things Do Not Help?

- Talk to your healthcare team as medications can sometimes help to decrease incidents from occurring.
- Talk to your healthcare team to rule out any bladder infections or constipation problems.

Sundowning

Dementia can change a person's internal clock that tells them when to sleep and when to wake up, making it harder for them to get a good night's rest. This lack of quality sleep can affect their mood and energy levels during the day. Sundowning also prevents the family caregiver from getting regular, restful sleep.

What Is Sundowning?

- Agitation, confusion, or restlessness that starts in the late afternoon into evening and night.

What Are Some Causes?

- Not doing any exercise or activity during the day.
- Dementia can change a person's internal clock that tells them when to sleep and wake up naturally.
- Low lighting during the day, or bright lighting at night.

How Can We Help with Sundowning?

- Have them exercise and do fun activities during the day, and relaxing activities in the evening.
- Turn off all electronics, lower the volume on the TV or radio, and do not let them drink anything 1 hour before bed.
- A nap during the day may help, but make sure they do not nap for more than 90 min.
- Dim any bedroom or living room lights 1 hour before going to bed.

What If These Things Do Not Help?

- Talk to your healthcare team about whether melatonin may be a good treatment.

Wandering

A person living with dementia may forget where they are, where they need to go, or how to get around. They may forget to do everyday things like getting dressed and even forget who their loved ones are. They could even go missing from home.

What Is Wandering?

- Forgetting how to get to places like the bathroom and the store.
- Forgetting where they are or where they should be like wanting to go home when they are already home.
- Forgetting how to do certain tasks like how to brush their teeth or put on their clothes.
- 6 out of 10 people with dementia will wander at some point in their life.

Information
on Wandering



What Are Some Causes?

- Dementia damages the person's memory, causing them to forget who people are; places they have been to before; and what certain objects are.

How Can We Help with Wandering?

- Create a daily schedule full of activities and tasks to keep the person busy.
- Remind them where they are and that they are in a safe place if they become confused about their whereabouts.
- Keep any keys to cars or rooms/closets with dangerous items out of sight.
- Never leave the person alone and avoid leaving any doors to the outside open or unlocked.
- Mask exterior doors with curtains or install door alarms.
- Prepare an emergency plan with their updated medical information and picture just in case they do go missing.

What If These Things Do Not Help?

- Consider asking for an occupational therapy consult, as they can help suggest changes to your home to decrease the risk of wandering.

Appendix B: Dementia in Persons with Intellectual and Developmental Disabilities

Children and adults with Intellectual and Developmental Disabilities (I/DD) are at higher risk of developing dementia. A diagnosis of dementia poses unique challenges for individuals with an intellectual disability because the characteristics of each may have some similarities (and, in the case of Alzheimer's and Down syndrome, a possible genetic link).

The KEY DIFFERENCE between dementia and I/DD is the loss of a person's typical level of functioning, or baseline.

A baseline provides the most reliable way to identify changes that may point to dementia. You can create a baseline informally by noting basic self-care skills, communication, talents, skills, daily activities, and hobbies throughout adulthood.

A baseline can also be established formally with a memory specialist (such as a geriatrician, neurologist, psychiatrist or neuropsychologist), where abilities can be reviewed, and memory abilities can be tested. These formal screenings are important to schedule throughout mid-to later-adulthood.

Common Signs of Dementia in a Person with an Intellectual Disability

- Confusion and problems with recent memory
- Wandering or getting lost in familiar places
- Moving with rapid, shuffling steps
- Loss of bladder or bowel control
- Laughing or crying inappropriately
- Difficulty following instructions
- Loss of speech
- Disorientation
- Loss of daily living skills
- Changes in personality
- Long periods of inactivity or apathy
- The development of seizures

Resources
for Families
of I/DD



Appendix C: Resources for Caregivers

Taking care of a person living with dementia can be overwhelming. You are not alone. Along with your healthcare team, there are many resources available to you for support.

Online Caregiver Education

1. Alzheimer's Association

- Caregiver support groups & community education programs
- Access to local resources using the community resource finder
- Alzheimer's Association 24/7 Helpline - 800-272-3900
- TrialMatch - connects individuals with Alzheimer's, caregivers, and healthy volunteers to current studies

2. National Institute on Aging

- Educational resources
- Legal and financial planning information
- Tips for home safety

3. UCLA Alzheimer's and Dementia Care Program

- Caregiver Training Videos
- Common Challenges Videos

4. Family Caregiver Alliance

- Connecting Caregivers (support groups, events, classes)
- Participate in a study, Care for the Caregiver

Alzheimer's Association



National Institute on Aging



UCLA Alzheimer's and Dementia Care Program



Family Caregiver Alliance



5. Home Alone Alliance

- Educational videos and tip sheets in English and Spanish on:
 - Wound care
 - Mobility
 - Managing medications

6. Teepa Snow: Caring for Someone Who Has Dementia

7. Dementia Careblazers

Finding Local Resources

1. Family Caregiver Alliance

- Caregiver resources in Spanish, Chinese, and Vietnamese

2. Community Resource Finder

3. Eldercare Locator (acl.gov)

- Look up your local agency for a variety of resources, including:
 - Long-term support services and food assistance
 - Offers a search function for resources based on zip code/city and a toll-free support number, 1-800- 677-1116

4. Find a Respite Provider/ARCH National Respite Network & Resource Center (archrespite.org)

- Find local respite care, a service that provides temporary breaks for caregivers

Home Alone Alliance



Teepa Snow: Caring for Someone Who Has Dementia



Dementia Careblazers



Family Caregiver Alliance



Community Resource Finder



Eldercare Locator



Find a Respite Provider/ ARCH National Respite Network & Resource Center



5. National Adult Day Services Association (nadsa.org)

- Online database of adult day center locations
- Helps caregivers in locating local adult services

6. Department of Veterans Affairs Caregiver Support

- Offers veterans and their caregivers training, support groups, tip sheets, and other resources

7. Trualta

- Training for caregivers to take care of their loved one at home

8. Access Smart Patients

- Website with free, online discussion forums for patients and caregivers
 - Divided into different communities based on diagnosis
 - Discussion threads specific to disease, including Alzheimer's disease, Lewy body dementia, and more
 - Includes general forums for caregivers

9. Aging and Disability Resource Centers

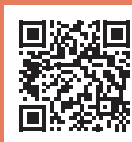
10. Area Agency on Aging

- Google your local aging office/chapter

National Adult Day
Services Association



Department of Veterans
Affairs Caregiver Support



Trualta



Access Smart Patients

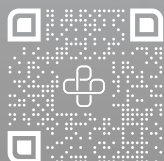


Aging and Disability
Resource Centers





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