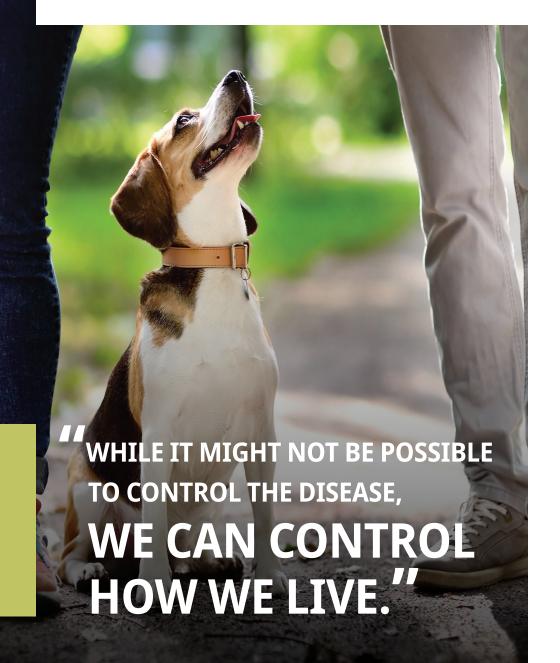


Our goal is to help you craft your journey, whether it's for yourself or for a loved one.



This book is written for people who have dementia and their loved ones who are in the important position of helping them. The first three parts of this book—pre-clinical, stage one and stage two—are written for the person who has been recently diagnosed. Sections three through five are written for the person who is offering care and support or acting as a power of attorney for someone who has been diagnosed.

Cognitive decline happens because of many different reasons. For simplicity, in this book we refer to Alzheimer's disease because it is one of the most common causes of dementia.

In creating this book, we thought, "What if this were me? What would an informed friend make sure I knew?" The product is a friend's guide to helping you navigate this disease in the most proactive way possible.

This booklet is not meant to be a medical guide or the last word on Alzheimer's. Instead, this guide is meant to give you some tips for navigating your life, based on our experiences. You can find additional information, on the National Institutes of Health's website: nia.nih.gov/health/alzheimers.

As a non-profit memory care community, everything we do is designed to help you whether with resources, classes or if you entrust us with the care of you or a loved one. Call us at (704) 327-3249 or visit AldersgateCCCRC.com to learn more.



### An Ode to Positivity

Congratulations for empowering yourself with information. At this writing, approximately 50 million people around the world have Alzheimer's, and even more people are supporting them. Together we are taking positive steps, collaborating, caring and researching. All of us are doing our best and we look forward to a time when the cure is found. Until then, we have access to a tremendous amount of information, techniques and ideas on how to live with Alzheimer's.

You have been dealt a challenging hand and now the question is, how will you play it? Fear and anger are natural feelings and should be honored. Learning as much as you can about life with Alzheimer's is an excellent starting place. Our best advice is to hold onto pragmatism; focus on what you can do today to positively affect the situation, no matter how big or small.

Pay attention to the thoughts and actions that will create optimum outcomes whether that's in designing your life around Alzheimer's or in the simple tasks of getting up and getting dressed in the mornings. Maintain a long-term and a short-term view.

Practicing self-care, reaching out to others and finding resources available for your support are also excellent starting places. A vast network of people are ready to support you.



### **Part 1. PreClinical**

The physical manifestation of Alzheimer's disease starts in the brain years before Alzheimer's symptoms appear; this is the *preclinical* stage.

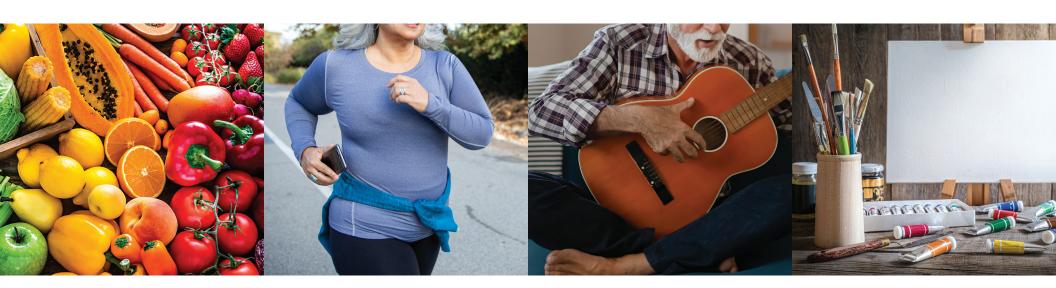
A large body of research suggests a healthy diet, exercise, solid sleep, meditation and giving the brain a variety of new experiences might contribute to the slowing down of symptoms. It's a good idea for anyone to adopt these healthy habits whether or not they have a genetic propensity for Alzheimer's. Even for people with Alzheimer's symptoms, these habits can make a positive difference.

### Diet

Eating foods rich in omega-3 fatty acids, diets higher in protein with a wide variety of vegetables gets you a long way. Easy steps include eliminating processed foods, fast food, trans fats from deep frying, red meats and processed sugars. Design your dinner plate with <sup>3</sup>/<sub>4</sub> vegetables and fruits to <sup>1</sup>/<sub>4</sub> proteins and carbs.

### **Hobbies**

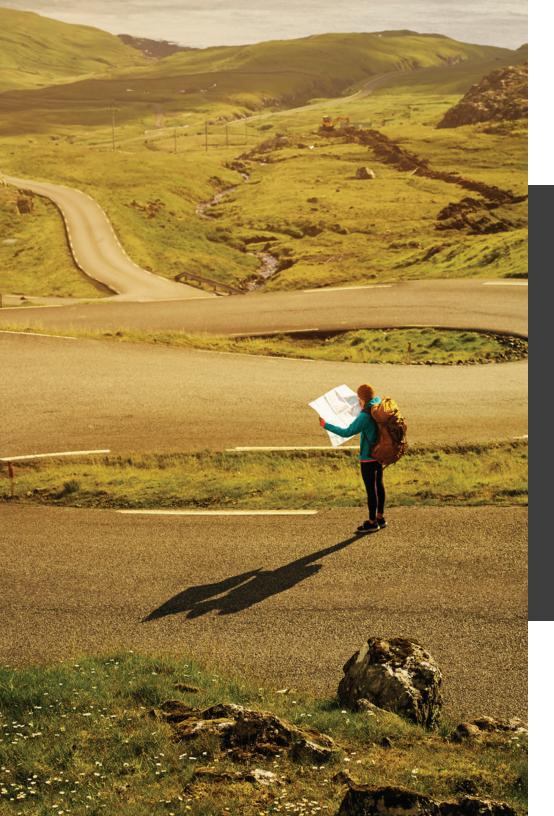
Establishing new hobbies promotes brain plasticity, as does learning new activities. One recommendation is to engage in hobbies and activities that you can maintain if your symptoms of Alzheimer's progress. Knitting, painting, mosaics, crafts, puzzles, and listening to music are a few examples.



### **Exercise**

A regular aerobic exercise routine such as vigorous walking, biking or jogging has been recommended by nearly every research study and institute. Why? It stimulates the brain and promotes brain plasticity. Aerobic physical exercise has been shown to improve cognitive function in elderly persons, with benefits seen in motor function, cognitive speed and attention. So just do it!

While lifestyle changes won't reverse Alzheimer's or cure it, even after the diagnosis, it can help to slow the progression. That's why we encourage everyone to create a lifestyle that is conducive to positively impacting our brains.



# Part 2. Early Stages

Helpful advice for what to do first upon being diagnosed and in the early stages of Alzheimer's.

An Alzheimer's diagnosis is life changing and will bring with it a myriad of emotions. And even though you probably know people who've had similar diagnoses, it's difficult to understand how Alzheimer's will affect you.

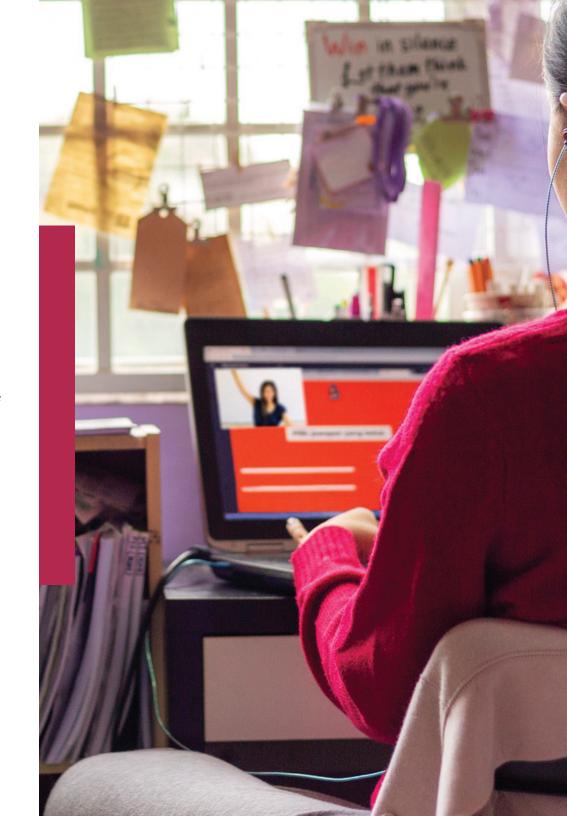
In the early stage of Alzheimer's, a person may function independently and live a very fulfilling life, especially with a healthy diet, exercise and mindfulness. He or she might still drive, work and be part of social activities. Despite this, the person might feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

### **Early Stages**

Symptoms might not be widely apparent at this stage, but family and close friends might take notice. A doctor can administer different tests to determine if your symptoms are consistent with Alzheimer's disease or another type of dementia.

Upon diagnosis, it will take time to understand how you're feeling. Speaking openly to close family and friends can be helpful. They might have questions, or not understand Alzheimer's, and so you might invite them to join you in learning more. Another helpful way of understanding your emotions is to journal about how you're feeling.

Speaking with others who have been diagnosed with Alzheimer's disease can also be helpful. Thanks to the work of Alzheimer's advocacy groups, the mystery and stigma of having Alzheimer's has diminished over the years, and more support groups are available. A lot of information on the topics of medicine and research is also publicly accessible. There are even available services that provide tips and tools for living with Alzheimer's, such as home renovations or home health care.



### **Write Your Pathway:**

You are in the driver's seat. Others living with Alzheimer's before you have created a lot of helpful tips.

- 1. Home Design: Use contrast and color to help navigate. Change light switches to a high contrast color and label "ON" and "OFF" in large letters. If mirrors become a challenge remove them from the household and redecorate with framed images of friends and family, or photos that spark positive feelings. Change lamps to be touch lamps. Consider changing kitchen cabinets to clear fronts.
- **2. Command Center:** Add a large bulletin board by your dining table or kitchen to use as a command center for reminders. Create a designated area here to place your glasses, keys and cell phone.
- **3. Dates & Appointments:** Use an oversized calendar and locate it near the comand center bulletin board.
- **4. Contact List:** Create a phone number list that includes a photo of each person you call.
- 5. Household Cleaners, Water Temperature: Place household cleaners in a locked area. Lower hot water temperatures to 120 degrees.
- **6. TV Remote & Telephones:** Get a TV remote like the *Flipper*<sup>TM</sup>

- designed to make accessing television easy. Choose a new cell phone like the *RAZ*<sup>TM</sup> and consider an Alexa or Echo for the home.
- **7. Home Location.** If your current home is in an area that requires driving to get anywhere, consider relocating to a neighborhood that offers walkable streets and shops. You'll want to be able to walk to nearby destinations.
- **8. Fence Your Yard:** Outdoor time is especially good for people with Alzheimer's. Living in a home with a fenced yard and outdoor activities such as a garden, a work bench and outdoor seating will be helpful. Having a lockable gate will be a key to keeping yourself safe in the future.
- **9. Get a Bicycle:** As driving no longer becomes an option, riding a bicycle can be your new mode of transportation, assuming you live in a bike-safe neighborhood. Download an iPhone App similar to *AllTrails*, a hiking application that tracks your trail so you can backtrack.
- **10. Use Uber or Lyft:** Practice using these rideshare services as a potential alternative to driving.
- **11. Get a Medical Alert Bracelet:** These bracelets now come in beautiful designs, and can be critical for helping people or medics who want to help you get home if lost.

### Next, organize your plan of action.

While you're healthy, and of clear mind, it's important to formally write your end-of-life plan. End-of-life planning has four components:

1) completing an advance directive (AD) or living will, 2) appointing an individual with durable power of attorney for health care, 3) having a document outlining your distribution of assets, and 4) specifying your preferences for the type and place for your care.

• Declare a Power of Attorney: Work with an attorney to designate a first, second and third in line power of attorney to handle your financial and medical affairs. Completing this process early will minimize the possibility of confusion or family friction about who is in charge. Be sure to distinguish the difference between designating somebody who is simply close to you, such as a spouse or a child, and somebody you know and trust. You want to appoint someone who can honor your medical wishes. Trustworthiness is a baseline, but other important characteristics to look for include intelligence, positive assertiveness, the ability to clearly and calmly articulate on your behalf and somebody who is willing to take the time and go the extra mile to ensure you are in the best care.

- Decide when to stop driving. Talk with a trusted friend or family member for signs to recognize. It will be easier if you make that determination before the disease progresses and will make it easier on your loved ones if they know they made the decision based on your wishes.
- Your Finances: Gather all sources of income and assets for your legal power of attorney, who can be different than your medical power of attorney. Give them clear instructions on the level of discretion you desire they use with partners, siblings and/or family members. Make a financial plan about care costs you might incur in the future. If you will need financial assistance for care, research it in advance, before you need care.
- Plan Your Future: Many people choose to "age-in-place" and live in their own residence as long as they possibly can. Another option is to choose a continuing care retirement community that offers a full continuum of care. You can move in as an independent living resident and feel assured that assisted living and memory care will be available as you need it. You will want to plan where and how you will live in the later stages of Alzheimer's. See more information on choosing a memory care community information on page 41.



# Part 3. Moderate Middle Stage

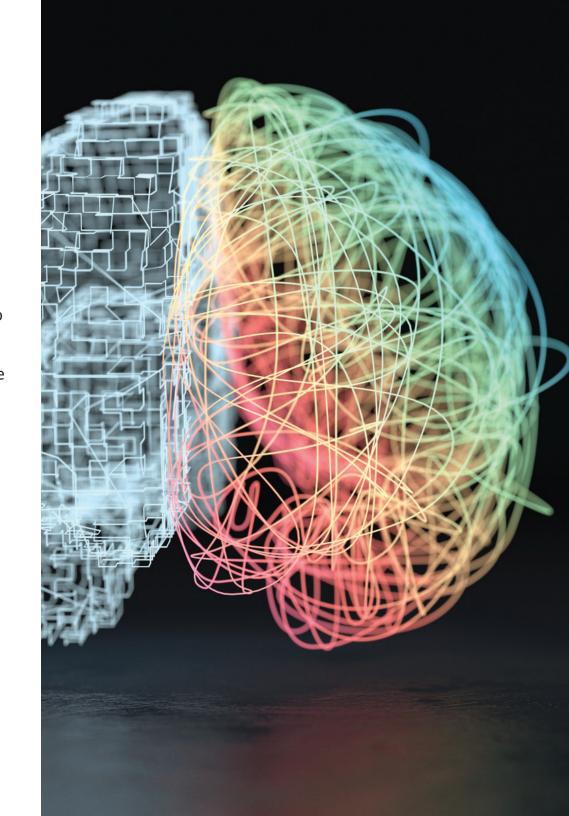
Improvisation is a positive way of living and caring for your loved one.

The middle-stage of Alzheimer's is typically the longest stage and can last for many years. As the disease progresses, the person with Alzheimer's will require a greater level of care.

# During the middle stage of Alzheimer's, dementia symptoms are more pronounced.

The person might confuse words, get frustrated or angry, and act in unexpected ways, such as refusing to bathe. Because the chemistry of the brain is changing, a person's personality can change. This can become very frustrating for the individual because it can also become difficult for the person to express their thoughts and perform routine tasks without assistance. Losing control of your body and your mind can be embarrassing and scary for the person who is diagnosed, so to set them at ease it will be important to decide what matters and what doesn't. When the person with Alzheimer's isn't "making sense" decide if you should correct them or if let it go. Here are a few suggestions:

- Whether the person is accurately describing something. If they are talking and believe they make sense, go along with it and be pleasant. Continue the conversation and speak with them.
- Whether a person can remember what just happened or where they are. Correcting the facts can erode their self-esteem, so be patient and accept their version of reality.
- Whether they feel like partaking in old routines or rituals. Recognize
  they may no longer want or recognize their old routines and seek
  help if it interferes with their ability to carry out activities of daily
  living (e.g., bathing, dressing, eating)



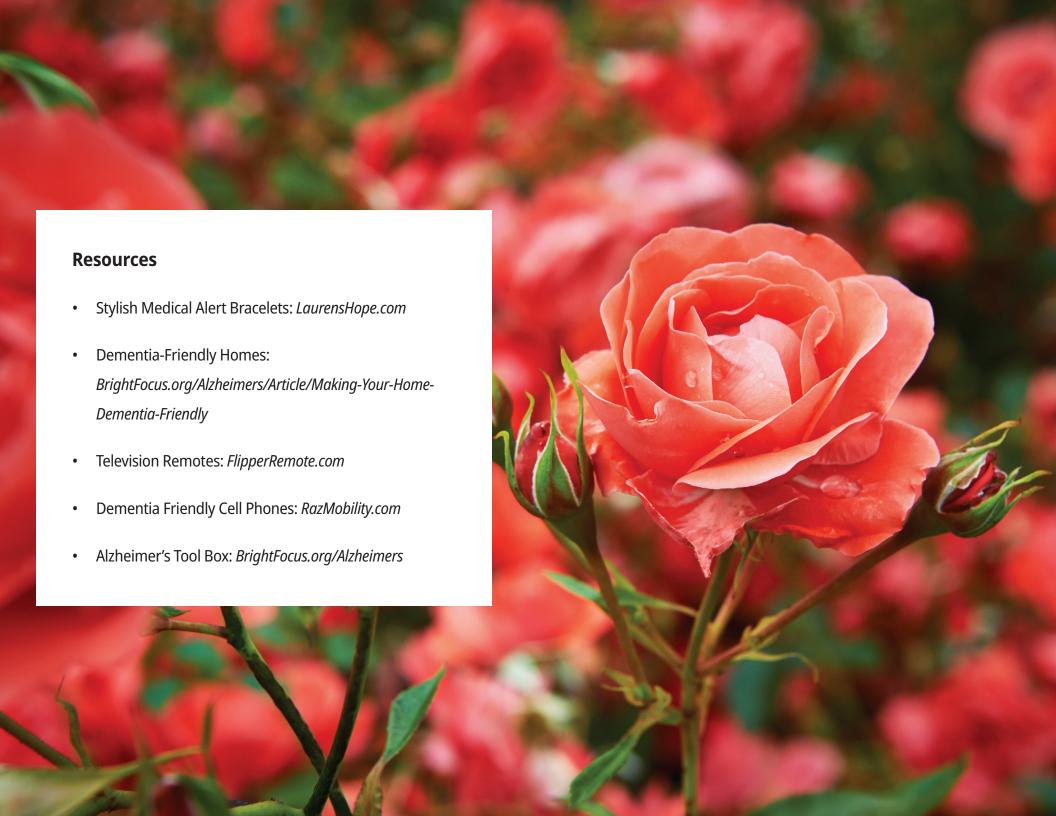
# It can be difficult for everyone involved to accept changes in routines.

A person with Alzheimer's might think they are still well enough to drive to the store or iron a shirt, making it challenging for loved ones to take away the freedom of certain tasks. During the middle stages of a loved one's disease, try to divert their desire to partake in unsafe activities. Instead, distracting them by spending time doing a favorite hobby might divert their attention away from the activity that posed a danger.

When needing to get things done, try rephrasing your requests. Rather than ask if they want to take a shower – which will likely be answered with a "no," try asking, "Do you want to shower now or would you like to shower in 10 minutes?

Also keep in mind that a person with mid-stage dementia might begin to rely on someone to help them compensate for the loss of a word, name or place. This might be a spouse who finishes a sentence or an adult child who knows what they are intending to say.







## **Part 4. Late Stages**

### **Watch for Changes**

If you see a big change in your loved one being able to recognize you or he or she seems agitated with your company and that change happened very quickly, a call to his or her doctor might uncover something else going on. A change in medication, infections such as UTI (urinary tract infection), even constipation can contribute to changes in behavior. Always notify your doctor if you notice rapid changes in function or behavior.

### **Late Stages**

During later stages of dementia your loved one may call you by another name, may not recognize you, or may relate to you as a younger version of yourself. It can be very disheartening when this happens. As difficult as it can be, honor his or her reality by asking him or her to share what they are remembering. Strive to keep them feeling safe, secure and understood.

If your loved one is remaining at home, it might be helpful to remove clutter and begin downsizing his or her wardrobe. Your loved one might begin to wear layers of clothing on top of each other, like putting a hat on top of a hat or putting a blouse over a jacket. If this happens, slow down and remember their dignity, then gently and slowly help them with proper dressing.

Too many choices are difficult for persons in the middle and later stages of the disease. Reduce their clothing choices to only include their favorite pieces, clothing that is easy to put on and take off.

Buttons, zippers and snaps can become challenging, so try to keep clothing that is easy to pull up and pull over such as slacks with elastic waist bands and tops that are loose fitting.

If you are assisting your loved one with dressing and bathing and toileting, you might want to look for clothing that is designed to make the task easier for the persons receiving and giving care. You can find

stores online that specialize in Alzheimer's and carry products and clothing designed with the needs of patients in mind. Two examples of online retailers include the Alzheimer's store (Alzstore.com) and Buck and Buck (BuckAndBuck.com).

If your loved one begins to get lost easily or is asking to see someone who may have already passed, he or she is likely no longer safe to be alone. They might regress to an earlier time in his life and express a need to go home to see his parents, or call out for a pet that passed away years earlier. She might want to walk to her childhood home, or think she "has to get home before dark." Even though these types of requests might be surprising and confusing to hear, they are very realistic in the eyes of someone in the later stages of dementia.

Despite an altered sense of reality, acknowledge their reality and add to it. For example, some people notice how the companionship of a stuffed toy or robotic animal that resembles an old pet, can be quite comforting to the person with Alzheimer's. Following up conservations with such questions as, "When was the last time you talked to your mom? and "Where was she when you last saw her?" can also be reassuring.

There might be anxious moments. When your loved one feels an urgency to complete routine tasks such as cooking, putting out the

trash, or needing to get the car fixed, this urgency feels very real and very important to them. If possible, use this time to offer your help and prepare, or pretend to prepare, something together in the kitchen. Take them in the car for a drive and let them know the car is working fine because you already took it in for repairs. Simply getting out and enjoying a scenic drive can be relaxing for everyone.

Avoid challenging their sense of reality by correcting the facts with comments like "You don't have to cook for anyone, no one is coming." Or "There is nothing wrong with the car, Dad, you don't even drive anymore." These kinds of responses may initiate anger or increase the anxiety.

Remember to try and stay in the moment with your loved one until you can gently begin to redirect to a conversation or activity that is more manageable.



### **The Caregiving Role Amplified**

The later stages of dementia can be very difficult on the primary caregiver. Bathing, dressing and grooming and other activities of daily living likely require assistance and supervision. Your loved one might need to be convinced to take a shower and will likely need help with washing. She might need to have clothes selected for her and she might need your assistance to get dressed. When these routines require help on a daily basis, it can become very exhausting for the caregiver.

Initially, an individual might only need prompts or cues to perform these tasks, such as reminders to shower or having clothes laid out on the bed. But when your loved one displays resistance to showering or eating and becomes angry and frustrated, look for things that might be causing discomfort or creating irritation. It might be that the chair he sits in while eating is uncomfortable. Or, he prefers the shower water to be warmer, but he cannot communicate that fact to you. To make the experience more pleasurable, try warming the bathroom before shower time, warm a towel by placing it in the dryer, put non-slip bathmats on the floor so his feet are not on cold tile floors. Little details like these can make a shower more inviting.

Even though these daily activities can be challenging, try speaking in a calm voice. Speak slowly and don't move rapidly or try to rush the task. Work on performing activities of daily living at the same time each day.

Establishing a routine might help your loved one to get familiar with what is expected.

Important: If all of the above does not seem to be working, stop and redirect the energy and try again later.

In some cases, dementia patients might exhibit behavior that you have never seen. Profanity might be spoken from someone who would never have used it before. Exhibiting sexual behavior that might be inappropriate such as masturbation or trying to touch you inappropriately can indeed happen. Changes in the brain, as a result of the disease, are responsible for these unusual behaviors. Your loved one likely doesn't understand that what they are doing is inappropriate, and it's unlikely it is on purpose. So, even though these behaviors might cause you some embarrassment, try to respect the person and their dignity, and not hold them at fault.

Stay calm but be firm when communicating that behavior is inappropriate. Do not send a mixed signal by laughing or smiling about the behavior. Show through your body language that this is not acceptable. Firmly say no, shake your head while speaking and use a facial expression that matches your words.

Try to redirect the person by turning on the TV/radio, presenting a

snack or giving them something to fidget with in their hands. Ask for help with a task that may redirect their thoughts—helping to fold towels or matching colored socks. Move to another area of the home to change the environment; it might be something in the space that is triggering the behavior. Keep them busy because boredom may contribute to outbursts of inappropriate behavior.

If the above suggestions fail, you might need to try being firmer by establishing eye contact, raising your voice and using a stern tone while saying "NO, this is not appropriate." Let them know this is not acceptable to you.

Be sure to let others who might be in contact with your loved one know about these inappropriate behaviors so they are not caught off guard. Let them know what they should do if they witness these behaviors. Ask for forgiveness on behalf of your loved one and help the others understand that this is the disease triggering the changes and inappropriate conduct.

To help prevent situations that involve inappropriate touching, try giving your loved one something to hold onto, such as a doll or a stuffed animal or a fidget blanket. This might help your loved one to satisfy the need to touch something.



### **Aggressive Behaviors**

Aggressive behaviors can be very difficult for caregivers to manage. The behavior may be physical and confrontational and you may have to try many times to redirect your loved ones to more appropriate behaviors. In some cases you may not be able to redirect.

In these situations, your loved one might not be able to communicate how he is feeling. Is he in pain? Is he thirsty or hungry? Are his clothes and footwear causing any discomfort? Could he have a urinary tract infection? Is he sleep deprived, tired and irritable?

Is your loved one over-stimulated? If so, try quieting his space to see if that helps. Turn off the TV, and turn on some calming music. Ask people in surrounding areas to avoid talking or interacting with him too much.

At this stage your loved one will likely find it very difficult to communicate through speaking or writing. This can be very frustrating for everyone because they are unable to understand that something is wrong, and you cannot communicate to find out why they are angry or upset. In these situations, it is important to remain calm and patient.

Take a moment to step away if the situation escalates

If you find yourself in a situation where the tension is escalating, allow your loved one to be alone in a room where they are safe. Allow them the space to get through the moment. Speak with his doctor to see if a medication could be causing the aggressive behaviors. Medications might need to be added or adjusted to curb the aggressiveness. Also take time to evaluate your own emotions that might be contributing to the behavior. Your loved one might be picking up on your feelings of frustration. By this point, you might be feeling that it's time to start the process of transitioning the caregiving role to a memory care community.



# Part 5. Tips on Choosing a Long-Term Care Community

How to choose a memory care community and overcome the fear of letting go of your full-time caregiver role.

There is a point when letting go of your full-time caregiver role is the best option. For a spouse who is taking care of a husband or wife, the timing is critical for your personal health. All too often, an older caregiver's health can deteriorate because of the stress and physical demands that come along with caring for a loved one with mid- to late stages of dementia.

### **Tips on Choosing a Long-Term Care Community**

Exhaustion, sleep deprivation and stress can take a toll on any individual. Caring for a loved one with mid- to late-stage Alzheimer's can cause all of the aforementioned. The time to ask for help or to look at future options is right now. If you are just starting to care for someone, now is the time to set up your support team, get involved with your local Alzheimer's chapter and attend a support group, even if you go only once a month. Find a trusted relative or friend to sit with the person you are caring for and make the time to find support and fellowship.

Wherever you are on the caregiver journey, understand that you will likely be unable to sustain the level of care that is needed without it being unhealthy for yourself. Consider getting help. Memory care communities and homes can help with responsibilities 24/7. With this help in place, your responsibilities can return to being a loving spouse, grandparent, adult child, or friend. Despite knowing that the help is needed, it can also evoke feelings of guilt for some people. For these reasons, this time of change is sometimes filled with many conflicting emotions.

Read on to learn how to get information about memory care communities in your area.



# There are three kinds of memory care communities:



Larger communities, nonprofit Life Plan communities and for-profit communities will often offer memory care along with independent living, assisted living and skilled nursing. Their memory care community is within the larger community or could also be a detached memory care center on the campus. Most commonly with nonprofit Life Plan communities, the organization will invest heavily in developing a highly specialized memory care community based on the household model.

These types of communities are fantastic options for married couples because one person might want to live in an independent living apartment while the spouse lives nearby in a memory care unit. You can have as much time as you like with your loved one, but you will not have to do the showers, dressing, medication management and all of the other hands-on care that is needed. This scenario returns some normalcy to your daily routine and allows you to be around others who might be in your same situation or have already had the experience. Fellowship and support are very important.

Larger communities often provide chef-prepared meals, transportation services, housekeeping and activities among other services. Lodging and services range in price, offering different options and monthly fees. Some charge a monthly fee for an apartment or suite, plus level of care cost, based on assessed needs. The price might change as your loved one's care level needs increase. Others might charge an all-inclusive price that is based on the size or location of the apartment or suite.

### **Purpose-Built Memory Care Communities** are

communities that only accept residents who have a memory care diagnosis. These communities can vary in size, with most accommodating 40 to 60 residents. Because these communities are only providing memory care, their staff often has received specialized training. (Although the larger continuum of care communities also give their care teams specialized training.)

Because property developers realize how the design of living spaces can affect our mood and behavior, the interior design of memory care communities can be much more friendly and inviting. Designs often include open doors to outdoor spaces so residents can have the feeling of independence, and wander through garden spaces or sitting areas, while still being in the sight line of the care team. Large living areas and TV lounges are furnished with the residents' needs in mind.

Hallways might form squares that lead back to the same place to aid those who often walk or wander. Some people with dementia find it difficult to sit still and feel the need to be in motion. To ensure safety, alarms or other devices are used on entrances, exits and windows. Most will have fob or key-pad entry to the residences.

Prices will vary depending on your location. Most of these communities offer tiered pricing depending on the suite. Suites might be private with a private bath, or private with a shared bath or shared with a shared bath.

Some will have an all-inclusive care cost while others might base cost on an assessed level of care. Again, within Life Plan communities, they oftentimes offer a specialized memory care community that offers the same.



# What kind of memory care community is Cuthbertson Village at Aldersgate?

In the last several pages, we discussed the different kinds of memory care communities available. Cuthbertson Village Memory Care is part of Aldersgate, a large Life Plan community located on a spacious wooded campus in Charlotte, NC. Aldersgate offers a full continuum of care, including independent living, assisted living, health services, and memory care.

Newly built, Cuthbertson Village is a 180-degree shift from "institutional" care to "neighborhood living." In fact, Cuthbertson Village has no nurses' stations. Instead, care partners wear smart technology devices that allow them to roam freely and engage more frequently with residents. With one of the best team member-to-resident ratios in the state, you can count on your loved one being well cared each day.

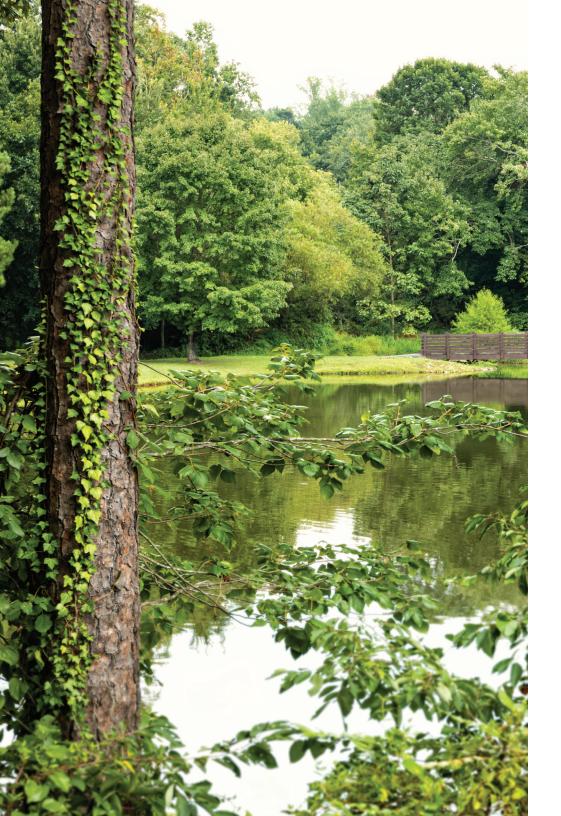
Besides private rooms for residents, each household has a beautiful living area with a fireplace, flat-screen television, open kitchen, private dining area and large outdoor courtyard. At the heart of the household is an indoor atrium providing a bright environment with intimate seating, a chapel, beauty salon, movie theatre and the Hummingbird Café, perfect for events and cooking demonstrations. Socialization is natural in this welcoming environment.



### **Opening Minds through Art (OMA)**

Cuthbertson Village is the only community in North Carolina to offer the ground-breaking Opening Minds through Art (OMA). This award-winning, evidence-based, intergenerational art-making program is for people with neurocognitive disorders. Through OMA, elders express themselves, despite their diagnosis. The projects are intentionally structured to promote the social engagement, autonomy and dignity of the artists with dementia.

To learn more about OMA and Cuthbertson Village, see the booklet's back cover for contact information.



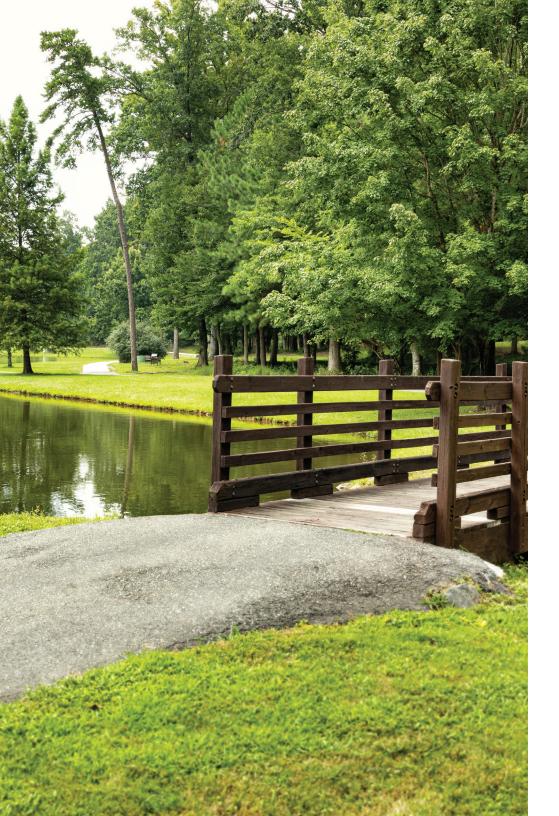
### How can I pay for the care that my loved one needs?

Most all-senior care centers, communities or homes are private pay and vary in price.

Health insurance and Medicare do not pay for long-term care, so be sure to check if your loved one has a long-term care insurance policy. Most all providers will accept and submit the needed paperwork to get the benefit started. This can save you and your loved one the expense of care.

Veteran's benefits might be available to you if you or your spouse served in the military. There are some criteria but a call to your local VA office can get you the information you need to see if you qualify. Most all senior care providers will take veteran's benefits and assist with submitting the paperwork needed.

Medicaid benefits are available for those who qualify. Because each state oversees Medicaid, check with your local Council on Aging to get information about how to start the process and paperwork. Unlike the other benefits we have already covered, Medicaid is not accepted in every center, community or home. Only those who have signed up and been approved can accept Medicaid.



### 25 things to look for when choosing memory care:

- 1. Is the care community licensed with the state for the level of care your loved one needs? *Confirm the licensing.*
- 2. What are the latest state survey results for the care community you are looking at? *Search the web for your state's department of health and look at the latest survey results.*
- 3. Is the care community easily accessible for you to visit often?
- 4. When touring, is the community clean and free of odors? *If you like* a place, go back at different times and during the weekend to get a clearer picture.
- 5. Are the residents clean and well groomed?
- 6. What does mealtime look like? Are there healthy choices or alternative choices for my loved one?
- 7. Ask the community if there is a dining process for serving during mealtimes? Do they focus on quality dining experiences?
- 8. Ask about regular daily procedures for ensuring residents receive sufficient hydration, exercise and socialization. Procedures increase the likelihood of the activities being followed through.
- 9. Ask about philosophies on pharmacological usage versus natural mitigations for acting out.
- 10. Do the staff seem happy, do they smile and speak with you when you are touring?

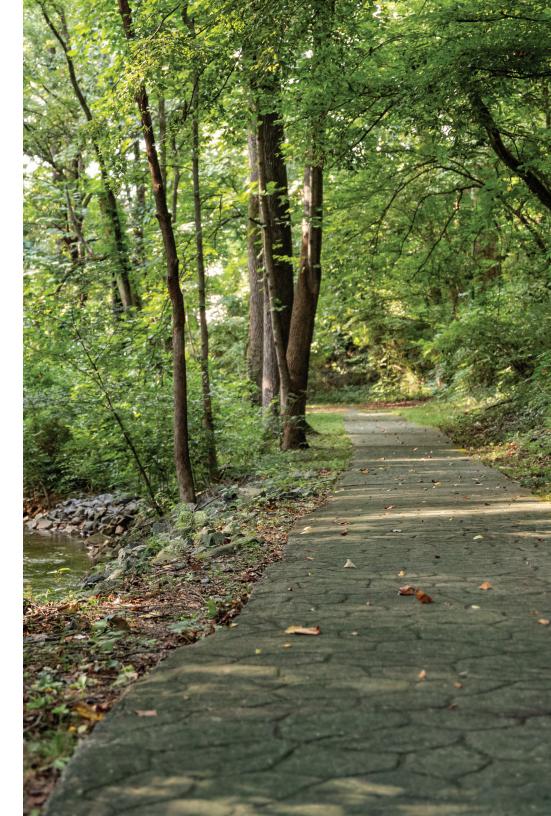
- 11. Are there planned activities for the residents? Ask for the activity calendar and, if possible, attend an activity with your loved one to see how they interact with the residents.
- 12. Do the residents get to enjoy time outdoors? Take them for outings?
- 13. Meet the director or manager of the community and ask how they handle a family member's concerns, how do they communicate and follow up?
- 14. Are there outside provider services that come to the community? Such as visiting physicians, barber/hair stylists, foot and nail care providers, or in-house visiting lab work.
- 15. Who is the management company for the community? *This could* be different than the ownership of the community, and you might want to research the management company information or reviews that you may find helpful. Nonprofit organizations are often the most stable and offer the best quality care.
- 16. How long have the key positions been employed? *This can give you* an idea if there is longevity in the staffing and might indicate that staff are treated well.

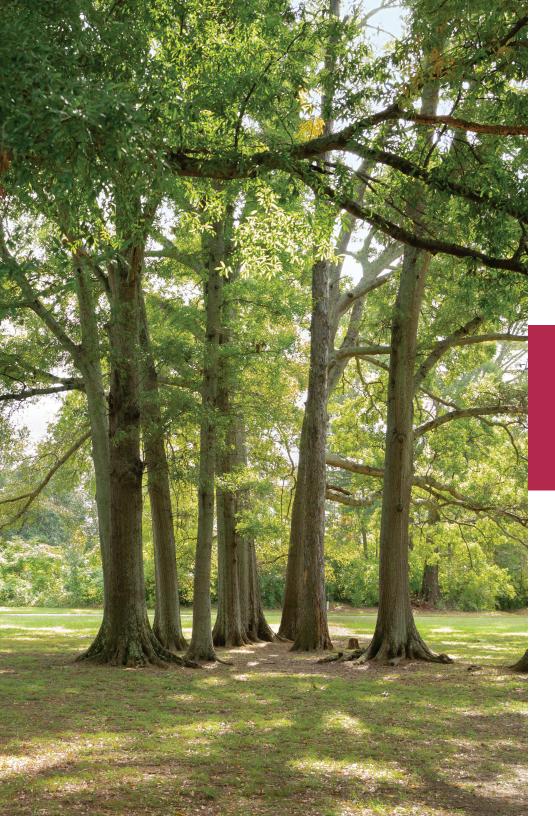
17. How often do they raise monthly fees and what is required as a notice if you choose to move your loved one?

53

- 18. Are there any fees or costs that are going to be charged above the monthly rental/care fees?
- 19. What is the move-in and move-out criteria? Most communities will not allow your loved one to stay if they become a danger to themselves or to others as they do not have the facilities or staffing to work with behaviors.
- 20. How are families notified if there is a fall or change in condition with your loved one?
- 21. What is the protocol if I want to take my loved one out for the day or to spend a night away from the community?
- 22. What are the visiting hours? *(Close family should have access anytime)*
- 23. Are residents allowed to have pets or are there times when pets may visit your loved one?
- 24. How does the community make you feel overall? If it feels right for to you, that is a good start.
- 25. Does this community have a good health & safety record?

It can be very overwhelming to try and research all of this on your own. To make it easier, find a local senior housing placement service that has experience with the local providers in your market. These services are generally free to use and can do a lot of the leg work for you as well as fielding the calls from sales and marketing staff at the communities.





# **Last Stage**

While this booklet has been created to help guide people in how to live with Alzheimer's disease, there will come a time when it's time to go. And while we will not spend a significant amount of time here, we have a few thoughts to share. When thinking about the last stages, we'd like refer to the early stage in this booklet when we discussed assigning a power of attorney. It's at this stage that a person can write their health care directives and have them notarized and registered with the state.

With appropriate care and life support, patients can survive in this final stage for a number of years; however, a number of accommodations might need to be made. For example, if a person loses the ability to eat, chew and swallow food, he or she might require a feeding tube. The decision to accept or decline a feeding tube can be difficult for the caregiver to make, so it's important to anticipate these scenarios early, while the person with Alzheimer's has the cognitive ability to document his or her wishes in writing.

Another point to consider when choosing a community option is how the community will handle the end of life. Will they honor your end of life plan? For example, a Life Plan community or a continuing care retirement community will most likely offer hospice onsite in their skilled center.

# "INDIVIDUALLY, WE ARE ONE DROP. TOGETHER WE ARE AN OCEAN."

## —Ryunosuke Satoro

If we leave you with nothing else from this booklet, it's reassurance that you are not alone on this journey. All of us here invite you to call us at any time for assistance or more information. In the meantime, we are providing a list of trusted resources that we hope will be helpful.

We also want to leave you with a message of hope. Thousands of scientists around the world are working hard every day to find treatments and cures for dementia, and we encourage you to learn about the latest research and treatments by visiting the National Institutes of Health's website.

Thank you.

### Miles from ordinary. Full of extraordinary.

Aldersgate is a 62+, nonprofit Life Plan community offering hundreds of acres of stunning nature. We offer beautiful design, plentiful amenities and a full continuum of care like none other. Close by, you'll find eclectic East Charlotte restaurants in historic, artsy neighborhoods where there's always more to explore.

- A variety of independent living options from stand-alone cottages to a variety of apartments, some brand new, and villas offering a full continuum of care including independent living, assisted living, memory care, skilled nursing and rehabilitation.
- Indoor swimming pool, wood shop, exercise classes, ice cream parlor, dog park, walking trails, lake, salon and spa.
- Six dining venues: The Gatehouse Dining Room, Gatehouse Bar,
   Market Place Café, The Rose & The Ivy Pub, On Common Grounds
   Coffee Shop and Scoops Ice Cream Parlor.
- Asbury Health and Rehabilitation Center on Aldersgate campus has a top rating by Medicare and ranked "Best in Nursing" by U.S. News in 2019.



### Visit our website at AldersgateCharlotte.com.

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