



## **Dementia Live® Empowerment Tool for Family Communications**

As a caregiver, it is crucial to communicate with all family members who need to know about the health and wellbeing of loved ones, especially those with dementia. There are times when the communication may be difficult. Taking the time to prepare and develop strategies for communicating with family members can help relieve the strain of communicating and caregiving.

### **SETTING UP COMMUNICATIONS:**

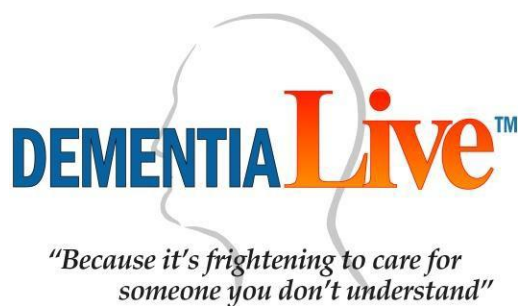
1. **Identify one person who relays all information to the rest of the family.** One point of contact can reduce time for the main caregiver.
2. **Find the simplest way to share information.** It can be by group email or conference call, depending on the nature of the information to convey.
3. **Share what you can when you can with your main point of contact.** If it is a check-in once a week or more frequently, do what works for you and keeps everyone updated as need be.
4. **Also consider what the message or update is.** Decide if you should be the person to convey the message.

### **KEEP IN MIND**

5. **If you have family members who are unable to visit frequently may be upset when seeing your loved one after a long period of time.** They will likely see noticeable changes as the dementia progresses at each visit. Communicating these changes will help prepare them, but they will likely need your support.

6. **Family members who are out of town may have more questions or opinions on what should be done.** Understand that they may feel the need to be more involved to compensate for not being able to be more involved. Find support to help you cope with additional questions and opinions.
7. **If you have a supportive family member, ask that person to help you as you go forward.** Have someone supportive available to help you vent and cope if you need to.
8. **Remember to share positive news when possible.** Share positive days that demonstrate when your loved one with dementia is happy.
9. **Help manage expectations.** For family members who do not understand or are in denial, enlist other family members for support in helping to relate information that may be difficult to learn.
10. **Do not talk about your loved one with dementia as if they are not in the room when they are present.** If you have information to share that you believe will upset your loved one, do not share it in their presence.
11. **Share information and resources.** Encourage your family members to get support for coping with their emotions and the changes in your loved ones.
12. **Your loved one with dementia is still with you.** Although they are different, the person inside remains. Help communicate this message to your family members.
13. **Seek additional information and support as needed.** There are several local and state agencies that can provide additional information about resources for you and your loved one. Area Agencies on Aging and the Alzheimer's Association are two sources for additional support and information.





## **Dementia Live™ Empowerment Tool For Improving Care Processes**

We recommend an **assessment tool** be used as a checklist prior to beginning care. This will be helpful in determining:

1. The person's habits (eating, daily schedule, napping, toileting, etc.)
2. Family member's input and choices concerning care
3. Observation to help determine the person's current abilities to perform daily tasks, and areas where assistance is needed.

### **Key Areas of Care**

**Bathing** can be frightening, uncomfortable and embarrassing, especially for new care partners. A person with dementia may forget how to bathe or become more sensitive to hot or cold water. As a result, bathing may cause anxiety and resistance to care.

Suggestions:

1. Be sure that you have a clear assessment of bathing habits so that fear and anxiety can be minimized.
2. Safety should be a priority at all times.
3. Help the person to feel secure by calmly coaching (through talking and demonstration) each step of the process.
4. If privacy is a concern, loosely wrap the individual in a towel during bathing and try sponge baths.

**Oral Care** is vitally important to overall health, prevention of infection, eating difficulties and pain and digestive problems. A person with dementia may forget how to brush or why it is important.

Suggestions:

1. Coach them through short simple steps and demonstration (hold toothbrush, put toothpaste on the brush, brush teeth).
2. If a person has dentures, recognize that they may prefer not to wear them all the time (eating may be one of these times because dentures can become loose.)
3. Look for signs of discomfort and infection so that a physician can provide proper care. Someone with advanced dementia, consider using a "toothette", which is a simple cushion swab for the mouth.

**Dressing** should be an area that is discussed with family members and observed prior to starting to provide help.

Suggestions:

1. Simplify clothing choices while allowing as much decision making as the person with dementia is comfortable and capable of providing.

2. Calm verbal and demonstrative coaching will help alleviate frustration and anxiety. Gently help them with their clothing, remembering they are generally not as flexible as the average person, and you do not want to stretch or pull muscles that may cause pain.
3. Comfortable clothing will generally be preferred, even if they like to “dress up”. Clothing that is easy to put and take off, well- fitting non-slip shoes and layering is a good plan.

**Toileting** is often a fragile topic. Many people with dementia have accidents because they may forget where the toilet is, no longer recognize the need “to go”, are unable to initiate the activity, or wait until it’s too late. Many persons in later stages of dementia lose control of their bladder and/or bowels. If this happens, have a doctor evaluate potential causes of incontinence.

Suggestions:

1. Assess urinary and bowel patterns or incontinence including: smell of urine or feces in the home or on clothing, soiled clothing, use of adult undergarments, or increased privacy while laundering or bathing.
2. Create a toileting schedule that may reduce or eliminate accidents.
3. Suggest going to the kitchen or to do some other activity as a way to get the individual up and moving and then as you start walking suggest a stop at the bathroom.
4. Maintain exercise, healthy diet and sufficient fluid intake to maintain health and regularity.
5. Be supportive and help to reduce feelings of embarrassment.

**Eating and Drinking** abilities and preferences will change overtime as a result of dementia. The individual’s ability to sequence and prepare even simple meals will decline as will their ability to remember to eat or drink, remember when they last ate, know or say they are hungry or thirsty. Sensory changes will affect their food and drink preferences. At the same time, food and mealtime can be very enjoyable if prepared and presented appropriately for their needs.

Suggestions:

1. Observe eating and drinking patterns, food/drink preferences and challenges. To the extent possible involve the individual with dementia in determining food preferences and as needed, ask their family for their food favorites and dislikes and note that preferences can change overtime. The goal should be to make mealtime as enjoyable as possible while also meeting nutritional needs.
2. Utilizing cups, dishes and utensils may become difficult. With proper assessment, it may be possible to adjust the way food is prepared so that they can eat with as much independence as possible.
3. Meal time should be a pleasant experience. Try not to rush, limit distractions and extraordinary confusion during mealtime and engage with them as much as you feel comfortable with doing.





## **Dementia Live® Empowerment Tool for Long Distance Caregiving**

When a loved one is diagnosed with Alzheimer's disease or another type of dementia, it is painful and upsetting. Being a caregiver who lives far away makes things even more difficult. There are ways to be involved in your loved one's care from a distance.

### **IF YOU ARE THE PRIMARY CAREGIVER:**

1. **Set up communication channels with your loved one's care providers.** Arrange for video calls. Include other family members or caregivers if possible.
2. **Document the information you receive.** When/If you participate in doctor visits by phone or meetings with other care providers, take notes. Doing so will help you keep track of progress. Write down questions before you conduct the meetings.
3. **Find out if all the legal paperwork is in order.** If documents such as power of attorney for health care is not in place, it is important to get it completed sooner than later. Do so while your loved one can participate in the decision-making process.
4. **Make a list of what you need help with.** There will likely come a time when people will offer to provide help. By having some ideas in mind, it will be easier to request help.
5. **Share information with your loved one.** Decide if/when you will share a diagnosis. In some cases, caregivers do not tell their loved one, who undoubtedly knows something is wrong. Having a diagnosis may help relieve your loved one's stress by putting a name to their condition. In some cases, caregivers feel the diagnosis will create more stress and uncertainty. Determine what will be best for your loved one.
6. **Share information with family members and other caregivers.** Keep them up to date in order to keep them involved. They will be better equipped to support you.

7. **You will get questions and opinions about your loved one's care.** Be open and to communicating with family members. Take what you can from the advice and opinions you receive and disregard the rest.

**IF YOU ARE THE NOT PRIMARY CAREGIVER:**

8. **Set up communication channels with your loved one's primary caregiver.** If possible, conduct video calls. Keep in touch in a way that works for them.
9. **Ask the primary caregiver how you can help.** Consider ways to help that do not require you to be onsite. Be open to providing support where you can, even if it is not what you had in mind.
10. **Offer to document information in doctor or care provider visits.** Doing so will help you keep track of progress. It will also be helpful for the primary caregiver to focus on asking questions knowing that you are keeping notes.
11. **You will have questions and opinions about your loved one's care.** Remember that your loved one's primary caregiver is doing the best they can. Ask yourself if your opinion, advice, or question would be helpful if you were the primary caregiver before sharing your thoughts.

**IF YOU ARE OR ARE NOT THE PRIMARY CAREGIVER, KEEP IN MIND:**

12. **Do not feel guilty about your level of involvement.** You are doing all you can do, whether you are the primary onsite caregiver or not.
13. **Remember that you will see changes in your loved one that may be unsettling.** When you are not able to see your loved one frequently, the changes can be stark from visit to visit. Be prepared and accept where your loved one is at that moment.
14. **Seek additional information and support as needed** Area Agencies on Aging and the Alzheimer's Association are two sources for additional support and information.





## **Dementia Live® Empowerment Tool for Creating a Welcoming Environment for Family Visits**

### **How Families May be Feeling**

As aging services providers look to welcome family members back into their communities, creating a warm and welcoming environment is more important than ever.

For families who have not seen their loved ones for an extended period due to the COVID-19 pandemic feelings of loss and grief are not uncommon. However, they may be experiencing other emotions as well.

How might you feel if you could not directly see, touch, or talk to one of your family members for a year or more? Consider some of the emotions they may be feeling:

- Regret at the loss of valuable time spent with their loved one, especially holidays, birthdays, graduations, weddings. This loss can make families feel very sad and frustrated.
- Surprise by physical and cognitive changes that may have occurred. This is especially true for people living with dementia.
- Stress and uncertainty from lack of routine communication, which leads to consistent worry.
- Fear about COVID or other infectious diseases that may have adverse effects on their loved one.
- Guilt for not having their loved one at home, especially over the past year.
- Anger toward community staff about the frequent changes in state and federal policies. While staff had no control over these changes, families may direct their frustration and confusion toward community staff.
- Despair from lack of control or ability to change the situation. The pandemic was out of everyone's control, and families may be feeling especially anxious about their decisions.

Family members may not be impacted by all these feelings, but it is important to be aware and sensitive to the types of the feelings they may be experiencing.

## How Families May React to You

As families visit in person again, be prepared for all sorts of reactions. Keep in mind that their behavior may have nothing to do with you. They may be reacting to the feelings mentioned above.

Don't be surprised if visitors:

- Do not understand your role on the care team
- Do not recognize you when you are wearing a mask
- Ask a lot of questions you may or may not be able to answer
- React with intense emotions when seeing their loved one
- Seem overly critical of new procedures, especially infection control
- Appear angry because of the changes in their loved one
- Are extremely complimentary of staff – absorb this one for sure!

## How To Create a Warm and Welcoming Environment for Visitors

- Wear your name badge.
- Say hello when visitors enter the room.
- Make eye contact.
- If needed, help them locate their loved one.
- Help them find rooms that have been repurposed.
- Introduce yourself and your role, then say something like, "I'm so glad to meet you. We are happy that you are here to visit."
- Use a genuine and caring tone of voice. You may still be wearing a mask so people may not see your smile directly, but they can sense your warm and caring self by your eyes, body language and tone of voice.
- Answer questions to the best of your ability. If you don't know, then say so, and direct them to the person who can answer the questions.
- Say something positive about their family member such as:
  - "I so enjoy singing with your mom!"
  - "Your husband and I really enjoy watching the birds at the feeder"
  - "I really like to hear your wife talk about living in her hometown"
- When the visit is over, reassure them that you are looking forward to seeing them again.





## Understanding Noise and Dementia

### Empowerment Tool

Hearing is typically not affected due to dementia, however, people living with dementia tend to respond to noise on a sensory level rather than intellectually. Sensitivity alterations, combined with age-related hearing deterioration, often lead to noise-induced stress reactions as opposed to using noise to support how we process what is happening around us. Combined with other sensory challenges (sight, touch, etc.), the effect can cause a dramatic change in a person's behavior who is living with dementia.

The following tips will help care partners reduce what is often called 'noise pollution.'

#### TIPS FOR REDUCING NOISE

##### **Dining**

- **Challenge:** Dining areas often have multiple layers of noise that can cause unrest and agitation. If a TV or radio is on while others are talking and dishes or cutlery is clattering, this can lead to a heightened sense of disorientation.
- **Solution:** Observe how much noise is taking place and reduce or remove as much as possible. Have quieter, calming background music and ask others to refrain or limit conversations. Always observe the person's reaction and adjust as needed.

##### **Open Spaces**

- **Challenge:** Be aware that noise in public areas might sound louder than in enclosed spaces due to sound reverberation. Something as simple as a med cart being wheeled down an open hallway can often sound noisier to a person living with dementia.
- **Solution:** Observe how much noise is taking place and reduce or remove as much as possible. Be mindful of where others are in terms of uncontrolled noise happening in open spaces. Gently redirect the person to a smaller, quieter place if you notice signs of agitation or distress.

## **Bathrooms**

- Challenge: Acoustics in bathrooms can be particularly challenging. Flowing water and a flushing toilet can startle a person living with dementia or make it difficult to concentrate.
- Solution: Coach the person, letting them know when water will be turned on or off or when a toilet will be flushed to reduce alarm for the person

## **At Night**

- Challenge: A person with dementia must have a good night's sleep and maintain a regular sleep schedule. Unfamiliar or disturbing noises at night or even noise from washing machines, TVs, or other household items may keep a person from getting and staying in a deep sleep.
- Solution: Work to keep noise to a minimum, especially for those more sensitive to noise. Shift routines or relocate tasks to areas that are further away from bedrooms.

## **Other Tips**

- Limit the TV being on unless a person is watching it. Don't use the TV as background noise.
- Limit the use of alarms, phones, doorbells, and alarm bells
- Mealtime should be calm and relaxing. Quiet music may be acceptable but limit multiple conversations, dishes, and TV clanging.
- Reduce background noise a few minutes before engaging in conversation

## Caring for the Caregiver Empowerment Tool

As a caregiver, taking care of yourself is just as important as taking care of your loved one who has dementia. While it is difficult to imagine taking time out for yourself in the midst of caregiving, it will improve your ability to continue caring as your loved one's dementia progresses.

### WHERE TO BEGIN:

- **Identify what brings you enjoyment.** What are things that make your life enjoyable? It could be a hobby like reading, gardening, creating, or playing music. Maybe it's exercise or playing a sport with others. Whatever it is continue to fit it into your schedule regularly. You deserve some time to yourself.
- **Move your body.** Stretching can help you release stress. A walk can help you refocus your thoughts. Whether it happens at home, outside, in a gym, or somewhere else, make time to move each day even if only for a few minutes.
- **Maintain a routine as much as possible.** It may be more difficult to incorporate activities as time progresses. Do the best you can to maintain your routine.
- **Make a list of where you could use help.** People in your life will likely ask how they can help from time to time. By having some ideas in mind, it will be easier to accept help.

### KEEP IN MIND

- **You do not have to do everything on your own.** Find ways to bring other people into your loved one's care. As the disease progresses, it may be more difficult to introduce other caregivers into your loved one's care.
- **You are not the only person who can provide care for your loved one.** There is a reason that nursing homes have three shifts of direct care staff to take care of residents during a 24-hour period.

- **You will not do everything perfectly.** Mistakes will happen. Give yourself the grace of forgiveness when things don't go right.
- **Manage your expectations of your loved one.** Each day may be different. What worked to calm, soothe and engage your loved one yesterday may not work today. Accept what your loved one can do at each moment. Engage them where you can.
- **Manage your expectations of others.** Even when family members or friends offer to help, it may not be the kind of help you want or need from them. Remember that people will give you what they can. Be open to accepting their help.
- **Manage your expectations of yourself.** Remember that you can only do so much. Give what you can when you can. Be patient with yourself. Treat yourself as you would treat a friend going through the same situation.
- **Find the positive when and where you can.** Celebrate what you can. It can be as simple as your loved one enjoying an activity or being at peace.
- **Your loved one with dementia is still with you.** Although they are different, the person inside remains. Find ways to connect – music, pets, photos, whatever works for them and brings them comfort. Laughter and humor are also beneficial.
- **Seek additional information and support as needed.** There are several local and state agencies that can provide additional information about resources for you and your loved one. Area Agencies on Aging and the Alzheimer's Association are two sources for additional support and information.

## Better Communication & Understanding Empowerment Tool

Dementia gradually diminishes a person's ability to communicate. Here are ways to help you better communicate with a person living with dementia.

### TIPS FOR EFFECTIVE COMMUNICATION

- **Eye contact is always best!**

Position yourself on their level and establish direct eye contact.

Speak calmly in a normal tone of voice. A gentle hand touch can be an effective tool for engaging with a person living with dementia.

- **Listen with understanding and interest.**

Dementia does not take away a person's feelings or the need to be understood. Validate concerns and help the best you can.

- **Keep conversations short and simple.**

Dementia often challenges a person's ability to process information quickly. Slow down and give the person time to process and respond. Silently count to 10 before moving on.

- **Never argue!**

As their care partner, it's your job to creatively step into their world with empathy, understanding, and love.

- **Reminisce.**

People living with dementia often find security and peace by sharing old memories and life stories. When things become overwhelming or difficult, do your best to shift the conversation.

## The Driving Dilemma

### Empowerment Tool

The subject of ending driving for someone with dementia is one of the most difficult issues facing caregivers. Anticipating how your care partner will react can create apprehension and anxiety. Handling this subject proactively may help ease the situation.

Driving a vehicle requires coordinated cognitive skills that include:

- Visuospatial skills to accurately position and maneuver a car and judge distances
- Attention and concentration
- Working memory

As these skills become impaired with dementia, most clinicians advise that people with moderate to severe dementia should no longer drive a vehicle. In some cases, people in the early stages should also stop driving.

While this conclusion is logical and prudent, it is often met with heavy resistance from the person living with dementia. The ability to drive is very much tied to independence, and most people don't easily give that up. As well, they are losing their ability to recognize and accept their deficits.

The overriding consideration is the safety of others and your care partner.

**IMPORTANT:** Do not wait until it's too late. Anticipate and prevent. Ride along periodically with your loved one driving, and look for these signs:

- Getting confused when driving to familiar places
- Not staying in the proper lane
- Confusing the brake and gas pedals
- Failing to observe traffic signs
- Making slow or poor decisions
- Hitting the curb when driving
- Driving too slowly or speeding
- Becoming angry or confused while driving (the Mayo Clinic)

## TIPS IN THE BEGINNING

- Talk about this topic early on when your care partner is capable of rational discussion—set parameters to trigger the end to driving that you can agree upon.
- Put the parameters in writing with the signatures of all concerned.
- Be aware of the person's feelings about the impending change.
- Involve other family members in the plan to avoid future disagreements or misunderstandings.
- Discuss this issue in the presence of professionals who understand the issues and can facilitate the conversation.
- Seek a driving evaluation at a minimum every six months as changes in cognitive capability can progress rapidly.

## WHEN IT'S TIME TO STOP DRIVING

Some individuals, recognizing the risks, may limit or stop driving independently. However, many caregivers must step in and facilitate the conversation.

- Remember that logical thinking may not be present at this point. Therefore, this may be a moment you must gently take into your own hands.
- Seek the support of professionals and other family members if needed, without ganging up on your care partner.
- Acknowledge their feelings on the subject. Allow the anger without fighting back or arguing.
- Do not put off the decision out of guilt or based on the reaction of your care partner.
- If you run into resistance, refer to the signed parameters adopted early on.

## IDEAS WHEN FACING RESISTANCE

When faced with resistance, you may need to employ what is referred to as a “therapeutic fib.” In other words, your motivation for adjusting the truth is out of concern for the safety and well-being of others and your care partner.

- Hide the car keys.
- Disable or sell the car.
- Move the car out of sight. Memory loss will probably work in your favor.
- Replace the car keys with a set that won't start the car.
- Avoid over-explaining; use distraction techniques.





## Engaging Activities and Life Enrichment Empowerment Tool

Engaging activities and meaningful pursuits are as important for the well-being of an individual living with dementia as any person. Like anyone, people living with dementia want others to honor their preferences and help empower them with a continued sense of meaning and purpose.

With experimentation and planning, you can set the stage for meaningful activities to engage the senses and encourage the use of an individual's strengths and abilities for enjoyment and sustained independence.

### TIPS FOR ENGAGING ACTIVITIES & LIFE ENRICHMENT:

- **Focus on interests and abilities** to create meaningful moments that will be enjoyed by the person with dementia and you!
  - **Gather details about an individual's life story to create personalized activities.** Being sensitive to language and communication abilities, ask about past accomplishments, hobbies, favorite music, favorite Bible stories, travels, and unique talents and skills. Ask family members and friends for their historical knowledge and continued involvement. An individual in the later stage of dementia will more likely remember people, places, and feelings that were significant to them in their adolescence and childhood.
- **Know current cognitive and functional abilities to inspire success.** Whether using a numerical system for dementia staging, the GEMS® classification categories, or general stages of 'mild, moderate, and severe' dementia, it is critical to know the individual's current level of abilities.
- **Offer personalized activities matched to a person's ever-changing abilities, interests, and preferences** to empower and inspire an individual to remain productive and successful for as long as possible. Experiment and recognize what engages an individual with dementia today may or may not engage them another time. Notice distractions in the environment and check your level of interest in the activity.

- **Notice how abilities and energy levels fluctuate throughout the day and adjust as needed.** Plan activities for when the individual is most likely to have sustained energy and attention. Change up, shorten, or end an activity if you notice increasing restlessness, frustration, hunger, thirst, and weariness.
- **Respect preferences for solitary or social pursuits.** Watch for responses to a variety of individual and group activities. For many, individual and small group activities are more engaging and satisfying than large group activities.
- **Appeal to and engage the senses of individuals in all stages of dementia.**  
 Suggestions include:
  - A. **Cooking** engages all the senses and can stimulate conversation and appetites. Prepare and enjoy favorite recipes and assign roles and tasks to ensure success and enjoyment.
  - B. Colors and scents of spices, flavors, textures, and sounds associated with ethnic and traditional local dishes can stimulate and please or suddenly displease the senses. Preferences and tastes change!
  - C. **Nature walks** to gather items for collages, smell the roses, or listen to the birds provide exercise purpose, and enjoyment.
  - D. **Digging in the dirt**, planting, weeding, watering, and harvesting are productive and satisfying
  - E. **Coloring, painting, or playing musical instruments** can be a fun and valuable means of expression when verbal skills and understanding decline.
  - F. **Favorite music** can be enjoyed alone using an mp3 player and headphones, a personal radio, or a group. Be sensitive to the level of stimulation in a group and be prepared and situated to easily leave the group if over-stimulation sets in.
  - G. **A hand or foot rub** with scented lotion can be calming for both the giver and the recipient.
- **Engage and equip relatives and friends of all ages** to join in activities; you will enrich their lives and the individual with dementia.

The positive feelings and connections created through person-centered activities make them meaningful and fun for individuals living with dementia.

## Understanding Caregiver Burnout

### Empowerment Tool

Caregivers are often so busy caring for others that they neglect their own emotional, physical, and spiritual health. The demands on a caregiver's body, mind, and emotions can easily become overwhelming, leading to fatigue and burnout.

#### WHAT CAUSES CAREGIVER BURNOUT?

1. **Role confusion or reversal** – It can be difficult for a person to separate their role as a caregiver from the role of spouse, child, friend, etc. This role reversal is not a natural or easy process and leads to stress on both care partners.
2. **Unrealistic Expectations** - Caregivers expect their care will positively affect their care partner's health and happiness. This may be unrealistic for patients living with a progressive disease such as Alzheimer's Disease or Parkinson's Disease. This can lead to feelings of helplessness and hopelessness.
3. **Guilt** - Caregivers may feel guilty for not spending enough time with their loved ones or not being able to tend to their own family's needs or neglecting friends. Resenting the role of caregiver can lead to feelings of guilt.
4. **Lack of Control** – Lack of family support, money, resources, and skills often leave caregivers feeling overwhelmed. The realization that many of these circumstances are simply out of one's control can lead to feelings of anger, frustration, and depression.
5. **Denial** – Many caregivers simply cannot see when they are experiencing burnout and eventually get to the point where they cannot function effectively. They may even become sick themselves.

## WHAT ARE THE SYMPTOMS OF CAREGIVER BURNOUT

1. Disrupted sleep patterns
2. Altered eating patterns
3. Increased food or alcohol consumption
4. Frequent headaches or sudden onset of back pain
5. Increased reliance on over-the-counter pain remedies or prescribed drugs
6. Irritability, fear, and anxiety
7. Impatience, especially over minor issues
8. Overreacting with anger toward a spouse, child, or older care recipient
9. Withdrawing from social activities
10. Loss of compassion and empathy for the care recipient and others
11. Resenting your care recipient and the situation
12. Neglecting or mistreating your care recipient

## HOW CAN I PREVENT CAREGIVER BURNOUT?

1. Caring for yourself is critically important! Set realistic goals that will help you better care for your physical health, and emotional and spiritual needs. Caring for yourself will ensure better care for your loved one
2. Be open to accepting help from others – family, friends, or professionals
3. Seek a support group to share your feelings with others who are going through similar situations
4. Be realistic about your loved one's illness, especially progressive diseases such as Alzheimer's, Parkinson's, and other degenerative illnesses
5. Talk to a professional. Therapists, social workers, and clergy are all trained to counsel individuals dealing with a wide range of emotional issues
6. Educate yourself by learning about caregiver issues, your care recipient's illness, aging issues, and other matters. Education empowers caregivers and reduces stress
7. Maintain healthy eating and lifestyle habits
8. Exercise regularly
9. Practice deep breathing, yoga, or other holistic techniques to help reduce stress
10. Laugh! Humor helps alleviate stress and accentuate the positive
11. Learn to say NO and not feel guilty. Caregivers can't do it all, and by setting limits and boundaries, you are caring for yourself and those you love
12. Develop tools to respond to behavioral expression, especially for those living with dementia. Touch, music, pets, nature, and reminiscence are all proven therapies that have tremendous benefits for both care partners.

## Enhanced Nutrition and Dining Experience Empowerment Tool

Improving nutrition and the dining experience is certainly possible, whether in a community-based setting, a hospital, in the home or even in a restaurant. Below are things to consider and ways to assist an individual living with dementia to maintain independence as they enjoy mealtime and get needed nutrition.

### TIPS FOR ENHANCED NUTRITION & DINING EXPERIENCE

It is helpful to start by thinking about your five primary senses: vision, hearing, smell, taste, and touch, and how each is involved with eating and enjoying food.

- **Keep the plate within the field of vision.** Changes in peripheral vision and depth perception can mean a person with dementia will not be able to see a plate of food placed in front of them near the table edge and may see a plate across the table as theirs. Move their plate more toward the center of the table so it is more easily in their field of vision.
- **Present familiar foods, which are visually appealing.** Food should be familiar and easily recognizable. Studies show that it can be helpful to serve food on a colorful plate that is not the same color as the food being served. Mashed white potato may be hard to see when served on a white plate. Served on a red plate gives more contrast to the potatoes and makes them more easily seen and eaten.
- **Focus on a nutritionally balanced diet,** not the quantity of food.
- **This food looks delicious.** Words and smiles of encouragement can have positive effects on another person.
- **Serve foods that produce appealing sounds.** Some foods sizzle, others crackle or crunch when prepared, served or eaten. Be attentive to the sounds produced by various foods and aware of the individual's preferences and responses to each.

- **Reduce noise and distracting sounds in the dining area.** Provide a dining experience that is as soothing and pleasant as possible while focusing on nutritional intake. Dishes clanging, meal carts rolling down the halls, personal conversations between staff, the television blaring, and loud background music can all distract from eating and spoil the dining experience.
- **Appeal to the sense of smell.** Bread, cookies, cinnamon rolls baking, bacon frying, fresh coffee brewing, and popcorn popping attract attention and stimulate appetites. Make note of favorites and add them to the menus for meals, snacks, and activities.
- **Taste.** As tastebuds age and change, a person's favorite foods may change. Observe what foods are enjoyed and adjust menus and recipes as needed. The taste of sweets usually lasts. Ice cream, smoothies, and shakes (with or without dairy) are often enjoyed and provide dense calories.
- **Texture and feel of food in the mouth.** The texture is an individual preference so make note of the reactions you get to the texture of meats, vegetables, sauces, and puddings and adjust as needed.

**Adjusting menus, recipes, and mealtimes can help to maintain independence and improve nutrition.** Finger foods are a great option to encourage independence and provide complete nutrition. Depending on chewing and swallowing abilities, include chicken or steak tenders with dipping sauce, fish sticks, French toast sticks, roasted vegetables, quartered sandwiches, small pizza rounds, fresh fruit pieces, and cookies enriched with protein, fat, and other nutrients. Be sure to pre-slice, cube, chop, mash, blend, or puree as needed.

Over time, brain changes caused by dementia gradually diminish a person's ability to know if they are hungry or full or remember if they've recently eaten. Be flexible with mealtime and try to keep a variety of favorite snacks readily accessible 27/7 – even after a meal.

## Dementia-Friendly Home Modifications

### Empowerment Tool

Adapting a home or living area to best accommodate the changing needs of a person living with dementia can be a significant challenge. Even simple modifications can make the home safer and allow the individual to remain independent or semi-independent in their own home for as long as possible.

#### KEY CONSIDERATIONS WHEN PLANNING MODIFICATION

- **Safety.** Providing a safe environment that enables greater independence for your loved one is the primary reason for environmental modifications. The challenge is to match the level of safety intervention with their changing abilities and disabilities.
- **Control.** People with dementia have the desire—and the right—to make decisions. The challenge is to balance their ability to control choices with maintaining their safety.
- **Maintaining independence.** People with dementia are constantly faced with what they can't do anymore because of the disease. To help them maintain self-esteem and high quality of life, it is critical to find ways to enable them to continue to do their personal care and daily tasks and activities as independently as possible.

#### **Create An Action Plan**

- **Assess the home.** Make a checklist of changes that will need to be made to accommodate changing cognitive and sensory abilities.
- **Prioritize modifications to be made.** Rank all modifications needed beginning with the most urgent safety concerns.
- **Make a schedule.** Write out a schedule for making the modifications including when they will be made and who will make them. Remember: making too many changes at once can cause anxiety, fear, and disorientation for your loved one and even trigger stress reactions. Modifications should be made gradually with enough time for adjustment.



All members of the household should be made aware of the modifications needed, the reasons for the modifications, and to the extent possible, be involved in the action plan for making the modifications.

### KEY AREAS IN THE HOME TO ADDRESS:

- **Kitchen.** Add an automatic shut-off function to any appliances that you can. Stoves, ovens, and microwaves can be disabled or unplugged if the person with dementia can no longer safely cook. Remove toxic cleaning supplies. Keep counters clear of clutter, placing small appliances and items in drawers, especially if they are not being used on a regular basis. Remove tripping hazards such as small rugs.
- **Bathroom.** Set the water heater temperature to no more than 120 degrees F. Install grab bars properly near the toilet, shower, and bathtub. Install textured stickers on slippery and potentially slippery surfaces. Supervise the use of hand razors, hair dryers, electric razors, curling irons, etc. Remove all medicines from cabinets and supervise the taking of all medication. Monitor toilet paper use and briefs to avoid jammed toilets and e-waste of unused briefs. As in the kitchen, remove cleaning supplies.
- **Garage.** Secure hand and power tools, lawn equipment, and other items that could be a hazard such as poisonous chemicals, paints, and fertilizers.
- **Outdoors.** Disconnect gas hookups from grills, lock fence gates, hide car keys, and monitor elders, especially in areas that are not enclosed.
- **Throughout the Home.** Firearms should be stored in a locked area. Use sturdy chairs that do not tip. Remove or tape down throw rugs and carpeting. Apply colored stickers to large windows and sliding glass doors. Remove objects that block walking pathways.
- **Doors leading Outdoors.** Assess on an ongoing basis the need for safety locks to prevent unsupervised exiting that could result in the individual with dementia becoming lost.

Be realistic about making modifications. It is impossible to prevent every problem that could arise. Try to make all changes while maintaining the same environment and routines. It will be easier for your loved one to adapt to a familiar environment than learn a new one.



## Encouraging Successful Family Visits

### Empowerment Tool

Family members are a critical component in the lives and care of elders, especially those living with dementia. Family members can help define and honor the personhood of their loved ones, support their abilities and well-being, and bring joy and reassurance to individuals with dementia.

Helping family members understand the changing needs and abilities of their loved ones can help turn otherwise stressful visits into ones that are rewarding to individuals with dementia and their family members.

#### TIPS FOR SUCCESSFUL FAMILY VISITS

- **Help family members understand dementia and its effects.** Most people know that the brain changes of dementia affect a person's memories. But most people do not know that dementia can also affect a person's mood, personality, reasoning, vocabulary and comprehension, articulation, balance, sensory and social abilities. Immersive programs like Dementia Live® can let people experience the effects of dementia for themselves.
- **Remind family visitors that individuals with dementia still have memories.** As the disease progresses, recent memories diminish or are lost altogether, and it's the older remembrances and associated feelings that define the personhood of the individual. Family members should be encouraged to ask questions about these early memories. Responses can offer new insights and details about their loved one's childhood and young adulthood while validating the personhood of the individual with dementia.
- **Use Validation, Not Re-orientation.** Help visitors understand that interest in and validation of an individual's reality is comforting to the individual. Attempts to re-orient their sense of time and place to match another's are fruitless, create frustration, and are upsetting for everyone.
- **Recommend families visit when their loved one is at their best.** Plan for success and help identify times of day the family might visit when their loved one is typically rested and refreshed.

- **Encourage family members and friends to introduce themselves during their visits.** Family members and friends should not ask someone with dementia to remember their name. Having self-adhesive name tags and markers ready for visitors may be helpful.
- **Keep family members informed of their loved one's changing condition, needs, and abilities.** The time elapsed between visits can bring about unexpected changes that are hard for family members to understand. Through emails, phone calls, and texts, try to keep family members informed of positive moments and incidents and changes in an individual's condition and abilities.
- **Handling grief and loss during visits.** Family members must grieve; dementia changes the person they knew and loved. Family members need compassion, not judgment, as they handle the intense feelings of loss and grief.
- **Remind visitors that individuals with dementia can interpret facial expressions, body language, and tone of voice even when words no longer make sense.** Sincere smiles, compliments, and patience are needed during visits. Expressions of shock and sadness can create internal anguish for individuals with dementia.
- **Show family members how to approach their loved ones with dementia.** Approaching from the side or the back can startle and even scare someone. Help visitors appreciate the reduced field of vision that comes with aging and dementia, the importance of approaching from the front, engaging at eye level, verbally connecting as approaching, moving slowly toward someone, speaking clearly and slowly, and having permission before hugging and touching.
- **Suggest ways to connect and engage positively.** Update family members on activities their loved one enjoys and offer supplies and instructions.
- **Help family members make a successful exit.** Leaving can be hard for everyone, especially when the individual with dementia wants the visitor to stay or they want to go home with the visitor. Be ready to assist if needed with an activity or part of the daily routine that the individual can move to when it's time for their visitor to leave. Moving to mealtimes can often be helpful.

## Understanding Care Options

### Empowerment Tool

The time may come when it is no longer safe to care for someone living dementia living in the home. Factors that contribute to a decision to seek care outside of the home may include:

1. Home modification is not feasible (inaccessible bathing, bedroom, stairs)
2. Safety concerns such as exit seeking at night.
3. Physical care requirements (lifting, incontinence, bathing)
4. Behavioral challenges
5. Caregiver stress/burnout
6. Financial burdens of around-the-clock care in the home

Selection of an appropriate care option is driven in large part by:

1. Geographic location.
2. The degree of physical and cognitive impairment.
3. Financial resources.

THIS GRAPH SHOWS RESIDENTIAL CARE OPTIONS, BEGINNING FROM THE LEAST TO MOST INTENSIVE LEVELS OF CARE

Assisted Living	Assisted Living Memory Care	Nursing Home (Long Term Care Facility)	Nursing Home Memory Care
Availability of 24-hour episodic assistance and moderate supervision	Structured/secured environment with regular availability of physical and cognitive care	Scheduled and unscheduled assistance available 24-hours for physical and mild-moderate cognitive care	Scheduled and unscheduled assistance available 24-hours for physical and moderate to late-stage cognitive care
Limited availability of licensed nursing care	Licensed nurse available 24 hours	Licensed and/or registered nurse services available 24 hours	Licensed and/or registered nurse service available 24 hours
Scheduled activities offered/resident directed	Higher level of structured staff-directed activities for memory-impaired	Structured staff-directed activities geared for physical and memory-impaired	Structured staff-directed activities geared for memory-impaired
Private pay only	Private pay only	Private pay, Medicaid, or Medicare for only short-term rehabilitation	Private pay or Medicaid

## FINANCIAL CONSIDERATIONS

- Evaluate the assets that are available to pay for residential care.
- Family members are not held financially liable for the cost of care.
- There are protections in place for a spouse who is still living at home.  
<https://www.medicaid.gov/medicaid/eligibility/spousal-impoverishment/index.html>
- Medicare does not pay for long-term care.
- Medicaid is the assistance program that supports the cost of care for persons with limited personal financial resources.
- Medicaid is only available in a licensed nursing home.
- Supportive living is the Medicaid-approved alternative to assisted living. Availability varies from state to state.

## WHERE TO BEGIN

- Contact your local Area Agency on Aging to request a casework consultation to determine the most appropriate level of care.
- Narrow down your desired geographic area.
- Isolate the available options based on the care and financial needs of your loved one.

## RESEARCH

- Talk with friends, clergy and other trusted sources for recommendations
- Schedule a visit to talk with an admissions counselor and take a tour. It is recommended that you do not take your loved one with you for preliminary visits.
- Find out the history of the organization:
  - Who is the owner or sponsor?
  - How long has the organization been in business?
  - Refer to nursing home compare.  
<https://www.medicare.gov/nursinghomecompare/search.html?>

## VISIT

- Prepare your questions in advance that cover these broad categories
  - Services, accommodations, and pricing.
  - Quality of life and amenities.
  - Availability.
  - Quality of care and staffing.
  - Contract and obligations.

## OTHER RESOURCES

<https://www.aarp.org/caregiving/basics/info-2017/assisted-living-options.html>

<https://www.nia.nih.gov/health/how-choose-nursing-home>

## Understanding Visual Perceptual Changes Empowerment Tool

The ability of the brain to process visual information sent from our eyes and turn it into a meaningful message or perception is known as visual perception.

Changes in the brain due to Alzheimer's Disease and other causes of dementia can affect the way the brain processes visual information and alter the perception of the world or the ability to understand it.

Different types of dementia can damage the visual-perceptual system in different ways depending on how the disease changes the structure of the brain. Common visual perceptual difficulties are:

- Less sensitivity to variations in the contrast between objects and background
- Diminished ability to detect movement
- reduced ability to see different colors
- Problems directing or shifting gaze
- Problems with recognizing things and faces
- Reduced sensitivity to depth perception

### COMMON VISION PERCEPTION CHANGES IN PEOPLE LIVING WITH DEMENTIA

1. The change in-depth perception doesn't allow them to understand exactly where something is in space making it difficult to reach for objects accurately.
2. They may have difficulty feeding themselves because they cannot recognize the food on the plate or find their drinking glass.
3. They may attempt to grab objects that appear on TV or pick up things depicted in a painting. They may also process images on TV for real people and become confused or frightened.
4. An uneven or heavily patterned floor can turn into an obstacle or a step, making them apprehensive to move. They may raise their foot, suddenly freeze, and then not want to continue.
5. A person living with dementia may have difficulty recognizing and distinguishing the faces of even close family members like children and siblings.

## COLOR AND CONTRAST:

For someone living with dementia, using contrasting colors can help to draw attention to objects making them easier to see. Examples:

- Serving meals on red plates can make each food item easier to see.
- Red plates may also stimulate appetite.
- Painting a door a color that contrasts with the wall makes the door easier to find.
- Putting colorful tape on the handles of walkers makes them easier to locate.
- A contrasting color toilet seat (ex: a black seat on a white toilet) makes the toilet stand out from the wall and easier to see.
- Color can also be used to highlight important objects and orientation points (ex: the toilet door), or for camouflaging objects the person doesn't need to use (ex: exit doors).

## KEY CONSIDERATIONS

- **Try not to make too many changes** to the location of objects in a person's environment. This can help the person feel confident and reduce their fear of tripping or falling.
- **The pupils take longer to adjust to light** for people living with dementia. Lighting should be even around the home and should minimize shadows – some people resist going near dark areas in corridors and rooms. Consider assistive technology products such as automatic lights.
- **Stand straight in front** of someone living with dementia before you speak. Loss of peripheral vision causes them to only see things right in front of them.
- **Avoid 'busy' patterns** (ex: on the walls or floors) and changes in floor patterns or surfaces. They may be seen as an obstacle or barrier and the person may avoid walking in these areas.
- **Remove clutter and obstacles** to reducing the risk of trips and falls.
- **Regular eye check-ups** continue to be important for people living with dementia to maintain their quality of life.

## Healthcare Acronyms

### Empowerment Tool

#### Healthcare Acronyms

<b>AD</b>	<b>Alzheimer's Disease</b>
<b>ADL</b>	<b>Activities of Daily Living</b> (dressing, walking, bathing, eating)
<b>ALF</b>	<b>Assisted Living Facility</b>
<b>AMA</b>	<b>Against Medical Advice</b>
<b>CCRC</b>	<b>Continuing Care Retirement Community</b>
<b>CMS</b>	<b>Centers for Medicare and Medicaid Services</b>
<b>CNA</b>	<b>Certified Nursing Assistant</b>
<b>DME</b>	<b>Durable Medical Equipment</b>
<b>DNR</b>	<b>Do Not Resuscitate</b>
<b>EMR</b>	<b>Electronic Medical Record</b>
<b>EOB</b>	<b>Explanation of Benefits</b> (Medicare)
<b>HHC</b>	<b>Home Health Care</b>
<b>HMO</b>	<b>Health Maintenance Organization</b>
<b>ICF</b>	<b>Intermediate Care Facility</b>
<b>LOS</b>	<b>Length of Stay</b>
<b>LTC</b>	<b>Long Term Care</b>
<b>MCO</b>	<b>Managed Care Organization</b>
<b>OT</b>	<b>Occupational Therapy</b>

<b>PCA</b>	<b>Personal Care Assistant</b>
<b>PCP</b>	<b>Primary Care Physician</b>
<b>POAHC</b>	<b>Power of Attorney for Healthcare</b>
<b>POLST</b>	<b>Practitioner Order for Life Sustaining Treatment</b>
<b>PPO</b>	<b>Preferred Provider Organization</b>
<b>PRN</b>	<b>Pro re nata</b> (medication as needed)
<b>PT</b>	<b>Physical Therapy</b>
<b>RN</b>	<b>Registered Nurse</b>
<b>RX</b>	<b>Prescription Drug</b>
<b>SNF</b>	<b>Skilled Nursing Facility</b>
<b>TCU</b>	<b>Transitional Care Unit</b>
<b>UTI</b>	<b>Urinary Tract Infection</b>



## Long-Distance Caregiving Empowerment Tool

When a loved one is diagnosed with Alzheimer's Disease or another type of dementia, it can be painful and upsetting. Being a caregiver who lives far away makes things even more difficult. There are ways to be involved in your loved one's care from a distance.

### IF YOU ARE THE PRIMARY CAREGIVER

- **Set up communication channels with your loved one's care providers.** Arrange for video calls. Include other family members or caregivers if possible.
- **Document the information you receive.** Write down questions before meetings with doctors or other care providers. During these meetings use your list of questions and take notes. Doing so will help you keep track of progress.
- **Find out if all the legal paperwork is in order.** If documents such as power of attorney for health care are not in place, it is important to get it completed sooner rather than later. Do so while your loved one can participate in the decision-making process.
- **Make a list of areas where you need help.** There will likely come a time when people will offer to provide help. By having some ideas in mind, it will be easier to request help.
- **Share information with your loved one.** Decide if/when you will share a diagnosis. In some cases, caregivers do not tell their loved one, who undoubtedly knows something is wrong. Having a diagnosis may help relieve your loved one's stress by putting a name on their condition. In some cases, caregivers feel the diagnosis will create more stress and uncertainty. Determine what will be best for your loved one.
- **Share information with family members and other caregivers.** Keep them up to date in order to keep them involved. They will be better equipped to support you.
- **You will get questions and opinions about your loved one's care.** Be open to communicating with family members. Take what you can from the advice and opinions you receive and disregard the rest.



## IF YOU ARE THE NOT THE PRIMARY CAREGIVER

- **Set up communication channels with your loved one's primary caregiver.** If possible, conduct video calls. Stay in touch in a way that works for them.
- **Ask the primary caregiver how you can help.** Consider ways to help that do not require you to be onsite. Be open to providing support where you can, even if it is not what you had in mind.
- **Offer to document information in doctor or care provider visits.** Doing so will help you keep track of progress. It will also allow the primary caregiver to focus on asking questions knowing that you are keeping notes.
- **You will have questions and opinions about your loved one's care.** Remember that your loved one's primary caregiver is doing the best they can. Ask yourself if your opinion, advice, or question would be helpful if you were the primary caregiver before sharing your thoughts.
- **Do not feel guilty about your level of involvement.** You are doing all you can do, whether you are the primary onsite caregiver or not.
- **Remember that you will see changes in your loved one that may be unsettling.** When you are not able to see your loved one frequently, the changes can be stark from a visit to visit. Be prepared and accept where your loved one is at that moment.
- **Seek additional information and support as needed.** Area Agencies on Aging and the Alzheimer's Association are two sources for additional support and information.

## Making Difficult Decisions

### Empowerment Tool

The journey of caring for someone with dementia will likely include events that require making difficult decisions. Regardless of the underlying cause, dementia is 100% progressive. Therefore, the needs of a person with dementia continuously evolve. Caregivers regularly need to adjust and modify the plan of care to preserve the safety, health, and well-being of everyone involved.

Decision-making is best accomplished before a crisis. While the road ahead may not be crystal clear, it is important to prepare for issues that may lie ahead.

#### MEDICAL CARE

Advanced directives are written legal instructions regarding preferences for medical care. An individual needs to be competent in understanding what is being signed, so for persons with dementia, it is essential to execute these documents early on.

- **POLST stands for Physician Order for Life-Sustaining Treatment.** It is a signed medical order reflecting a person's wishes at end-of-life that remains with the person across all care settings and must be honored by all healthcare providers. They are intended for people who are seriously ill or frail. Forms are state-specific.
- **Durable Power of Attorney for Healthcare.** This document allows an individual to appoint another person (agent) with authority to make medical decisions if that individual becomes incapacitated.

Execute these documents early on to alleviate crisis decision-making during a medical emergency. Decision-makers can then have peace of mind following the true wishes of their loved ones.

## LIVING ARRANGEMENT

Many people with dementia can live at home with the support of a caregiver. However, the time may come when this is not possible for various reasons. A decision to transition your loved one to a memory care community is not a sign of failure. Here are some tips to ease the process:

- Discuss this possibility early on with your care partner.
- Include extended family in the discussion. This will help to avoid emotionally charged disagreements down the line.
- Explore together the resources and options available in your area. Select preferred providers before their services are needed.

## END OF LIFE/HOSPICE

The journey through the stages of dementia may lead to a decision that involves the extent of continued treatment/medical intervention. The natural progression of the underlying disease process includes the eventual failure of effective systems. A person in the late stage of dementia is at risk for medical complications, including infections and the inability to swallow. Here are some tips to guide end-of-life decisions:

- Understand that you are not ending someone's life- the disease process is responsible.
- Rely on advanced directives, if present.
- In the absence of advanced directives, consider these ethical principles:
  - a. **Beneficence.** Are you easing suffering?
  - b. **Dignity.** Is this how your loved one would want to continue living?
  - c. What would most people want for themselves in this situation?
- Include immediate family in the decision process.
- Call upon end-of-life professionals such as Hospice Care to guide you through the process.
- Seek the support of others. Call on family, friends, counselors, spiritual leaders, and others in your support network.



## Preventing & Responding to Stress Reactions

### Empowerment Tool

As dementia progresses, a person may have difficulty expressing what they need. When this happens, behavior may become a means of communicating. The unpredictability of these changes in behavior can be stressful for caregivers. Anticipating behavior changes and the root cause can be extremely helpful in learning to prevent stress reactions and responding in the moment.

#### TIPS FOR UNDERSTANDING EXPRESSIONS OF NEED

- **Responding.**

Ask yourself why your care partner is this way. Is their agitation an expression of pain? Is their reduced appetite due to ill-fitting dentures? Back up to what was happening just before the stress reaction – this may hold the clue to what the behavior means.

- **Look for a pattern.**

Talk with other members of your care team (including family) and see if you can observe a pattern related to the behavior. Does the person respond or react this way at the same time of day or in the same situation?

- **Be positive.**

Behavior that is met with a positive response will generally be repeated. Don't be condescending, but somewhat encouraging. We all like to feel that something we do is appreciated and done well.

- **Look at your nonverbal communication.**

People living with dementia can be sensitive to changes in facial expression, posture, mood, or tone of voice. Take a minute to assess what message your face, mood, and body position may be communicating.

- **Smile!**

We've heard it a hundred times, but a smile can go a long way. When your smile may make the most significant difference is when it's the most challenging to do. So, take a deep breath, count to 3, smile and be positive.

- **Validate, join and distract.**

One effective method for managing a stress reaction is to connect with the person's emotion, then calmly and gently redirect the conversation or activity. If, for instance, they insist on wanting to leave, your response might be, "I know you miss your daughter. I see these pictures of her. Can you show me your beautiful family?" And redirect them to the family photo album.

- **Step back when necessary.**

Stress reactions can often be spontaneous and sometimes a person will respond physically. Never argue or be assertive back. The safety of both you and your care partner is always a priority. It's okay to pause, take a breath, and ask for someone else to take over.

## Redirecting Repetitive Behavior Empowerment Tool

Repetition, both verbal and physical, is a common symptom of dementia and may increase as decline progresses. While generally harmless, it is one of the behaviors that is most distressing to caregivers. Redirection or distraction is a technique that shifts the focus away from the repetition toward a different situation or activity and brings a person with dementia back to a place of well-being.

Repetitive behavior can be a response to feelings such as fear, anxiety, hunger, thirst, or boredom. They may indicate toileting needs or feeling too hot or too cold when the person can no longer find the words to express these needs.

### TIPS FOR RESPONDING TO REPETITIVE BEHAVIOR

- Realize that their thoughts and feelings are real and are influencing the behavior.
- Do not shut down the behavior right away (unless there is imminent danger).
- Offer reassurance vs correction. It is not helpful to attempt reorientation by saying, “you don’t need to go home, you are home.”
- Remain calm, friendly, and helpful.

## EMPLOY REDIRECTION TECHNIQUES

You will be more effective in ending the unwanted behavior by understanding and then addressing the thoughts and feelings behind the behavior. Shutting down the behavior right away will likely make the person even angrier. Over time, you will learn which distractions are most effective.

- Look at the environment. Is it too hot or too cold? Is the space calm and comforting or noisy? Sometimes it's the environment that needs redirection.
- Ask questions. If they keep asking to go home, ask "Where is home?" to see which home from their lifetime they are talking about. Then keep asking questions about that home. You can repeat questions if needed. Dip into long-term memory vs the present.
- If they are constantly walking, walk along with your care partner. Forcing him/her to "just sit down" will cause more agitation. Guide to a safe place such as an enclosed backyard. Getting someone outside in a safe manner is a good distraction.
- Turn on favorite music and use reminiscence to distract thoughts. Ask, "who sings this song," and then talk about when and where.
- Take a car ride if your care partner thinks it is time to go somewhere. Many times, circling the block will do it.
- If your care partner is worried about the children, find a photo album and reminisce.
- Find a purposeful activity that your care partner can feel helpful and successful.
- Always acknowledge feelings, "I'm so sorry that you are worried about getting the bills paid on time."
- Use touch. A gentle back, hand, arm, or foot rub is very effective in breaking the repetition cycle.
- Create a busy basket and have it on hand to distract your care partner into a new task.
- Offer food or drink.



## Parkinson's Disease

### Empowerment Tool

It is now recognized that Parkinson's disease (PD) is much more than a motor disorder. Tremor, slowness, stiffness, and walking trouble are only part of the picture. Non-motor symptoms in Parkinson's Disease are common and affect cognition, mood, sleep, autonomic function, and sensory function. Source: American Parkinson Disease Association.

#### COGNITION

Approximately 50% of people with PD experience some form of cognitive impairment

- Memory. This is one of the most concerning symptoms of the disease for people with Parkinson's and their families and includes difficulty retrieving information from working memory. This impairs the ability to complete familiar tasks.
- Attention. Difficulty completing complex tasks due to an ability to concentrate.
- Mental Processing. Noticeable delay in responding to verbal or behavioral stimuli and completing tasks.
- Hallucinations/Delusions- experienced by up to 40% of persons with PD.
- Problem Solving. Trouble planning, organizing and completing activities.
- Language. Difficulty with word-finding and talking under pressure or stress.

#### TIPS TO SUPPORT BRAIN HEALTH

- Encourage regular exercise
- Eat a healthy, balanced diet
- Avoid cigarettes and drink alcohol only in moderation
- Engage in "brain games"
- Maintain a regular sleep routine

## TIPS FOR CARE PARTNER

- Keep track of cognitive changes and report in a timely manner to a health provider
- Exercise patience and be aware of unrealistic expectations.
- Avoid using phrases like, “don’t you remember” or “I already told you”
- Support independence and avoid behaviors that promote learned helplessness
- Use reminiscence to inspire sharing of memories and life stories
- Offer reassurance during hallucinations vs arguing

## MOOD

Parkinson’s can cause mood disturbances and impact how a person thinks and feels.

- Apathy. Having a lack of motivation and interest in activities
- Anxiety. Uncontrollable worry
- Depression. Feelings of hopelessness and unrelenting sadness and loss
- Insomnia. Sleep deprivation affects mood, and mood disturbances affect sleep

## TIPS FOR SUPPORTING QUALITY OF LIFE FOR CARE

- Remain social with friends and loved ones to guard against isolation
- Maintain a low-stress environment
- Report new symptoms in a timely manner to healthcare providers
- Avoid cigarettes and ensure no more than moderate alcohol consumption
- Build a support network
- Accept your limits and be aware of signs of burnout
- Be mindful of your own emotions- they are just as important as the person with PD

Sources:

<https://www.apdaparkinson.org/resources-support/for-caregivers/>

<https://www.michaeljfox.org/news/new-guide-navigating-cognitive-changes-parkinsons-disease>

<https://www.parkinson.org/Understanding-Parkinsons/Non-Movement-Symptoms>

<https://www.parkinson.org/understanding-parkinsons/what-is-parkinsons>

## Easing Holiday Stress for Families

### Empowerment Tool

Holidays or special family occasions can add stress for people visiting with the elders in your care. Visitors are likely to have feelings of grief and sadness as they face a “new normal”. There are proactive steps you can take to prepare your staff to respond to and possibly prevent the emotional reactions they experience from stressed family visitors.

#### UNDERSTAND FAMILY STRESS TRIGGERS

Emotions at the holidays can range from joy to despair and everything between and can be complicated by the emotions of caring with a loved one living with dementia. They may also be feeling:

- Guilt related to holiday separation.
- Shock of realizing the changes in cognitive functioning since their last visit.
- Sadness that their loved one is not capable of engaging in traditional holiday celebrations.
- Anger about their sense of obligation to make the holiday joyful for their loved one.
- Overwhelmed trying to maintain traditions.

These and other stress triggers may present themselves as anger outbursts directed at caregivers. If you find yourself on the receiving end, here are some helpful tips.

#### RESPOND WITH EMPATHY AND PATIENCE

- Exercise patience and be aware that the issue isn't personal.
- Acknowledge the feelings being directed towards you, respond by saying, “I hear you and I understand that you are upset about this.”
- Do not argue or turn the exchange into “you're wrong, I'm right.”
- Ask the visitor to take a moment, breathe, and calmly talk about the issue.
- Assure the person that you care and will do everything you can to make the situation better.

## Tips to Reduce Holiday-Induced Stress Reactions in Families

We know the importance of maintaining an environment of peacefulness and calm for individuals living with dementia. The holidays often bring a frenzy and swirl of activity that can be very overwhelming for everyone, most especially for those living with dementia. Preparing families in advance of this reality could help reduce family stress - incidents.

- Ask visitors to check their stress at the door.
- Proactively communicate with out- of -town visitors about changes they can expect to see in their loved one to avoid unexpected surprises.
- Educate families to examine any unrealistic expectations about participation in holiday celebrations.
- Work with families in advance to create a holiday reminiscence basket that caregivers can use to engage with their loved one. Encourage them to use reminiscence to inspire sharing of holiday memories.
- Support special-small group holiday events and include family members.
- Reinforce that celebrating holidays in familiar environments offers the best opportunity for success.

Sources:

[The Holidays and Alzheimer's | alz.org](https://www.alz.org)

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