

DEMENTIA

# Navigating the Dementia Journey



**HomeCare**<sup>™</sup>  
ADVOCACY NETWORK

Relationship-Driven Senior Care<sup>SM</sup>

## ***I know how devastating a dementia diagnosis can be.***

*At age 49 my step mom, Fran, was diagnosed with early onset Alzheimer's disease. Our family was heartbroken and worried about an uncertain future. However, with the help of family members, friends and professional caregivers my dad was able to help Fran live a full and happy life for more than 14 years,*

*During that time, our family (kids included), experienced a lot of the joys and challenges that come with caring for someone who has dementia. As home care providers, we've learned even more - and we would like to share some of what we learned with you.*

*In this E-book you will find information and tips that we hope will help you celebrate the good days and simply survive the difficult ones.*

*If you have additional questions or concerns, give us a call - we'll do our best to answer them. We also offer free Family and Friends Dementia workshops. The two-hour sessions, which are open to everyone, are designed to help family members and friends understand what to expect with dementia and how they can better care for their loved ones and themselves.*

*May God bless you throughout this journey.*



**Sierra Goetz**

CO-FOUNDER AND OPERATIONS DIRECTOR  
HomeCare Advocacy Network

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# 1 / What Is Dementia



The Alzheimer's Association defines dementia as a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. There is no cure.

Dementia is not a single disease. In fact, there are more than 100 diseases that may cause dementia. Alzheimer's disease is the most common cause - accounting for 60%-80% of cases.

It's currently estimated that 55 million people worldwide are living with dementia. That number is expected to rise to 139 million by 2050.

## 2 / What You Can Expect

Dementia is progressive. Signs and symptoms may be relatively mild at first, but they will worsen over time. It affects everyone differently, but it typically progresses through three stages.

### ● EARLY STAGE (MILD)

In the early stage of dementia, a person may function independently - perhaps still driving, working and taking part in social activities. Symptoms may not be widely apparent at this stage, so they may attribute it to simple memory lapses, such as forgetting familiar words or the location of everyday objects.

### ● ● MIDDLE-STAGE (MODERATE)

Middle-stage dementia is typically the longest stage - possibly lasting for many years. During the middle stage, the dementia symptoms are more pronounced - the person may confuse words, get frustrated or angry and act in unexpected ways. Damage to nerve cells in the brain can also make it difficult for the person to express thoughts and perform routine tasks without assistance.

### ● ● ● LATE-STAGE (SEVERE)

In the final stage of the disease, dementia symptoms are severe. Individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. Communicating pain becomes difficult and, as memory and cognitive skills worsen, significant personality changes may take place.

MILD ➔ MODERATE ➔ SEVERE



## 3 / Living In Their Reality

We embrace the [Rachel Wonderlin](#) approach to dementia care. Instead of forcing your loved one to live in your reality, embrace their world - no matter where it is.

For example:

*If your dad believes he's a teenager - reminisce about his time on the football team.*

*If your mom will only get dressed when she thinks it's time to go to church - tell her you're taking her to church.*

*If you have to tell your veteran dad that the general is coming for inspection in order to get him to shower - do it.*

Don't think of it as lying. Understand that you're showing compassion in the best possible way, because you are choosing to live in their reality.

## 4 / Slowing Progression With Mind Games

Brain exercises provide a simple way to improve memory and problem-solving skills while reducing the risk of dementia and slow cognitive decline.

**Word Puzzles.** Word search, jumbles and crossword puzzles are a good way to get the brain buzzing.



**Sudoku.** If words aren't your senior loved one's thing, try Sudoku.

**Reading.** With books, seniors will likely enjoy much more than a good story. In addition to improving memory and sharpening the decision-making process, reading can help reduce stress and enhance sleep.



**Card Games.** From Solitaire to Poker or Go Fish to Crazy Eights, card games are an excellent way to stimulate the brain.

**Arts and Crafts.** Engaging in arts and crafts not only keeps the brain active, but it keeps fingers nimble, too.



**Music.** Whether playing an instrument or singing along to a favorite song, music stirs happy memories, encourages socialization and promotes overall mental health. Calming music has the power to transform the atmosphere within the home, particularly during moments of agitation.

**New Skills.** Learning something new is not only fun, but it can also help stimulate the brain.

## 5 / Completing Everyday Tasks



Many people with dementia lack the ability to organize, plan, initiate and successfully complete day-to-day tasks.

✓ **Schedule wisely.**

Some tasks, such as bathing or medical appointments, are easier when the person is most alert and refreshed. Allow some flexibility for spontaneous activities on particularly difficult days.

✓ **Take your time.**

Anticipate that tasks may take longer than they used to, and schedule more time for them. Allow time for breaks during tasks.

✓ **Involve the person.**

Allow the person with dementia to do as much as possible with the least amount of assistance. What we do for them we take from them.

✓ **Provide choices.**

Provide some, but not too many, choices every day. For example, provide two outfits to choose from or ask if he/she prefers a hot or cold beverage.

✓ **Provide simple instructions.**

People with dementia best understand clear, one-step communications.

✓ **Limit napping.**

Avoid multiple or prolonged naps during the day. This can minimize the risk of getting days and nights mixed up.

✓ **Reduce distractions.**

Turn off the TV and minimize other distractions at mealtime and during conversations. This will make it easier for the person with dementia to focus.

*Many people with dementia lack the ability to organize, plan, initiate and successfully complete day-to-day tasks.*





## 6 / Communicating Effectively

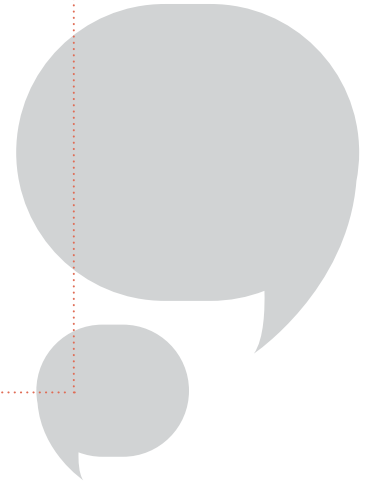
The inability to communicate can be frustrating for everyone, so it's important to have patience, good listening skills and different strategies.

### YOUR APPROACH:

Smile & approach from the front with a warm, easy manner.

Carefully monitor your facial expression, body language and tone of voice.

Remain at or below eye-level so the person can see your full face easily.



- Engage in one-on-one conversations in a quiet space with minimal distractions.
- Speak slowly and clearly.
- Maintain eye contact. It shows you care about what he/she is saying.
- Give the person plenty of time to respond so he/she can think about what to say. We recommend the 7&7 rule = **Say 7 words and wait 7 seconds for a response.**
- Be patient and offer reassurance.
- Ask one question at a time.
- Ask yes or no questions.
- Avoid criticizing or correcting.
- Avoid arguing. If the person says something you don't agree with, just let it be.
- Offer clear, step-by-step instructions for tasks.
- Give visual cues. Demonstrate a task to encourage participation.
- Written notes can be helpful when spoke words are confusing.





## 6 / Maintaining A Healthy Diet

Encouraging someone with dementia to eat nutritious meals can be a daily challenge - especially during the middle and late stages of the disease.

✓ **Limit distractions.**

Serve meals in quiet surroundings, away from the television and other distractions.

✓ **Keep the table setting simple.**

Avoid patterned plates, tablecloths and placemats that might confuse the person. Using color to contrast plates against a tablecloth or placemat can make it easier for the person to distinguish the food from the plate or table. Provide only the utensils needed for the meal to avoid confusion.

✓ **Check the food temperature.**

A person living with dementia might not be able to tell if something is too hot to eat or drink.

✓ **Offer one food item at a time.**

The person may be unable to decide among the foods on his or her plate. Serve only one or two items at a time.

✓ **Be flexible with food preferences.**

It is possible the person may suddenly develop certain food preferences or reject foods he or she may have liked in the past.

✓ **Allow plenty of time to eat.**

Keep in mind that it can take an hour or more for the person to finish a meal.

✓ **Eat together.**

Keeping mealtimes social can encourage the person to eat.

✓ **Keep in mind person may not remember when or if he or she ate.**

If the person continues to ask about eating breakfast, consider serving several breakfasts - juice, followed by toast, followed by cereal.







## 7 / Improving Home Safety

With a few simple modifications, you can help loved ones living with dementia remain safely in their homes for as long as possible.

### Doors & Windows

- ✓ Make sure all windows have working locks.
- ✓ Add childproof doorknob covers.
- ✓ Install additional locks higher up on doors, so they're out of the senior's line of sight.
- ✓ Put locks on fence gates.

### Kitchen

- ✓ Put brightly colored labels on cabinets.
- ✓ Remove burner knobs or install knob covers.
- ✓ Add safety latches to doors and cabinets.
- ✓ Remove knives, scissors and other sharp objects.
- ✓ Install a single-lever faucet that can help balance water temperature.



### Lighting

- ✓ Install bright lights.
- ✓ Add nightlights in hallways, bathrooms and along stairs.

### Temperature

- ✓ Install a smart thermostat that can be managed remotely.
- ✓ Set the temperature on the hot water heater to below 120 degrees.
- ✓ Remove space heaters.





## 8 / Limiting Travel Frustrations

Vacationing is a wonderful opportunity for quality family time, but traveling with someone who has dementia can be challenging.

✓ **Plan ahead.**

Create packing lists, check travel times, research accommodations, review emergency plans and make sure you have medical records and insurance information.

✓ **Pack wisely.**

In addition to proper clothing and medications, pack something that might help your loved one feel more at ease in unfamiliar surroundings.

✓ **Consider the destination.**

Choose a destination that is suitable for your loved one's needs and abilities.

✓ **Account for travel time.**

Sitting in the car for hours on end may be very uncomfortable for them, so consider breaking up the drive. If time is tight, flying might be the best option.

✓ **Alert airport, hotel and restaurant staff.**

Communicate with those who engage with your loved one, so they are aware of the situation.

✓ **Keep a routine.**

Maintaining a familiar routine (meals, medications, etc.) can help reduce your loved one's anxiety and confusion.

✓ **Don't try to do too much.**

Carefully consider the time, duration and kinds of activities you plan.

✓ **Be patient and flexible.**

Allow for plenty of breaks and give your loved one time to adjust to any new surroundings.





## 9 / Providing Helpful Products

Whether mild or advanced, if your loved one has dementia, here are 10 products that can help make their everyday lives easier.

- ★ **Weighted blankets or lap pads.** Weighted or sensory blankets or lap pads can reduce anxiety, calm nerves, provide comfort and promote deep sleep.
- ★ **Weighted stuffed animals.** People who can no longer have pets may feel especially comforted by a stuffed animal that looks like a former pet.
- ★ **Calming scents.** Scented candles, diffusers or essential oils can be used to create a calming, stress-free environment.
- ★ **Fidget toys.** They keep hands and minds busy in safe, soothing ways.
- ★ **Oversized digital clock.** A simple, easy-to-read clock with programmable reminders is a good way to prompt them with daily routines, such as taking medications.
- ★ **Jumbo print wall calendar.** A calendar that's easy to read and understand can help people with dementia keep track of time.
- ★ **Universal big button TV remote.** With only a few large, back-lit buttons, this remote can replace most standard TV controllers.
- ★ **Sound reduction devices.** Earplugs or noise cancelling headphones will help reduce sensory overload, so they can stay calm and enjoy an outing.
- ★ **Massage tools.** Handheld massagers or massage pillows can provide a sense of relaxation and comfort for those with dementia.
- ★ **Activity books.** Coloring books or puzzle books promote cognitive stimulation and reduce boredom.





## 10 / Avoid Caregiver Burnout

Caring for someone who has dementia is a job with no off-time - you're on duty 24/7. It's important to manage stress in order to avoid caregiver burnout.

✓ **Accept or ask for help.**

If help is offered, take it. If you have to ask family or friends for assistance, do it.

✓ **Delegate.**

Make a list of daily tasks and, when possible, delegate.

✓ **Take breaks.**

Understand that it's okay to take breaks from caregiving. Visit friends, go to a movie, get a massage - anything that can help you relax.

✓ **Prioritize self care.**

Eat well, exercise, relax and get enough sleep. If you're not healthy, the quality of care you're able to provide will suffer.

✓ **Get connected.**

Take time to learn about resources in your community, including options for meal delivery, transportation and housekeeping.

✓ **Join a support group.**

A support group can validate your feelings, offer encouragement and help you overcome some of the challenges you face.

✓ **Enlist the help of a professional caregiver.**

Whether it's for a few hours a day or a few days a week, a professional caregiver will ensure your aging loved one is getting the best care possible - while giving you a much needed break.

*It's important to manage stress in order to avoid caregiver burnout.*

**24/7  
JOB**



It is our privilege to work with families who are navigating a dementia journey. We hope these tips will help make the good days better and the challenging ones bearable.

We also invite you to attend our Family & Friends Dementia training sessions. These free, two-hour sessions are designed to help loved ones learn more about the disease and ways to cope with its challenges.

For information about training sessions or our specialized dementia care services, please visit our website ([hcanthrive.com](http://hcanthrive.com)) or call your local HCAN-supported office.



## RESOURCES

[Alzheimer's Association](#)

[Alzheimer's Foundation of America](#)

[Centers for Disease Control and Prevention](#)

[Dementia Society of America](#)

[National Institute on Aging](#)

[Family Caregiver Alliance](#)

[Mayo Clinic Alzheimer's Disease Research Center](#)

[HomeCare Advocacy Network](#)

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[HCANthrive.com](http://HCANthrive.com)

