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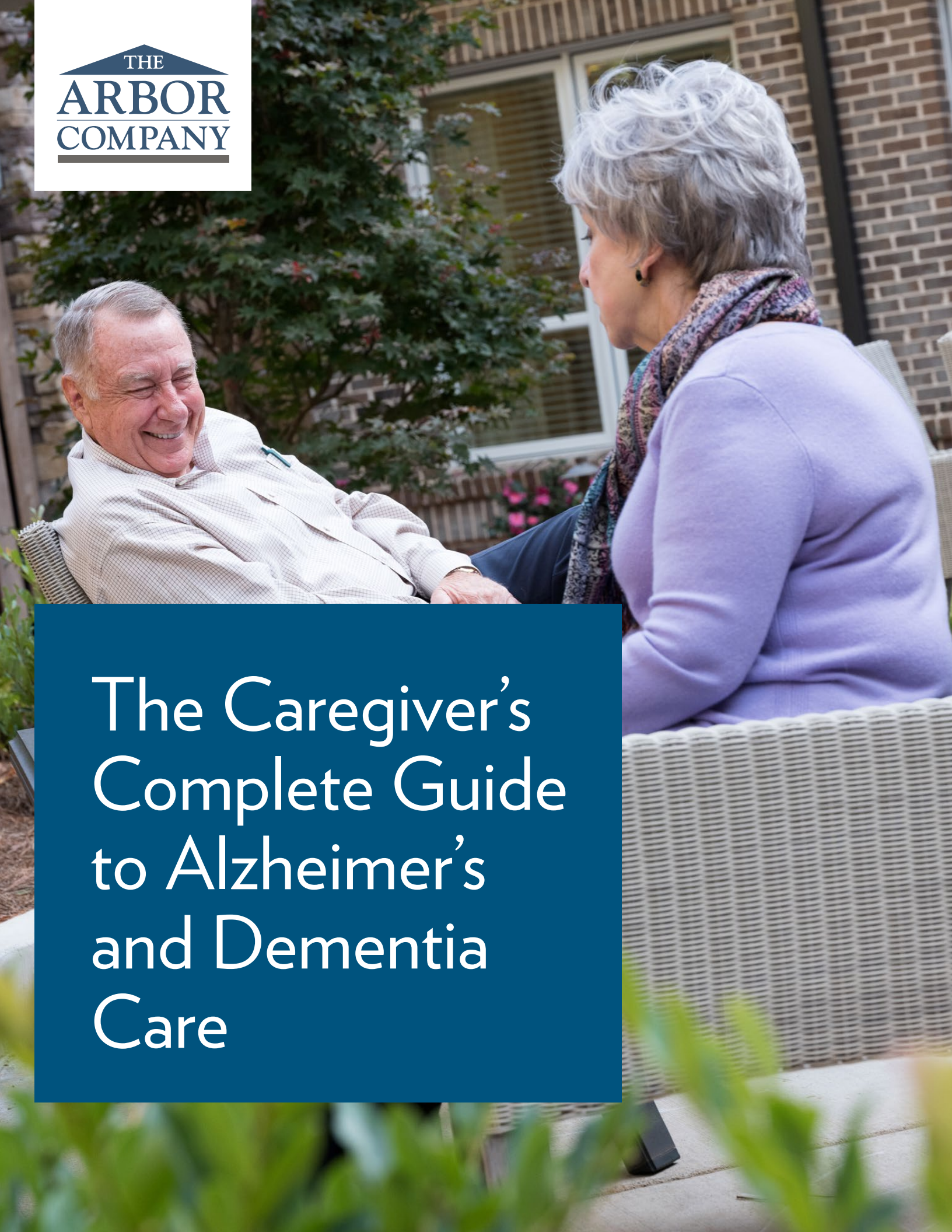

The Caregiver's Complete Guide to Alzheimer's and Dementia Care

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INTRODUCTION

Dementia. It's a scary word shrouded in secrecy and myth. People who have been recently diagnosed with dementia and their caretakers rarely know what to expect. It's tough for doctors to make accurate predictions about this poorly understood group of diseases. That can make it hard to plan for the future.

While dementia can be scary, it also presents an opportunity for a deeper connection with your loved one. Caregiving is tough. It's also profoundly meaningful. You've transitioned from child to adult. Now your parent is transitioning from caregiver to care recipient. This is what you need to know to make the transition easier for everyone.

WHAT IS DEMENTIA?

It's common to hear people use the terms "Alzheimer's" and "dementia" interchangeably, but dementia actually refers to a class of diseases. All dementias are progressive diseases that steadily erode memory and cognitive functioning. Dementia is most common among seniors, for whom age-related brain changes can damage cognition. It's possible, though, to develop early onset dementia. Some dementias, such as primary progressive aphasia, may even affect young people.

The symptoms vary quite a bit, particularly in the early months and years. Alzheimer's disease is the most common form of dementia, affecting an estimated 5.7 million Americans. Other forms of dementia, such as dementia with Lewy body dementia, vascular dementia, Huntington's disease and frontotemporal dementia, are also relatively common. One in three seniors shows signs of some type of dementia at the time of death.

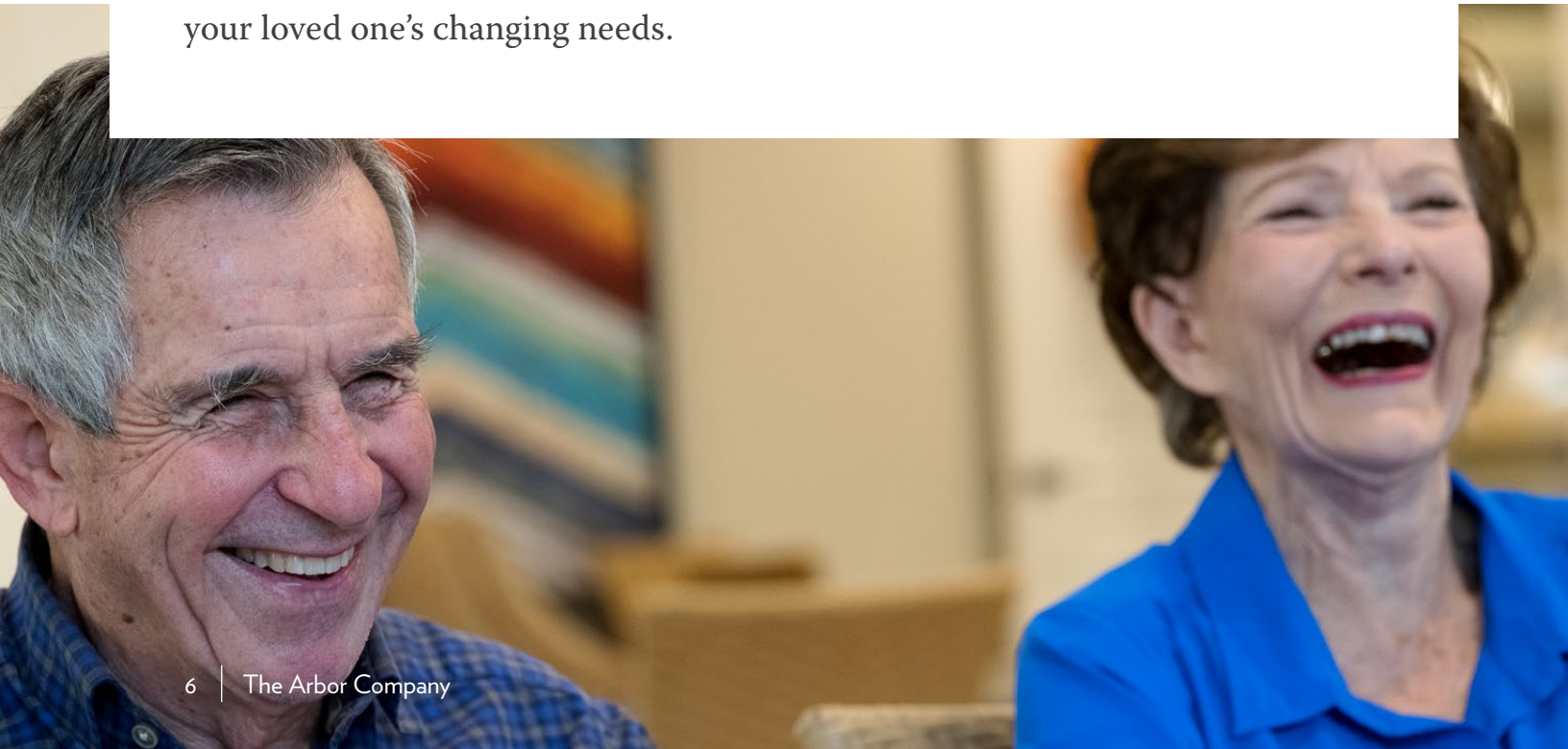
Dementia is most common among seniors, for whom age-related brain changes can damage cognition.

Dementia causes a wide variety of symptoms. For instance, while Alzheimer's disease typically begins with short-term memory issues, frontotemporal dementia's first sign is typically a change in behavior.

It may be helpful to think of dementia as a funnel. At the broad top of the funnel, different diseases show very different symptoms. As dementia progresses and moves toward the narrow part of the funnel, the symptoms of various types of dementia look increasingly similar.

Ultimately, dementia is a terminal illness that affects far more than just memory and brain function. It causes a range of physical ailments, from swallowing difficulties to trouble moving, and is ultimately fatal. However, people can live with dementia for many years. Some survive for decades. It's possible to live for many years without serious symptoms, and the most advanced stages of dementia are usually the shortest.

This can put caregivers and their loved ones in a state of limbo and confusion. They may not know what to expect, or what the future holds. Yet it also means a chance for meaningful time together. Dementia does not have to mean an end to a joyful, fulfilling life. Instead, the goal should be to find ways to accommodate your loved one's changing needs.



WHAT CAUSES DEMENTIA?

Research on dementia is ongoing, and some types of dementia —particularly Alzheimer's — remain poorly understood. Research does show that brain plaques, which are thick protein tangles, tend to be present in the brains of people who have some types of dementia, including Alzheimer's and frontotemporal dementia. As these plaques accumulate, they may make it more difficult for the brain to send nerve signals and encode new memories.

All forms of dementia are due to progressive damage that harms nerve cells. For instance, Huntington's disease is a genetic disorder that causes the slow destruction of neurons in the brain. Vascular dementia occurs in people with decreased blood flow in the brain, often due to a stroke. This can ultimately lead to neuron death.

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With the exception of Huntington's disease, for which there is a genetic test, there is no way to reliably predict who will get dementia and who won't. Some risk factors for dementia include:

- **Alcohol abuse:** Alcohol abuse can cause damage to blood vessels in the brain. It may also kill brain cells. Chronic alcohol abuse is also the most frequent cause of a type of dementia called Korsakoff syndrome.
- **Age:** The single biggest risk factor for dementia is age. The overwhelming majority of people with dementia are over the age of 65. Nearly one in three seniors over the age of 85 has some form of dementia.

- **Family history:** Dementia runs in families. Researchers have identified some genes, including APOE4, that greatly increase the risk of developing Alzheimer's. However, even in a family with many dementia cases, not everyone will get dementia. Genetics aren't the only factor, either. Many people with genes for Alzheimer's do not develop dementia.
- **Overall health:** Research has shown that strategies for improving overall health, such as eating a healthy diet, exercising and remaining at a healthy weight, can reduce the risk of dementia. Some research has even shown that exercise can counteract the effects of genes for Alzheimer's.

Dementia is unpredictable. It's not your loved one's fault. Yet caregivers often worry about their own dementia risk. Even if your loved one has a genetic form of dementia, there is still a good chance you won't get it — particularly if you take good care of your health. That means practicing self-care as the demands of caregiving grow.

Research on dementia is ongoing, and some types of dementia — particularly Alzheimer's — remain poorly understood.

WHAT ARE THE EARLY WARNING SIGNS AND SYMPTOMS?

Dementia is not curable. So many people who have symptoms shrug their shoulders and resist a diagnosis. They don't want to know they have a terminal illness. Yet dementia is treatable. Medications, a supportive environment, and lifestyle changes may slow the disease and keep your loved one safe. Perhaps most important of all, a delayed diagnosis can greatly endanger your loved one's health and well-being. The benefits of an early diagnosis include:

- Time to plan for your loved one's caregiving needs.
- A chance to get finances in order. For example, will your loved one need to apply for Medicaid or tap into retirement savings? Consulting with a financial planner or lawyer now, while your loved one is able to think clearly, can offer significant reassurance for the future.
- A record of your loved one's diagnosis. Insurance may need a specific diagnosis to cover treatment your loved one will eventually need. In some cases, Medicaid offers coverage to people who make more than the maximum Medicaid income if they are "medically needy." So a proper diagnosis is key to accessing benefits.
- Preventing some medical complications. Knowing which type of dementia your loved one has can help you prevent serious medical complications. Some dementias cause difficulties with mobility or swallowing. Planning for and treating these challenges can keep your loved one safe.
- Getting an accurate assessment of your loved one's needs. The early signs of dementia aren't always obvious, particularly if you don't regularly see your loved one. You need a clear idea of their cognitive abilities so that you know if it's safe for them to drive, live alone or be home alone.

Early Warning Signs

Any change in your loved one's thinking, personality, mood or memory warrants a call to the doctor. So it's helpful to know what's normal for your loved one. Depression could be an important warning sign in someone who's always had a sunny disposition, but it might mean little in someone who has always struggled with depression. Some early warning signs to watch for include:

- Problems with short-term memory, such as forgetting things done recently.
- Executive functioning issues, such as getting lost or forgetting how to make a favorite recipe.
- The appearance of confusion during conversation.
- Changes in language.
- Difficulty following stories.
- Increased apathy.
- Changes in sleeping or eating habits.
- Changes in mood or behavior, particularly if those changes seem extreme.

Stages of Dementia

Like other terminal illnesses, it's possible to assign a stage to dementia. Staging gives an idea of how much cognitive decline a person has and what care they might need. Because dementia is unpredictable, however, there's no set time period for each stage. Knowing the stage of dementia doesn't reveal how much time a person has left or how long they will be able to care for themselves. The stages of dementia include:

- **Stage 1:** No notable signs of cognitive decline.
- **Stage 2:** Very mild cognitive decline. Stage 2 describes normal cognitive changes associated with aging. For example, a grandmother might momentarily forget a grandchild's name, or call them by the wrong name.

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- **Stage 3:** Mild cognitive decline. This is the earliest sign of noticeable dementia, and it includes some short-term memory changes. It lasts an average of seven years before full dementia sets in.
- **Stage 4:** Moderate cognitive decline. At this stage, a person may have more trouble with daily tasks. They may continue living alone with help, or they may need some part-time assistance. Managing finances and traveling become difficult.
- **Stage 5:** Moderately severe cognitive decline. By this stage, memory impairments are severe, and a person will need help with daily tasks.

- **Stage 6:** Severe cognitive decline. At this stage, a person with dementia might seem like a totally different person. Memory difficulties are severe, and they may not remember loved ones. They may also begin to experience physical issues, such as trouble controlling the bladder or bowels.
- **Stage 7:** Very severe cognitive decline. By this stage, a person with dementia may lack the ability to speak or communicate. They may appear not to know what is going on, and they will need help with all daily activities. They cannot be left alone, even for brief periods.

WHAT KIND OF CARE DOES SOMEONE WITH DEMENTIA NEED?

Dementia changes over time. Early in the disease, a person with dementia may need no care at all. As the disease progresses, they will need more extensive care. Providing a safe, nurturing environment can help your loved one enjoy their life, keep them safe and even improve cognition. Some factors to keep in mind when preparing your home for a person with dementia include dementia safety, diet and nutritional issues, psychological needs, and stimulation and support.

Dementia Safety

In some ways, preparing your home for someone with dementia is a lot like babyproofing. Unlike a baby, who becomes more competent with time, your loved one will need a progressively more controlled environment. In the early stages of dementia, you may be able to leave your loved one alone for brief periods. As the disease progresses, a person with dementia must have constant supervision.

Providing a safe, nurturing environment can help your loved one enjoy their life, keep them safe and even improve cognition.

Some important things to consider when assessing safety issues include:

- **Driving.** Is it safe for your loved one to drive? Can you block their access to a car?
- **Cooking, electricity and fires.** A failing memory means your loved one might forget to turn off the stove or blow out a candle.
- **Nutrition.** Your loved one might forget to eat, or forget that they just ate. Help them remember to eat regularly.
- **Wandering.** In the later stages of dementia, some people begin wandering. This can be especially dangerous in neighborhoods with heavy traffic. Walk together instead, and take proactive steps to prevent wandering. Know that your loved one might even go wandering at night, when everyone is sleeping.
- **Aggression and fear.** Consider how you might feel if someone you didn't recognize came into your room, demanded you take off your clothes and attempted to make you shower. That's how people with dementia often feel when they can no longer recognize their loved ones. Fear can make your loved one behave erratically, and even aggressively. Be sensitive and patient, and don't push them to do things unless they're absolutely necessary. There's probably no reason your loved one needs a daily shower or a fancy hairstyle.

Diet and Nutritional Issues

The need for good nutrition doesn't end with dementia. In fact, a poor-quality diet can worsen the symptoms of dementia. So it's important to help your loved one eat a healthy, balanced diet.

Some people with dementia get unusual food cravings. It's also common for them to crave strong tastes, since dementia can dull the senses. Don't be surprised if your loved one wants a lot of very spicy or sweet foods. It's important to choose your battles here. Your loved one is struggling with a terminal illness. So while it's important to keep them healthy, it's also important to allow them some small pleasures.

Some strategies for good nutrition include:

- Involving your loved one in food preparation.
- Offering a wide variety of healthy foods, but allowing your loved one to choose what they eat.
- Giving your loved one nutritional supplement drinks, such as Ensure or Boost.
- Offering nutrient-dense smoothies. Try protein powder blended with frozen berries, avocado and a banana. Add some honey for flavor.

As dementia progresses, your loved one may have difficulty swallowing. Dementia can undermine the swallowing reflex or make it difficult for your loved one to remember to swallow. Some people hide food in their cheeks, choke or attempt to swallow food whole. Others begin refusing to eat. Consult your loved one's doctor for help. They may need swallowing therapy. In some cases it's necessary to switch to a liquid diet.

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Psychological Needs

The fact that your loved one is no longer able to do specific tasks, like driving, will not remove their desire to do those tasks. Likewise, the fact that a person needs more support to explore the world does not mean they no longer want to be a part of that world.

Seniors with dementia are just like everyone else. They have interests and psychological needs, particularly in the early stages of dementia. Try planning outings with your loved one to help them enjoy the activities they once enjoyed alone. Adult daycare, classes at your local senior center and access to plenty of home-based activities can be helpful.

As your loved one's cognition declines, they may be less able to do activities they once loved. The avid gardener may now prefer to simply look at or pluck the petals from roses. Try to find ways to incorporate once-beloved activities into your loved one's life. You might also try some new activities that require fewer cognitive resources. Some great options include:

- Adult coloring books.
- Painting, sculpture and other art forms.
- Listening to music.
- Listening to the radio or watching TV.
- Putting together simple puzzles.
- Spending time outside watching the birds.

Stimulation and Support

Dementia is painful to watch. It's even more painful to experience. In the early stages, your loved one may be plagued by anxiety and depression about the future. Consider talking to their doctor about medication that may help. People with dementia may also benefit from therapy and support groups.

As dementia progresses, it's common to feel isolated and scared. Help your loved one spend time with family members. Give them lots of affection, and most importantly, follow their lead. If they want to spend time alone, allow them to do so. But if they appear anxious and needy, find ways to give them more affection, support and time.

Family therapy can help your family find ways to meet your loved one's needs without draining your family's emotional resources.

When Is It Time for Senior Care?

Dementia looks different in every senior. Some seniors have a slow decline and ultimately die of something else before end-stage dementia. Others spend many years in a state of severe cognitive decline. Likewise, some families have the emotional, financial and seasonal resources to provide 24/7 care to the very end. Most don't.

There is no surefire signal that it's time for senior care. It's normal to feel conflicted and uncertain about this decision. To help make the decision, ask yourself two simple questions:

1. Am I able to provide the care my loved one needs? If you can't meet your loved one's needs, if they are frequently getting injured or if your home is not safe for a person with dementia, it's time for a higher level of care.
2. Can I care for my loved one without harming myself? Don't take pride in destroying your own life to care for your loved one. Many families find that their relationship with a loved one actually improves when someone else begins providing care. Your well-being, your finances and your family's health do matter. If you can't care for your loved one while also caring for yourself and your family — and doing some things you enjoy — it's time for senior care.

WHAT DEMENTIA CARE GIVES YOU

Dementia care provides your loved one with a safe, secure, nurturing environment. It provides plenty of opportunities for socialization and enrichment, all within a home environment that provides monitoring and greatly reduces the risk of serious accidents. The best dementia care communities offer these advantages:

- Nutritional resources. This includes a variety of delicious meals tailored to many different health conditions. Dementia care communities also offer help with swallowing issues and encouragement to eat healthy foods.
- Family support. Meet with a care counselor, learn about dementia or attend a family support group.

- A variety of enrichment activities. From dancing and yoga to arts and crafts, your loved one will have a chance to participate in a wide range of activities.
- Supportive care. Your loved one will receive care from a skilled team of experts, rather than from a single family member. This means there's no burnout or frustration — just gentle, loving care.
- A completely safe environment. No longer do you have to worry about your loved one's safety. They'll get plenty of socialization and lots of enrichment, but without having to worry about driving or taking other needless risks. Because your loved ones will be more stimulated, they'll also feel less desire to wander. If they do, the gentle staff at a dementia care community will ensure they remain safe, not frightened or confused.

Dementia care is different from traditional senior living because it offers comprehensive, 24/7 care from dementia experts. This approach to dementia meets your loved one's social, nutritional, psychological and health-related needs all under one roof.

Many caregivers find that quality dementia care greatly alleviates the challenges of caregiving. This frees them to enjoy a mutually beneficial and nurturing relationship with their loved one again. Instead of spending their time fighting about showers or worried about safety, they can enjoy family games, music, reminiscing or just quiet time in calm contemplation.

HOW TO MAKE THE TRANSITION TO DEMENTIA CARE

If you're ready to begin researching dementia care options, a number of sources can point you in the right direction. Consider asking friends, a doctor you trust or a local senior center for a referral. Then take time to research your options. Read online reviews, and look at factors such as location. Consider how easy or difficult it will be to visit your loved one at each community you consider. Then dig around on the community's website. Do you like what you see? Do they offer the services your loved one needs?

This preliminary search can help you narrow your list down to a number of excellent options. The next step is to visit the communities in person. Try eating a meal on-site to get a feel for the food quality and social culture. Then ask lots of questions about daily life. Don't shy away from talking to family members visiting their loved ones. They may be a rich source of knowledge about the community and about dementia care in general.

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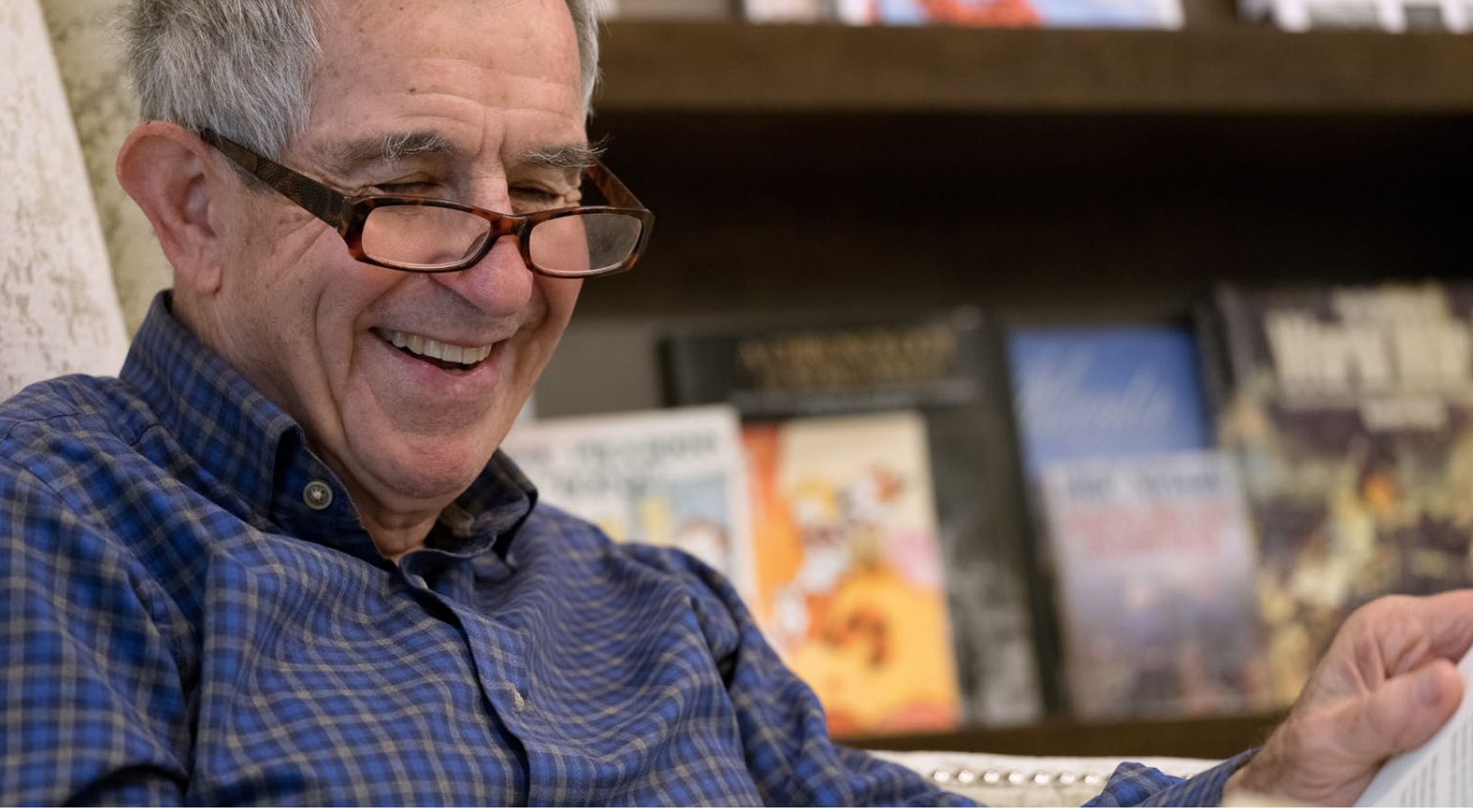

Take your loved one with you on the tour. Even if they can no longer speak, their reactions to various communities can help you choose the one that best meets their needs. This is their future home, so it's important to ensure it's a good fit.

Don't be surprised if you get some pushback from other family members. Many families believe it's best for people to age at home. The problem is that the family members who most strongly advocate for this position are rarely the ones providing daily care. They don't know how challenging dementia can be. They don't understand the daily needs of a person with dementia. So don't allow their judgment to influence your decision. As a caregiver, it's your responsibility to use your experience in making the best decision for your family. Guilt should play no role in this decision.

Once you decide on the perfect dementia care community, it's time to begin the transition. Many caregivers are surprised that the transition is more difficult for them than for their loved one. People with dementia may welcome the transition to dementia care because it means more enrichment, more socialization and fewer disputes with family members. Even so, you can help to make the transition as smooth as possible. The following strategies may help:

- Visit the community with your loved one several times before the move.
- Talk to your loved one about the move. Even if they appear not to understand, repeating the same message can help prepare them. They may understand more than you realize.
- Pack some of your loved one's most treasured possessions. A family photo, a beloved blanket or stuffed animal and favorite music can all help them feel more at home.
- Talk to the community about strategies for making a smooth transition. They may have a welcome team or offer specific tips tailored to your loved one's needs and ability level.

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- Visit your loved one as frequently as you can. Include other family members and friends in the visits. If you feel overwhelmed by frequent visits to your loved one, consider a visit chain. Rather than all visiting at once, have each family member visit on a different day.

Dementia care can be life-changing for tired caregivers and their anxious loved ones. So give it time. Ask for help when you need it. And rest easy, knowing that while dementia care is a great choice, it's also normal to feel a little conflicted about the decision. Being a good caregiver means knowing when you can no longer do it on your own. So feel proud of your decision to get your loved one the additional care they need.

HELPFUL BOOKS AND RESOURCES

Knowledge is power. The following books offer valuable insights and can help you feel less alone:

- What if it's Not Alzheimer's? A Caregiver's Guide to Dementia ➡
- Mike & Me: New Hope for Alzheimer's Couples Everywhere ➡
- Dancing With Elephants: Mindfulness Training for Those Living With Dementia, Chronic Illness or an Aging Brain ➡
- The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss ➡
- The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer's Disease and Other Neurocognitive Disorders ➡
- The Dementia Handbook: How to Provide Dementia Care at Home ➡
- Let's Talk Dementia: A Caregiver's Guide ➡
- The Ally Bally Bee Project ➡

Support groups offer many resources. Find a caregiver support group through the Alzheimer's Association.

The National Institute on Aging offers a wide variety of resources, including details on dementia clinical trials, help in finding senior care and legal information. For help with legal issues like estate planning or advice about whether or when to apply to Medicaid and Medicare, find a lawyer through the National Academy of Elder Law Attorneys.

Arbor is proud to support seniors and their families at all stages of dementia. We can take the stress out of caregiving, allowing you to enjoy your relationship with your loved one. To learn more, contact one of our local Arbor communities to schedule a tour.

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Need help exploring dementia care options? Arbor is here for you. Read about various levels of care, and how to choose the right one for your loved one, in our Comparing Dementia Care and Living Options guide.

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