Dementia

What You Must Know to Protect Your Loved One

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Introduction

Dementia is, without question, an unforgettable disease. It is one that ravages both the mind as well as the body, and often leaves family members feeling distraught, helpless and alone in its wake. If you or someone you love is in this position now or may be in the future, then this book is for you.

It is our hope that the information contained within will provide you with a better understanding and knowledge of the road that currently stretches onward before you. Our hope extends far beyond just that this book provides you with necessary information, however. Rather, we also hope that it will, perhaps in some small way, bring comfort to you and those around you, as well as anyone else who may be involved in the journey ahead.

We know that information on such a diverse medical topic can oftentimes be more than a little difficult to digest and retain, so to that effect this book has been written to be both informative and entertaining—to help ease any tension you may be feeling about the situation but also to help with retention, because there certainly is a lot of information.

The road that lies ahead of you will be tough, but it is important to remember that you are not alone. There is help, and a great many resources are available to you.

It is our hope this book will be one of them.

Chapter 1: Is it Really Dementia?

We face challenges from the time we are born until the time we die, and during all the time between. It is an inevitable part of the human experience. When we are young, we struggle with the simple things like learning to walk, talk, and understanding the difference between right and wrong, among a variety of other things.

As we grow into adults, the things we struggled with in younger years suddenly don't seem so difficult, while things like graduating college, picking a career, and subsequently spending a significant portion of our lives in that career, while also potentially balancing family and other responsibilities present significantly more challenge than anything we'd faced prior to that point, and makes the things we faced before seem like a walk in the park by contrast.

Older adults are faced with even *more* challenges—many of which are things that younger folks take for granted every day—like mobility, physical health and most other daily activities of life. And chances are good that if you are reading this, you or someone you love is facing an even greater challenge than that—

Dementia.

Just the sound of it lingering in the air in front of you may conjure up a variety of images in your mind. Perhaps you think of nursing homes or hospitals, filled with people who, because of just such a diagnosis, have lost all hope. Maybe, when you hear that word, you don't really know what to think and your mind is filled to the brim with nothing but confusion and questions. No matter what you think of, however, the one thing that many people can agree on is that getting a diagnosis of dementia (or any other big health issue for that matter) can be, and is, very scary and confusing.

The trick to dealing with scary and confusing things is to make them not scary and not confusing. But how to do that? You learn what exactly it is you're dealing with. Like a fighter training for a big match, you and your family must train and learn your opponent and their weaknesses inside and out. That means to define what exactly dementia is. Then, while you might still see the effects of the disease, you will have stolen from it the most effective tactic it has over you and your loved ones: fear.

In this chapter, we'll take a look at some of the basics of Alzheimer's and dementia, some do's and don'ts when it comes to figuring out if either is the correct diagnosis, we'll go more in depth on some things you need to know about each. This chapter will also cover the different types of dementia (and there are many), including symptoms and changes in the brain, and finally, we'll finish up with a summary of the disease. As you can see, we have a lot to cover, so let's get started.

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Basics of Dementia and Alzheimer's

Most everyone has heard of both dementia and Alzheimer's at some point in their lives. But since both diseases have to do with the brain and seem so similar, most also are very confused when it comes to defining them, which, as you know, is crucial to learning how to combat the problem. So just what *is* dementia, and does it differ at all from Alzheimer's?

The truth is that **dementia is a general term for a decline in mental ability bad enough to interfere with daily life**, however, it is *not* a specific disease. Rather, it is an umbrella term, one that describes a wide range of symptoms that are often associated with declining memory or other cognitive skills that are severe enough to cause a reduction in someone's ability to perform everyday tasks. Alzheimer's, meanwhile, accounts for anywhere from 60 to 80 percent of cases, making it the most common form of dementia. Vascular dementia, which can happen after a stroke, is the second most common type, but there are a variety of other conditions that can mimic or cause symptoms of dementia, including several that are reversible, such as thyroid problems or vitamin deficiencies.

But before we dig deep and really get into the ways dementia and Alzheimer's can affect us, let us first take a look at some do's and don'ts when it comes to determining whether someone's change in demeanor or their intermittent forgetfulness is just a normal part of aging, or if it's something more serious like dementia or Alzheimer's, or even if it really matters whether you call it either name if it is.

We've already said that dementia is an overall term, while Alzheimer's is a specific one, but if Alzheimer's *is* dementia, isn't that the end of it? Case closed?

Not quite.

Even after watching our loved ones decline from the manifestation of utter physical and mental health into people we don't recognize—people who were once so polite and had the memory of an elephant are now unbearably rude or forgetful—even then, a great many of us don't ever find out exactly what is causing the sudden drastic change of behavior in those we love. Many of us just learn to deal with the effects of such things, even when they've long become impossible to ignore.

What's more, as of the spring of 2014, the term "dementia" was officially changed to "major neurocognitive disorder" according to the DSM-5, which is the diagnostic bible used by psychiatrists. Major neurocognitive disorder should not be confused with mild cognitive impairment (or MCI), which has the possibility to evolve into Alzheimer's, which used to be called pre-dementia.

It's really no wonder that people have so many questions when it comes to determining if someone has dementia or if they're literally just getting older. Part of the reason for all the confusion has to do with the multitude of specific cognitive disorders that litter newscasts these days: diseases like Lewy-Body disease, Benson's syndrome (a variant of dementia) and another brain disease called Pick's just to name a few.

So, to help ease all of that, let's take a look at a few things that you **should** do as well as some you **should not** when it comes to determining dementia:

DO

- **Distinguish between "normal aging" and "something's not quite right here."** While it *is* true that a person's risk of getting Alzheimer's increases with age, it's also true that thinking skills slow down with age as well. However, biomarkers that are associated with Alzheimer's (and thus dementia) are thought to be distinct from the way a brain normally ages. However, a multinational survey from the Alzheimer's Association revealed that a whopping 60% of people believed erroneously that Alzheimer's was simply a natural result of getting older.

DO

- **Explore the cause of worrisome symptoms.** Even if you think you don't because you're afraid of the answer, you'll still want to, understandably, find out what's going on when your loved one suddenly becomes forgetful or develops other worrisome symptoms. In many ways, it's just as important to find out what the problems **are not**. This is so doctors and others can rule out or treat any other possibly causes that they know how to properly deal with. For example, symptoms of dementia that are caused by things like delirium and dehydration are resolved when the issue causing the problem is taken care of. Even progressive dementia, caused by things like Parkinson's, alcoholism, or a brain injury, it's important to treat the issue in all ways possible. As we mentioned earlier, in order to help clear up the confusion, you have to know what you're dealing with.

DO NOT

- **Get hung up on an exact name.** You don't obtain a diagnosis in order to label a person with one thing or another. No matter if it's Alzheimer's or vascular dementia, or Lewy-Body, a great many of your loved one's symptoms and all their care needs are very likely to remain the same. Though there *are* some differences, in most cases, knowing the specific name isn't going to make a person magically remember how to get dressed in the mornings or keep them from wandering from home and getting lost.

DO

- **Consider what may be behind a name.** Part of the reason why there's been such push for a more precise naming of such diseases has to do with the sorting of subjects for the purposes of researching them. When they can identify changes in the brain better than before, researchers are able to get more accurate insights into how drugs or other therapies can help. Many also say that giving a more accurate name, like major neurocognitive disorder can help to lessen the stigma behind the disease, since people tend to fear words like dementia (and demented) and Alzheimer's. So, what's in a name change? Consider this: in China, they're pushing to change the character symbol for dementia. Currently, it's represented by two characters that translate to insane and idiotic. And in Japan, they switched from characters that roughly translate to crazy person to ones meaning brain disease back in 2004. The results were less stigma behind the disease and more openness to getting needed treatment and support.

Now that we've seen the differences between Alzheimer's and dementia, and learned what to do and what not to do when making the determination one way or another, let's next go a bit more in depth into each and look at some more things that you need to know.

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As we've seen, there is a difference between the normal effects of aging and suffering from a disease like Alzheimer's or dementia. However, most of the symptoms associated with the disease normally develop over a period of time and gradually get worse as time goes on, until it becomes serious enough to disrupt activities of daily life. However, because those symptoms occur gradually, it can be difficult to determine what exactly is going on. So, the first thing to note is that **Alzheimer's is definitely not a normal part of getting older**, nor is it merely *just* a disease related to old age. As mentioned earlier, while getting older is indeed one of the greatest risks of developing Alzheimer's, and the majority of sufferers are aged 65 or older, it can also happen to those who are younger. In fact, up to 5 percent of people with the disease experience early onset Alzheimer's (also called younger-onset), which can occur as early as someone's 40s or 50s.

Another thing to remember is that Alzheimer's is a progressive disease that **worsens over time.** While in the early stages of the disease, one may experience things like mild memory loss, late-stage sufferers can lose their ability to hold a conversation completely or even become unable to respond to their environment. What's more—Alzheimer's is the sixth leading cause of death in the United States, and those who have the disease have an average of eight years to live after their symptoms become noticeable to others, but survival can be anywhere from four to 20 years, depending on things like age or other health conditions.

Finally, it is important to remember that **Alzheimer's has no current cure, though treatments are available for symptoms, and research is continuous.** Though any current treatments now available on the market cannot stop the progression of the disease, they can, however, temporarily slow the worsening of symptoms and even improve the quality of life for patients and their caregivers. Today, Alzheimer's isn't just some vast unknown thing. No, in fact, there is a worldwide effort currently underway to help find better ways of treating the disease, delay the onset, and even completely prevent it from developing.

Now that we've taken a look at some of the basics, let's next shift our focus to the symptoms of Alzheimer's and its effects on the brain. We'll also see the role of abnormal structures called plaques and tangles, as well as progression into the research of Alzheimer's.

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Symptoms of Alzheimer's

Everybody knows that there are many physical changes to our bodies as we age, but there are also mental ones as well, and a lot of us often take note of an eventual slowdown in our thinking or that we may have trouble remembering certain things as we get older.

While most everyone recognizes difficulty remembering any newly learned information as a classic early symptom of Alzheimer's, things such as serious memory loss, confusion, or any other major changes in the way our minds work can be a sign that brain cells have started to fail. As we said, having difficulty remembering things we've recently learned is the most common early indicator of the disease, and this is because the changes that come with having Alzheimer's most often affect the area of the brain that deals with learning. And as it continues to spread throughout the brain, it gives way to more and more symptoms that increase in severity. These can include the following:

- Disorientation
- Mood and behavior changes
- Deepening confusion about events, time and place
- Unfounded suspicions about family, friends and professional caregivers
- More serious memory loss and behavioral changes, and
- Difficulty speaking, swallowing and walking.

Individuals suffering from memory loss or any other possible signs of Alzheimer's might also have difficulty realizing they have a problem at all, and any signs or symptoms might be more recognizable by the person's family or friends. Anyone who experiences dementia-like symptoms should make an appointment to see their doctor as soon as they can, and if you need help finding a doctor that specializes in memory issues, your local Alzheimer's Association chapter can help.

Both early diagnosis and intervention methods have improved dramatically and continue to do so, and any treatment options and sources of support can work to help improve one's quality of life. Two helpful support options available to those who need them are ALZConnected, the Alzheimer's Association's message boards and online networking community, as well as Alzheimer's Navigator, a web tool that creates customized action plans centered around the answers you give through short, online surveys.

Next, we will take a look at Alzheimer's and how the changes that come with it can affect the brain.

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Alzheimer's and the Brain

The brain is an amazing organ that houses 100 billion nerve cells, called neurons. Each of these cells connect with others to make up communication networks, and groups of nerve cells have special jobs. Some help us to think, learn, and remember things, while others manage our senses, like sight, smell, and hearing.

In order to do the all this work, these brain cells operate much in the same way a factory does. They get supplies, generate energy, construct equipment and eliminate waste. They're also equipped to both process and store information as well as communicate with other cells. In order to keep us at our best requires coordination and great amounts of both fuel and oxygen. Many scientists believe that Alzheimer's keep these cell factories from running properly, but they aren't quite sure where all the issues begin. And just like in a real factory, when one system has problems, it causes problems in other areas. It is much the same way with the brain. As the damage done by Alzheimer's spreads, cells lose the ability to properly do their jobs and eventually die, leaving behind irreversible damage done to the brain.

Plaques and Tangles

Plaques and tangles are two atypical structures that tend to spread through the cortex as Alzheimer's progresses through the brain, and they are believed to the main cause of damage to and death of nerve cells. Let's very quickly define each, so that we understand better what they are:

Plaques: deposits of a protein fragment known as beta-amyloid that build up in the spaces between nerve cells in the brain.

Tangles: twisted fibers of another type of protein called tau (rhymes with "wow") that build up in the cells themselves.

It is, in fact, common for someone to build up both plaques and tangles as they get older, but those suffering from Alzheimer's normally build up many more than most. What's more—they tend to develop them in predictable patterns, normally beginning in the areas of the brain important to memory before they spread to other regions.

Scientists and researchers aren't quite sure what roles plaques and tangles play in the larger problem of Alzheimer's disease. Many of them believe they play some sort of critical part in blocking the communications between nerve cells as well as disrupting any processes that those same cells need in order to survive.

It is the destruction and subsequent death of these cells that causes issues such as memory failure, personality changes, difficulty managing daily activities, and other classic symptoms associated with Alzheimer's disease. However, there is hope…

Research and Progress

These days, Alzheimer's disease is front and center in biomedical research, and scientists and researchers are hard at work trying to decipher as many cryptic aspects of Alzheimer's disease and other related dementias as they possibly can. As much as 90 percent of what we even know about the disease itself has been discovered just within the last 15 years. Some of the most amazing progress has shed even more light on how exactly Alzheimer's affects a person's brain, and this leads to the hope that this better understanding of how it works will lead to new, better treatments, and many significant approaches are currently being investigated the world over.

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Now that we've covered Alzheimer's more specifically in detail, let's next turn our attention to dementia in general and take a look at some of the symptoms associated with it and how those symptoms tend to progress.

Dementia: Memory Loss and other Symptoms

While it is indeed true that the symptoms of dementia can vary greatly between individuals, at least two of the following core mental functions has to be critically impaired in order for a diagnosis of dementia to be considered:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception

People suffering from dementia may also have issues with the following:

- Short-term memory
- Keeping track of their purse or wallet
- Paying bills
- Planning out and preparing any meals
- Remembering appointments, or
- Traveling out of the neighborhood

It is also important to note that many types of dementia are progressive in nature—that is, any symptoms start out slowly and get worse over time. If either you or someone you love is experiencing any difficulties with memory or any other changes in thinking skills, don't just brush them aside. You or they should visit a doctor as soon as possible to determine just what is going on. And getting evaluated by a healthcare professional may reveal that it is nothing that cannot be treated. Also, no matter if the diagnosis is suggestive of dementia, getting an early diagnosis allows for the maximum benefits from any treatments that are available and also provides an opportunity for individuals to volunteer for any clinical trials or studies.

Next, we'll see some causes of dementia as well as take a quick look at how dementia is diagnosed before going through a quick summary to end the chapter.

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As we saw previously, dementia is caused by brain cells being damaged, and that damage then messes with the ability of the cells to communicate with each other. And when brain cells cannot communicate properly, things like thinking, feelings and behavior can definitely be affected.

The brain has many differing regions, and each of them are responsible for a wide variety of functions (such as memory, judgment or movement). After cells in a region are damaged, that particular region is unable to carry out its normal, necessary functions.

The differing types of dementia are associated with different types of brain cell damage within particular regions of the brain. As an example, in Alzheimer's, the hippocampus—which is the center of learning and memory in the brain—and the cells in this region, are often first to be damaged, which is why memory loss is one of the earliest signs of Alzheimer's disease. And while many changes in the brain that cause dementia are permanent and only get worse with time, thinking and memory issues caused by the following conditions might improve when the condition is treated or addressed:

- Depression
- Side effects of medication
- Excess use of alcohol
- Thyroid problems
- Vitamin deficiencies

Diagnosing Dementia

Unfortunately, there is no one, all-knowing super test that can be used to diagnose dementia. At least not yet. In the meantime, doctors are left to diagnose Alzheimer's and other types of dementia based on things like a careful medical history, a physical examination, laboratory tests, and the changes that have become characteristic of the disease, things like: changes in thinking, day-to-day function, and behavior associated with each type. Doctors are able to determine a diagnosis of dementia with a high degree of certainty. Even so, it can be quite difficult to determine the exact type of dementia due to the fact that symptoms and brain changes caused by the different types can overlap. In some cases, a doctor may even diagnose "dementia" and then not specify which type it is. If that happens, it may be necessary to make an appointment with a specialist such as a neurologist or gero-psychologist.

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Types of Dementia

Like we stated in the beginning of the chapter, there are a multitude of different types of dementia. Let's quickly take a look at some before we finish out this chapter.

The most common types of dementia are:

- **Alzheimer's**—indeed the MOST common form of dementia. It accounts for between 50 and 75 percent of all cases.
- **Vascular dementia**—this is a broad term used to describe problems associated with the circulation of blood to the brain.
- **Lewy body disease**—a form of dementia that is caused by abnormal structures in the brain called Lewy bodies, and the symptoms can overlap with Parkinson's disease.
- **Frontotemporal dementia**—the name given to a group of dementias caused by degeneration in one or both of the frontal lobes of the brain that often develops in those people under age 65.
- **Alcohol-related dementia**—occurs due to excessive alcohol intake, especially when combined with a poor diet that is low in Vitamin B1 (thiamine).
- **Dementia due to Huntington's disease**—is due to the fact that Huntington's disease is an inherited and degenerative disease of the brain that affects both brain and body and causes dementia in a majority of cases.
- **HIV-associated dementia**—is a form of dementia that is very rare.

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Summary

To review, let's quickly summarize a few of the things we've learned thus far.

- Dementia is the term that is used to describe symptoms from a number of illnesses that affect both the brain and someone's ability to perform everyday tasks.
- Alzheimer's disease makes up two thirds of dementia cases.
- Common early signs of dementia include progressive, frequent memory loss, confusion, and personality and behavior changes.
- Getting diagnosed early is important since it allows for early support, planning for the future, and support for the patient, and his or her family and caregivers.
- Medications can help with symptoms, but there is no cure.

It's also important to note that dementia can happen to anyone, and that the risk of developing it increases with age. However, the majority of seniors DO NOT get dementia, nor is it a normal part of aging, though it mainly occurs in those older than 65. In cases where people aged 40-60 *do* develop it, it is called younger-onset dementia.

Of course, all this is just a small sample of the things contained in this chapter, and we could spend much more time on just this portion of the discussion. But we must move on because there is so much more for us to talk about. In the next chapter, we'll see how to tackle the difficulties that come with approaching the conversation of dementia.

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Chapter 2: Approaching the Discussion

Ask any collector of anything ever what they are most proud of, and chances are good that they'll take you to see whatever it is they collect—whether comics, figures, memorabilia, or anything of the sort. Chances are also very good that they will then spend the next several hours explaining the ins, outs, and intricacies of the entire history of everything in their collection unless they are stopped before they start.

The point is simple, and you've likely found it by now. But just in case, the point is that there are things that we *love* to talk about. We can spend hours and hours looking up information and lore about our favorite things, and then sharing all that with people who (probably) don't really care when the best character on that one show left in the middle of season 26.

Conversely, there are also things that we dread talking or thinking about. For parents, it may be the conversation about puberty. Parents generally don't want to think about their children growing up and changing, but it's a natural part of life, and young people need good information, and most of us would rather they get it from us than from their peers, who may not know any more or better than they do.

Another thing that we'd much prefer to sweep under the rug, thank you, is getting a bad report from our doctor. We go in for a simple checkup thinking everything is okay, and then get blindsided by something we would never have imagined in a million years.

While we know that things like this happen all the time, it still hits us like an emotional sucker punch and turns our world on its head—and rightly so. It doesn't *have* to, and it certainly doesn't lessen the importance of getting the issue, whatever it may be, out in the open so it can be dealt with. After all, facing a health crisis alone isn't how something like that was meant to be handled, and it only winds up making us feel even worse than we already do, which is no good at all.

Now, I know what you're probably thinking, "Yeah, you're right…" You might even sigh to yourself when you think it. "But it's still hard, and I don't know *how* to talk about it."

And therein lies the problem, right? We don't like talking about tough things—we don't like talking about the birds and the bees with our children because we are afraid of not knowing enough, or that the things we *do* know are outdated by a million years. We don't like talking about our health crises because the doctor said we had some seventeen-syllable disease that we're not even sure is a real thing to begin with, and even if it is, we can't pronounce it anyway, so what's the point?

We don't like talking about difficult topics because we don't know how to bring them up. After all, you can't just blurt out that you have cancer in the middle of a family gathering for little Jimmy's 6th birthday, so instead we just hold that inside until it gets so heavy we have no choice but to come clean. But where (and how) do we even begin?

In this chapter, we'll look at how to approach the conversation of dementia, and the differing things that it brings with it. And like last time, we have a lot to get through, so let's get going!

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Okay, so you or someone you love has been diagnosed with dementia. What's the first step? Talk to someone you trust. If it is you with the disease, you might invite your parents or a trusted friend over for coffee to help ease any tension you might be feeling. You might start gradually, by sharing how you've been feeling lately and then gradually transition the conversation to the topic you really want to discuss.

If you are concerned for a parent or another older loved one, it's important to remember that, as hard as it is for you to either suspect or know what may be happening in the life of your loved ones, it's just as difficult for them, if not even more so.

One thing that you could do if they seem reluctant to talk about it is to remind them that you understand how hard it is for them to think or speak about these things, but that it is important to do so—not just so they can get the care they need, but so they can know that they are not struggling through these things alone.

A lot of times, older parents don't want to seem like a burden to their families, and that's a major contributor to the issue of keeping quiet on such an important issue. Another reason is that they don't want to necessarily make their families uncomfortable. After all, such things aren't exactly the most pleasant things to discuss. In fact, for those who have loved ones that *do* suffer from dementia, a whopping 50% of people said they did not even feel comfortable with having a conversation with someone if they were concerned about memory issues.

So, if that's the case and this applies to you, what are you to do. Let's take a look at some steps from the Alzheimer's Society in the United Kingdom that you can take to begin having a conversation about their health issues:

Step 1: Plan to have a conversation in a familiar and non-threatening environment.

Step 2: Explain why talking is important—you're worried for them because you care about them.

Step 3: Use some examples to make things clearer for them. It's important to remember to not create a sense of "blame". As an example, instead of saying that they couldn't make a cup of tea, you might say that you noticed they seemed to have difficulty making the tea.

Step 4: Have an open conversation and be honest and direct. Ask them how they're feeling about their memory.

Step 5: Make a positive plan of action.

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Now, let's take a look at some top tips.

Top Tips

- Be positive—a diagnosis can give people the access to help and support they need, or the GP can help you to rule out dementia and treat other symptoms. Raising any concerns you have to your doctor can be a big, positive, step forward.
- Make note of situations that have you worried. Give examples of instances that will help you to better be able to express your concern in a clear and real way.
- It is important to not get upset if the person refuses to accept the things you're telling them. Be willing to put yourself in their place and see things the way they do. It's very possible they may be frightened or confused.
- It is very important to use non-judgmental language when discussing dementia due to the stigma surrounding the disease. Be sure to remind them that it's not their fault they are going through this.
- Make sure to keep the conversation open and don't do all the talking yourself. As important as it is to share your concerns, it is also important to let the person share his or her own thoughts and feelings as well.
- Be ready to take action together. Make an appointment with the doctor once you've taken the time to talk about the subject so that you can begin working toward getting your loved one the help that they desperately want and need.
- Never make promises about what can be done or what the future looks like. You cannot control the future or the outcome, you can only offer support.

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Alright, so now you know a little more about what to do to sort of ease into the conversation. But even if you know those things, it can still be difficult finding questions to ask. After all, receiving a diagnosis of dementia or any other health issue immediately sets our minds buzzing and swirling with so many questions that they oftentimes will get all jumbled together in our minds so that we're left with nothing but a big ball of confusion by the time it's all said and done. So, next, let's look at a few of the questions you can use to get the ball rolling:

- "You seem worried. Mind if I talk about it with you?"
- "You don't seem much like yourself, how have you been feeling lately?"

- “I’d like to help in any way I can. Is there anything you’re finding particularly difficult at the moment?”
- “Would you mind if we took some time to talk about how things have been going for you lately?”
- “You’ve seemed really concerned about things lately. Is everything okay?”

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Once you’ve opened up lines of communication and gotten them talking about what they’re going through, there are other things that are important to their well-being that need to be discussed as well, so we’ll take some time and focus on those things for now.

As uncertain as the future can be when it comes to the day-to-day struggles of those individuals suffering through the disease and its effects on friends and family, planning for the future is most likely put on the back burner, but it’s just as important as anything else. Because the sooner legal plans are set into place, the more likely it is that the person suffering from the disease will still be able to actively participate in the planning process.

Why Plan Ahead?

Making legal plans beforehand is important for more than a few reasons. As we mentioned, getting started earlier allows the person to make his or her own wishes known with regard to future care decisions. This, in turn, gets rid of the guesswork that would otherwise be left for families, and allows the individual to designate decision makers on their behalf. Planning early also gives more time to work through both complex legal and financial issues that are normally involved in long-term care.

Legal plans should include the following:

- Plans for both health care and long-term care.
- Plans for finances and property.
- Naming another person to make decisions on behalf of the person with dementia.

In our law firm, we take a holistic approach by evaluating the financial, legal, and care needs of the individual. This creates a one stop shop for families trying to evaluate the many issues in the process.

Legal Capacity

In the simplest of terms, legal capacity is the ability to understand and appreciate the consequences of one's own actions and to make rational decisions. In many cases, if someone with dementia can understand the meaning and importance of a given legal document, then he or she likely has the legal capacity to execute (or carry out by signing) it.

The requirements of legal capacity can often vary from one document to the next, and that's where a lawyer can be of great assistance. They can help to figure out the level of legal capacity the person needs to be able to sign the document.

Before signing anything, though, a few things need to be done:

1. **Talk with the person.** You should find out whether or not the person understands both the document and the consequences of signing it. Make sure they adequately understand what the document explains and what they are being asked to do.
2. **Ask for medical advice.** If you still have concerns about the person's ability to truly understand, seek medical advice. It's possible that a doctor could help to determine the level of the person's mental ability.
3. **Take inventory of existing legal documents.** You should also verify whether any living wills, trusts and powers of attorney were signed before the person was diagnosed with dementia. He or she may not remember having completed them. And even if there *were* documents done in the past, it's still very important to look over them with another person for any corrections that might be needed and/or updates.

Meeting with a Lawyer

While it is, in fact, possible to complete some legal documents without the assistance of a lawyer, you should still get legal advice and services from an attorney. One specializing in the field of elder law would be especially helpful in that regard.

If you've already got a lawyer, then he or she might be able to you refer you to one who does specialize in elder law. Otherwise, several resources are at your disposal to help you locate any elder law services within your community.

There are four things that you should be sure to discuss with a lawyer, along with any other questions or concerns you might have.

Those four things are:

1. Does the elder law attorney prepare a life care plan for the client?
2. Does the law firm have a certified social worker or care manager on staff to advocate for the patient as their health changes?
3. Is the person's estate planning documents current and valid?
4. What coverage is available for long-term care services, including that which is provided by Medicare, Medicaid, veterans' benefits, and long-term care insurance?

Be sure to gather up all documents relating to assets the person has ahead of time so that you can bring them to your appointment. And speaking of things to bring to an appointment, let's take a look at a checklist of items you should have with you.

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Checklist: What to Bring to the Lawyer

- ✓ An itemized list of assets (like bank accounts, contents of safe deposit boxes, vehicles, real estate, etc.), including current value and the names listed as owners, account holders and beneficiaries.
- ✓ Copies of all estate planning documents, including any wills, trusts and powers of attorney.
- ✓ Copies of all deeds to real estate.
- ✓ Copies of recent income tax returns.
- ✓ Life insurance policies and cash values of policies.
- ✓ Health insurance policies or benefits booklets.
- ✓ Admission agreements to any health care facilities.
- ✓ List of names, addresses, and phone numbers of those involved, including family members, domestic partners and caregivers, as well as any financial planners and/or accountants.

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Now, let's take some time and check out five quick tips that can help you out too.

1. Those people named in the power of attorney document should also have a copy of and access to the original document.
2. The person with dementia should name a successor (or back-up) agent for power of attorney in the event that the agent may be unable to act one day.
3. The person should also consider a neutral third person to have power of attorney if those chosen do not agree to it.
4. Once a power of attorney for health care document and/or a signed living will is in place, a copy should be given to the person's doctors and other health care providers.
5. Consider choosing an attorney or a bank to manage the person's estate if he or she lacks a trusted individual with the time or expertise to do so.

You know, if you have children of your own, how awful you feel when they get sick with anything, even if it's just a simple cold. You would do whatever you could to take it from them if you could. In the same way, it can be physically and mentally overwhelming and even devastating to see your parents—people who would have done anything for you when you were sick—have to battle a disease such as Alzheimer's, a literal battle for their minds, and feel powerless to be able to actually stop it.

Even if you're in that position right now, even if you're feeling powerless, it's still very important to plan ahead for care, as doing so will better be able to get through the times that lie ahead. So, let's look at some things that you can do to help your loved one during each and every stage of the illness:

Some things you can do:

1. Get as much information as you can to be able to start making an informed plan.
2. Learn about the do's and don'ts of communicating.
3. Learn how to reduce stress—both in yourself and your loved one.
4. Get information about your options for assistance or in-home care.
5. Learn how to evaluate assisted living or nursing facilities.
6. Learn more by reading related articles.

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While we could almost certainly go in-depth on each and every aspect, and thus take up more time than we actually have, let us instead focus instead of the do’s and don’ts of communicating with someone with dementia. After all, the focus of this chapter is, indeed, communication, so it only seems logical to talk about that, right?

Let’s continue…

Communication Do’s and Don’ts

Do

- Avoid becoming frustrated by both empathizing and remembering that the patient cannot help it they are sick. It is important to make them feel safe rather than stressed, and this goes a long way to help with communication. Also, take a short break if you feel yourself getting frustrated.
- Keep all communication short, simple, and clear. Make sure to give one direction or ask one question at a time. Don’t overload them.
- If it seems the person doesn’t know who you are, tell them.
- **Call your loved one by their name.**
- Speak slowly. It may take them longer to process what it is you are saying.

Don’t

- Don’t ever say things like “Do you remember?” “Try to remember!” “Did you forget?” “How could you not know that?”
- Don’t ask questions that challenge their short-term memory, like “Do you remember what we did last night?” The answer will likely be no, which can be humiliating for them to admit.
- Don’t talk in paragraphs. Offer one idea at a time instead.
- Don’t point out his or her memory difficulty. Avoid remarks like, “I just told you that,” and just repeat it over and over instead.
- Don’t talk in front of the person as if he or she was not present. Be sure to include them in any conversation where they are physically present.
- Don’t use lots of pronouns, like “there, that, those, him, her, it.” Use nouns instead.
- Don’t use slang or unfamiliar words. The person may not be familiar with the latest terms or phrases.
- Don’t use patronizing language or “baby talk.” Nobody wants to feel like they’re being talked down to.
- Don’t use sarcasm or irony, even if meant humorously, as it can cause hurt or confusion.

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Finally, let's finish the chapter by looking at some tips that you can use to help keep conversations with your loved one both positive and valuable for all parties involved.

1. **Face-off:** Making friendly eye contact and using the person's name are good rules of thumb for conversing with anyone, and even more so with someone suffering from Alzheimer's or dementia. It is important to say their name, and assure them they have your full attention by facing them and looking them in the eye.
2. **Diminish distractions:** Background noises from things like a television, radio, or even a fan can be distracting to your loved one while having a conversation. This makes it more likely they'll lose track of what the discussion is about. Make sure to find a quiet place where both of you can talk in peace.
3. **Converse one-on-one:** Adding more people to a conversation just makes it harder for them to keep track of. Whenever possible, initiate a one-on-one conversation. Even smaller groups of three or four people can make someone confused and anxious, and those are things they don't need.
4. **Keep things simple:** Keep comments and conversations short and sweet, and to the point. Be sure and refer to nouns by their actual name. Say "bird" on a walk instead of "it." Also, too many choices can be confusing for someone with Alzheimer's or dementia. Instead of asking them what they want to do today—a questions which offers way too many choices and can lead to confusion, make a suggestion, like going to the park together.
5. **Avoid conflict:** Be sure and do not argue with someone who has Alzheimer's. You're not going to win and it will only serve to make both of you more agitated. You should also avoid inflammatory comments, such as: "I just told you that," and "You're wrong." It's very important to learn to recognize when giving in and walking away from a potential showdown is the better thing to do.
6. **Extra points for patience:** Have some patience when having a conversation. As hard as it might be, resist the temptation to complete their sentences for them—it isn't going to help them remember, and there's a good chance it will be more frustrating than helpful. Instead, try asking a question to help them remember what they were trying to say.
7. **Enter their world:** Having a conversation with someone who has Alzheimer's means making a pledge to temporarily come inside their world—which will be drastically different from your own. Depending on

which stage of the illness they find themselves, your loved one could believe that his or her deceased spouse is still alive or that they are an accomplished singer. And as long as it isn't hurting anyone, it can be best just to go along with it. If you feel guilty doing so, just remember that their mind is no longer their own and is now being controlled by a disease, and this means that no matter how hard you try, you're not going to be able to convince them they're wrong. Instead, giving them support and validation will greatly help to relieve any anxiety and brighten their mood.

8. **Clue into visual cues:** Body language can be a powerful conversational tool, no matter who it is you're talking to. Physical indicators can also be especially important when you're trying to have a conversation with someone struggling with cognitive issues and impairment. A person may not be able to verbally express things, but you can still see how they're feeling by paying attention to facial expressions and body positioning.
9. **Get creative with communicating:** If words just aren't enough to get the point across, take a chance and experiment with different types of communication. Make use of verbal, visual, and auditory cues to help your loved one better understand. As an example, if you'd like to know whether they want turkey or ham on a sandwich, you can pull out and point to each option while asking the question.
10. **Just keep talking:** Even if your loved one has limited powers of speech, or they are someone who can no longer talk at all, you still should not discount the power of communication and conversation. According to the Alzheimer's Foundation of America, having a conversation with a non-verbal sufferer is a great way to let them know that you still support them, not only as a caregiver, but more importantly a family member who loves them.

No matter what stage of Alzheimer's or dementia your loved one finds him or herself in, communication and human connection is still very much an important part of their well-being.

After all, just because they may be unable to talk and communicate the same way that you or I would do, that doesn't mean that they aren't still listening.

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As we continue together on our journey through to a better understanding of dementia, we will next look at how to deal with the denial of receiving just such a diagnosis.

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Chapter 3: Dealing with Denial

Everyone at some point in time has gone through a period of denial in their lives. Whether it was the realization that the Easter bunny doesn't exist or the fact that your parents aren't the superheroes you thought they were, we've all had those points in life where our souls have been crushed into a million pieces. And the longer we're around, the more we realize that, sometimes, things just don't get better.

Perhaps that's why we have trouble accepting an unexpected diagnosis from the doctor. We want to believe that our parents are unaffected by silly little things like health issues and will brush them off like nothing. Or maybe it's a diagnosis of our own that we're currently struggling with. No matter what, though, we can all agree that we all grapple with the issue of denial when facing seemingly insurmountable odds.

And that's okay.

It's perfectly normal and natural to *not* be okay when it comes to receiving a less-than-stellar report from the doctor, because we all want to be our best, and we cannot do that if we are sick. In the same way, our loved ones who are struggling through dementia are unable to be at their best because of the effects of the disease, and it's okay to find yourself in a place of denial and not be okay with that.

What is not good to do, however, is to stay in that place. It isn't helpful to your loved ones, and certainly not to yourself or your own family members who need you. Knowing that, then, what is one to do? How are we to handle the denial that comes with facing such a terrible disease?

In starting the chapter, let's first take a look at the five stages of grief. It is good to note that, while these stages are most closely associated with the loss of a loved one due to death, losing them to Alzheimer's or dementia still counts as a form of loss, so these stages are still appropriate here.

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Stages of Grief

1. Denial and Isolation

Appropriately, the first stage of grief is denial. After all, no one wants to think or admit that the person they have looked up to for their entire lives can be affected by a disease like dementia or Alzheimer's. However, to be unwilling to admit it is to deny the reality that it can and does happen, or perhaps that it *is* happening in your life right now. It's quite normal to try and rationalize overwhelming emotions, as that is a defense mechanism that helps to buffer the immediate shock of loss, or in this case, the diagnosis. It is a temporary response that helps us make it through that initial pain.

2. Anger

As we begin to emerge from the first stage, and the effect of shutting out the world begin to wear off, the pain of loss begins to once again reveal itself, but we still may not, and likely are not, ready to face it just yet. The intensity of emotion and vulnerability that we feel is redirected from inwardly, instead presented outwardly in the form of anger. Our anger could be redirected at inanimate objects, complete strangers, or even our own friends or other family members. Or maybe we even get angry with our loved one who is sick. While it does happen, if we take a minute to think rationally about the situation, we know deep down that they are not the ones to blame, and instead of being angry with them, we are actually angry with the disease.

3. Bargaining

When facing such overwhelming odds as dementia, we often seek to try wrestle back some sense of control in our lives from an uncontrollable disease. We might say things like "If only we had seen it coming sooner" or "If only I had treated them better back then…"

We may also try and make a deal with God or another higher power, but doing so doesn't help us to feel any better, and it certainly doesn't protect us from the harshness of the reality of things.

4. Depression

There are two types of depression that are often associated with grieving—the first of which is a reaction to the practical implications of loss. Sadness and regret are at the forefront of this type of depression. We worry about what to do next or that, in grieving, we have made ourselves unavailable to the other people who count of us. This phase can be made easier with just a bit of clarification and reassurance. Something like helping with household tasks or a few kind words can work wonders when we find ourselves in this stage of grief. The second type of depression tends to be subtler and, in a way, more private, though sometimes, it can be good to be reminded that we are not alone, no matter how isolated we may currently feel.

5. Acceptance

Coming to terms with something like a death or diagnosis of dementia is a very difficult process, and accepting it may be, honestly, unattainable for some. But it is important to grief—no matter its instigator—is a personal experience. No one can tell another person how to grieve or deal with a situation. It is important to remember, though, that there are others who can help you through it, and to let yourself feel those emotions of grief as they come.

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In this chapter, we will take a look at some things that will hopefully help you and the rest of your family members better deal with the denial of dementia, and in doing so, how you can help your loved one who is struggling through the disease.

The fact of the matter is that no one wants to acknowledge the thought that their loved one is suffering from an incurable disease, especially when it's one that ravages the mind in the way that dementia does. This presents one of the biggest challenges that individuals and families can face when it comes to battling the disease. As it is with anything important that needs to be addressed, so it also is in recognizing and working through the denial of dementia and coming to a place of acceptance where each person can work together for the good of the sick individual.

Doing so makes it possible to have much-needed discussions and to draw up care plans, while also letting the person with dementia also remain involved in the details for as long as possible. What's even better—once you get through all the necessary things, you can begin to seek joyful moments even in the midst of what are otherwise frustrating and painful times.

In speaking of denial, the person we should address before all others is that of the person experiencing the dementia him or herself. No one wants to believe that their recent bouts of forgetfulness could actually be signs of something more sinister lurking in the shadows. Once something more is suspected, the person will generally take action in effort to try and mask the symptoms or sweep them under the rug.

This is understandable for a couple of reasons:

- First of all, admitting that you have the signs or symptoms of some disease makes it real. And once it is, then it gradually seeps into your life until it becomes something more—a part of who you are—and begins to define you, to the point where it becomes the first people think of or see when they think of you.
- Secondly, if you acknowledge the disease, that means that you'll have to start giving up parts of your life, and will eventually wind up in a place where you won't be able to recognize those who love you, the things and places around you, or worse—yourself. Is there any scarier thought than that?

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The other half of denial comes from those close friends and family members of the person with dementia. As we said before, no one wants to think of someone they love and care for suffering with something like that, so we do our best to shove it in the deepest recesses of our minds, in the darkest closet, and slam the door shut. Maybe if we just don't *think* about it, maybe we'll wake up one day having imagined the whole thing.

The denial by friends and family tends to be really tough because there are some really complicated players and influences that are normally involved, such as: misdiagnosis or lack of a diagnosis by a medical professional you trust, lack of understanding of the group of diseases under the dementia "umbrella," as well as a feeling of general helplessness or confusion about what to do or where to go next.

Now that we've brought the subject of denial to the surface, let's next move on to see some things that we can do to be able to work through the denial and get to a place where helpful and positive actions are able to be taken and we can begin to move forward. It's also important to remember that it will take a great deal of patience, persistence and love for both your loved one, as well as yourself and everyone involved.

YOU

First of all, you're going to want to take some time and process things yourself. Especially when it comes to parents or spouses who are going through dementia, it can be very difficult to admit that something is wrong, and you may even try to find some other explanations for the changes in behavior that you'll no doubt have been witnessing.

What can help is to gather as much information and as many resources as you can and just study. Learn as much as you can about the disease and what you can expect moving forward. Like we said in the beginning of the book, the most important thing you can do is to take away your opponent's hold over you. If you take away dementia's ability to create fear in you, then you remove the greatest weapon in its arsenal.

It can also be of comfort to talk to trusted friends or clergy. While they may not have anything in the way of answers for you, just simply knowing that you aren't alone in your struggles can work wonders for your mood and overall outlook on the situation.

DOCTOR

Next, schedule a time to meet and have a discussion with a doctor. You're going to need him or her to understand your concerns and be able to give you the attention you need in order to get a proper diagnosis. The sad fact is that a lot of general practitioners and even some neurologists are not as familiar with dementia as you might think. Some people who are suffering with the disease can "pass" basic mental assessments but still have signs of dementia that someone who is actively looking for it can see. If, at any time you feeling like you're not getting the expertise or help you need, see another doctor.

This is incredibly important because things like medication and other preventative activities can be prescribed to help extend a good quality of life, and many times the diagnosis from a professional will help to get your loved one ever closer to acceptance.

YOUR LOVED ONE

You should also begin the first of many difficult and sad conversations with your loved one. There is really no easy way to say how tough this part actually is. Speak from a place of love and let them know that you are there for them and will face these difficult challenges together. After all, this isn't a time for anyone to be right, this is a time to be as supportive as it is possible for you to be.

It's important to note that your loved one likely won't (and doesn't) want to hear what you have to say, so it is possible they might react harshly. However, it is also important to remember that they are coming from a place of incredible fear and confusion just the same as you are yourself, and that they are not angry with your specifically, but rather at the way that having this disease is making them feel. They might even say things that don't make sense or possibly even accuse you of stealing things from them or that you're trying to manipulate them in some way. Remember that this is just part of the disease too. Keep yourself calm and take the time to remind yourself of this daily, and of the fact that because of this, they aren't in their right mind. When you feel that the time is right, you can suggest some of the steps we've outlined for you above.

It could take several months, but eventually they will come around to the ideas and suggestions you're making, and you should offer them a hug and attempt to laugh at these conversations. It may not always work, but it can help to move you forward and bring a little bit of peace, and you might even have a bonding experience over having gone through these times together. Moving forward, you should work to keep them occupied with various tasks and things that they love doing: like going for walks, going to a baseball game, or helping out with chores or cooking. That way, they aren't focused on the disease and can enjoy and take comfort in the things they love.

SUPPORT

Finally, you should try and find a support group as soon as you can, and if there is one in your area for your loved one with dementia, you should start suggesting the idea to them as soon as possible so they have time to warm up to the idea of getting involved. It can be very helpful not only for those with the illness, but their caregivers as well. The times ahead will be dark, and the road will have many twists and turns, and you and your loved one need to know that you're not dealing with this alone, and that's where building up your support group is an invaluable resource, as they can come alongside you and your family when the darkest times come.

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This chapter is all about the denial that comes along with the diagnosis of the disease, and as we've mentioned previously, it can be a healthy form of defense in the beginning, but eventually it will be something that needs to be dealt with, and both families and individuals will need to face the reality of the situation. Before that can happen, however, you need to come to the realization that you are in denial, so let's now turn our attention to eight different ways that you can learn to recognize denial before it becomes a real problem.

If you find yourself doing any one or more of these things listed below, you can know that you're dealing with denial:

- Ignoring tell-tale signs like your loved one either tripping or dropping things. These are more than just signs of general clumsiness—they can be indications that the nervous system isn't working properly.
- Rationalizing his or her behavior. Trying to rationally explain why someone would do something dangerous, like turning stove burners on and then walking away without putting anything on to boil can be a sign of denial. They have, unintentionally, created a dangerous situation, and that isn't something they would normally do if they were in their right mind, so there is no way to rightly explain why they would do such a thing otherwise.
- Allowing a loved one to walk the street alone when you know that he or she is able to get lost. Both getting lost and losing sense of direction can be and are symptoms of dementia.
- Expecting your loved one to follow their normal schedule. You have to be able to adapt to the changes caused by the dementia. They will not be able to go to work like normal, as much as they might want to do so. They may not even be able to get to the doctor. This is where a nurse's aide or making

use of your system of support can be a great help, as they can be with your loved one even if you can't be there yourself.
- Letting your loved one continue to drive or operate machinery. Drive them yourself or hire someone to do so if you are unable.
- Getting unreasonably angry. When in denial, people suppress their feelings. So, if something happens and your anger level goes beyond whatever it was that happened, this can be a sign that you are in denial. Once the denial stops, you can better regain control of your emotions once more.
- Projecting your own feelings onto your loved one. Your loved one may not be feeling how you think they are. You should take some time to really sit down with them and talk at length about how they are really feeling.

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If you find yourself really struggling with anything we've mentioned above, it could be helpful to get involved in psychotherapy with a trusted health professional or joining a support group. Talking with friends and other family members can be helpful, but it can also be detrimental—they could be just as sad, confused, or disturbed by the whole situation as you are yourself. Talking to objective professionals outside your circle of support can be more beneficial in helping you to work toward identifying and coming to terms with the denial you may be facing, and help you work on a plan to support your long-term emotional health.

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So far, we've taken a look at why denying dementia can be harmful mainly for the caregiver or other family members. But it's also not good for the individual with dementia as well. And while it's certainly not good for your loved one to be in denial, it's also rather understandable, isn't it?

I mean, they've basically been told that they've got a disease that is eventually going to make them literally lose their minds, and there's nothing they can do about it to make it go away. If it was you in that same situation, would you simply nod and agree with the diagnosis, or would you pause and question it, especially if you have been feeling well up to that point and just thought of your forgetfulness as "old age?"

How are they *supposed* to feel?

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Five Reasons for Denial

- **They haven't yet noticed any symptoms.** It could be that they have dementia and don't realize it because it hasn't affected their life too much yet. This can happen if a spouse or partner covers for them and helps with everyday activities they may normally struggle with if they were on their own.
- **It's a coping mechanism.** Sometimes, being in denial is nothing more than a way to hide the fear, uncertainty, grief, or even a sense of loss that they could be going through in the situation because of the prospects of the diagnosis and the future ahead of them. Such denial could manifest in things like general anger, moodiness and depression too, as well as them claiming that nothing is wrong, when indeed they are suffering.
- **They may not remember the diagnosis meeting.** It's quite possible that even if they are accepting of the situation at the time of diagnosis, there can also be a chance they have forgotten they received just such a diagnosis at a meeting within a few weeks.
- **They think it's just part of getting older.** The myth that dementia is something that simply comes with getting older is one of the biggest there is. Such a thing is just simply not true. Dementia is an actual, legitimate disease of the brain, and the decline in cognitive function that comes with it is very much different compared to the occasional absent-mindedness that can happen to everyone (not just older folks either).
- **The stigma of dementia.** Along with being wrongfully considered a "normal part of aging", people just didn't talk about having dementia until fairly recently. Even the idea of being "demented" carried with it implications and visions of mental asylums, so if someone exhibited symptoms of the disease, it wasn't talked about and likely swept under the rug. The idea that someone would be "put away" or left on their own in a nursing home means that individuals likely wouldn't want to draw attention to the fact they're sick, so they would try and deny that there is a problem.

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Now that we've taken some time and looked at some of the main reasons someone may be in denial about having the disease, it might leave you with some questions, not the least of which may be: "Okay, I *know* there's an issue, but I still feel so powerless. What can I do?" Oftentimes, family members and friends of those who have the illness are left knowing there is an issue, but they may be lost as to what there is for them to do to help. If this is you, fear not! Next, we will take a look at six ways that you can actively help your loved one and get through this together.

How Can You Help?

- **Accept that denial is often just a part of the journey.** While some dementia sufferers may downright refuse to accept the diagnosis at first, it is likely they will come to a place of acceptance as the condition progresses. They might not ever truly accept the diagnosis, but they'll probably come to a point where they will no longer deny there is something wrong.
- **Explain it in more gentle terms.** A lot of people shudder at the "D" word—dementia. It might scare them so much they just refuse to believe it. However, if you explain that the memory problems they're having is because their brain doesn't work as well as it used to, they could be able to better accept that. And many caregivers will say that, as long as their loved one can simply admit their memory isn't what it used to be, that is a step in the right direction toward accepting their situation.
- **Try a few therapeutic lies.** If your loved one refuses to accept the diagnosis, and are refusing both help and support because of it, then saying that any care professionals who are there are simply friends there to help the person out. A large percentage of older people can be (and are) fiercely independent and proud, and they aren't used to sharing their private business with strangers. If they are under the impression that the caregiver is there as a friend of a family member, they could be more ready and willing to accept them. And if it brings you more peace of mind, you could even just say that the caregiver is there to keep them company rather than actually "care" for them.
- **Appreciate that ignorance can be blissful.** If the person can't remember that they have issues with memory, and that's the reason they deny the diagnosis, then it's likely they will not be as stressed out about it. Conversely, if they are very aware of any memory issues, they could be really worried about the future.
- **Take measures to keep them safe.** No matter how much they might deny the problem, sometimes you may just have to work around them in order to keep them safe. Doing so can range from having a neighbor check in on them regularly, to installing aids around the house to help prevent accidents. There is a wide array of items that are available that can help keep them safe but that won't have an impact on their daily life. To see a list of just

such items, you can visit the following site for more information: https://www.unforgettable.org/safety.

- **Find ways to work around it.** If, indeed, your loved one refuses to accept that they have dementia, sometimes the only thing—the *best* thing, and the one least likely to be stressful—is to simply be there with them in the moment and not try to force anything on them they may not be ready for. After all, your main priority is to keep them safe and happy, and finding ways to work around it when they refuse to believe they need help is your main priority now.

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Sometimes, it isn't only the patient themselves that has difficulty accepting the diagnosis of dementia. Other family members or caregivers can also present a challenge by being unwilling to accept that someone is wrong with a person whom they love or care for very deeply.

Now, we will take a look at four reasons that other people besides the loved one may deny there is anything wrong. This is especially prevalent during earlier stages of the disease when symptoms and signs are less frequent or obvious.

Five Reasons They Might Deny It

- **They hope it might go away.** Dementia is, in fact, incurable, but knowing that doesn't stop people from hoping that the "good days" are actually signaling the person getting better. If the person who has dementia is still self-sufficient and able, family members or caregivers might brush off other signs and symptoms—like repeated conversations or lost journeys—as a one-time thing.
- **They rely on that person.** If a family member, like a husband or wife, refuses to accept the reality of the situation, it may be because he or she has always seen their spouse as a source of strength, information or support. They may not be read to take over things like paying the bills or taking care of the house, and that idea frightens them, hence the denial.
- **They don't see the person regularly.** All families are different, so some family members may not be able to see the person with dementia very often, so they may not see all the signs and examples that point to the person having dementia.

- **Fear about the future.** A major contributor to their denial might be, realistically, because they are worried about what lies ahead for them as caregivers and for their loved one specifically. There are loads of challenges that come with the disease, but taking time to learn about them can help the person be better prepared to face them as a caregiver.

How Can You Help?

- **Have a family meeting.** Doing so can help to instill reassurance and give you a chance to better explain the situation to family members, friends, or anyone else involved in caring for the person. It may be good to bring some literature, leaflets or even website pages for people to take and read or look up, since fear and denial are often a product of ignorance to what's going on. The person with dementia may or may not also want to be included during the meeting, though this depends on whether or not they've accepted the diagnosis themselves.
- **Explain that it's okay to be worried.** Like we've already mentioned, no one wants to think of their loved ones facing a problem like dementia, so obviously, hearing that someone they love has dementia is going to bring with it feelings of concern about the future. But explain to them that it's perfectly normal and natural to be worried. If they're still having trouble accepting the reality of things, just let them know that you're there to help and support them as much as possible as well.
- **Explain the implications of denial.** While you shouldn't actively try to scare someone, it is still greatly important that people understand not coming to a place of acceptance with the diagnosis can ultimately be detrimental for the health of the loved one and also their own if, in fact, they are the main caregiver.
- **Provide support where you can.** Whether this means helping to set up a lasting Power of Attorney (this is a useful document for anyone regardless of if they accept the diagnosis or not) or researching any benefits or care options that are available to them, let them know that you are there to help and support them as much as you can in any way that you can.

The Risks of Denial

If someone is persistent in their denial of a dementia diagnosis, it can have some rather serious and sad implications, and that is what we'll take a look at to finish out this chapter.

The risks of continuous denial are:

- **Accident and illness.** If someone with dementia is prone to walking off and getting lost, or is unsteady on their feet, simply refusing to accept this diagnosis could lead to a greater risk of accidents because of it. They might also be likelier to double dose any medication since they may not be able to remember if they have already taken it or not.
- **Family conflict.** Refusal to accept a diagnosis could lead to conflict with the family members who *do* accept it, as you try and work together to work out what's best for the individual.
- **Lack of medical help.** While there isn't a specific cure for dementia just yet, there are drugs that can be used to slow its progress. A refusal to accept that someone has dementia could potentially mean the person may not have access to drugs that could certainly help to improve any early symptoms they have.
- **Financial exploitation.** As the dementia worsens, it can be easier for people to take advantage of any memory issues or uncertainty and financially exploit the person, by getting him or her to sign up for schemes or to agree to things they shouldn't. Setting up legal documents to help them, like Lasting Power of Attorney, will work to reduce how likely they are to be taken advantage of. However, by refusing to accept the diagnosis, it may mean that it might be too late to set them up by the time the documents are needed, as the person with dementia may no longer be mentally able to do so.
- **Stress for the caregiver.** Finally, being in denial about dementia can bring great stress on the caregiver. Whether it comes by having to bathe, lift, placate or look for them, the stress that comes with caring for a loved one is only exacerbated by dementia. This is why denying the issue in the first place can make things even worse, since they won't often ask for or get the support they need to make life just a little bit easier.

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Whereas you may have never thought about the implications and complications that denial can cause, we hope that this chapter has helped to bring it more into the light so that you and your family can better support your loved one, as well as each other, as you all make the journey through this disease together.

In the next chapter, we will take a look at how to better understand the diagnosis of dementia.

What can be expected once it is received? What are some of the psychological and emotional impacts that dementia can have? What are some signs, symptoms, types and treatments available? We'll look at all this and more, so let's get right into it.

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Chapter 4: Understanding the Diagnosis

Imagine that you have the opportunity to visit another country. Perhaps you are one of those people who love to travel and often plan lavish trips months or maybe even a year or two in advance. Now, suppose that you were, in fact, *so* busy in planning your trip—making sure flights were booked, suitcases packed, and so on—that you have forgotten one of the most important parts of any visit to another country: learning the language.

Of course, making sure everything is in order beforehand is very important indeed, but once you arrive at your destination, you likely wouldn't make it too far if you hadn't taken the time to understand the language of the country you were going to visit, right?

Probably not.

In the same way, planning for dementia can be very similar. Oftentimes, just such a diagnosis sends not only your loved one into a frenzy, but everyone else too. Just the weight of that word—dementia—is almost crushing, and it can fill you and those around you up to bursting with questions and doubts and everything else—so much so that you can be so busy trying to wrap your mind around the whole thing that you can forget to take a minute to breathe and try to understand your next move.

If you have ever found yourself in such a situation, or you think it could happen sometime in the near future, don't worry; this chapter is dedicated to helping you better understand the diagnosis of dementia as well as how to better support your loved one, and goes along with those things. And hopefully by the end of it, you will feel better equipped and less apprehensive about facing your new enemy, because you will have a bit more knowledge and a bit more understanding, which will hopefully serve you well as you move into this new challenge of life together.

Speaking of challenges, as we saw in a previous chapter, challenges are a daily part of the human experience. Some of them are good challenges—those that help us to better ourselves by helping us to learn something new. Others are not so good and challenge us in negative ways that can affect us mentally, emotionally, or even spiritually. Dealing with dementia might most often be classified by many as something that challenges them in a negative way. After all, when you're dealing with dementia, you're dealing with things like memory loss, changing perceptions, relationships, or priorities, and much more, and often in drastic ways.

The good news, however, is that there are certain types of dementia that can be treated or reversed if it is caught in time, and coming to a better understanding of the different types of dementia, the causes of things like cognitive decline, and memory loss, as well as protecting the functioning of the brain through early intervention can help to improve the outcome and help keep a sense of control through even the toughest challenges.

There are a wide variety of symptoms that come along with dementia, such as memory loss, personality change, and impaired intellectual functions that are caused by disease or trauma to the brain. These things are not a part of the normal aging process, and are often severe enough to negatively impact daily living, independence and even relationships. When it comes to dementia, you might even see a noticeable decline in the areas of communication, learning, remembering, and problem solving. They can either happen quickly or gradually over a period of time.

Both the progression of the disease as well as the outcome of it may vary, but they are mostly determined by the type of dementia the person has and which area(s) of the brain is affected. Now, let's take a look at some more common signs and symptoms of dementia.

Signs and Symptoms

- Memory loss
- Impaired judgment
- Difficulties with abstract thinking
- Faulty reasoning
- Inappropriate behaviors
- Loss of communication skills
- Disorientation to both time and place
- Problems with gait, motor skills and balance
- Neglect of both personal care and safety
- Hallucinations, paranoia, and agitation

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You may also see that someone who has dementia exhibits some of the following:

- They repeatedly ask the same questions
- They become lost or disoriented in familiar places
- He or she is unable to follow directions
- He or she is disoriented as to the date or time of day
- He or she does not recognize and is confused about familiar people
- He or she has difficulty with routine tasks, like paying bills.
- He or she neglects personal safety, hygiene and nutrition.

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There are changes that are inevitable when it comes to aging, and they can be humbling, but also surprising. The skin wrinkles, hair color fades, bodies get colder or chill easier, and muscle mass is lost. What's more—the brain gets smaller too, meaning that your memory doesn't work as well and your mental speed slows down. However, while people do indeed experience both mild and gradual memory loss after age 40, severe and rapid memory loss is certainly not considered a normal part of getting older, and many people opt to help preserve their brainpower as they age by staying both mentally and physically active and making other healthy lifestyle choices.

The most common forms of normal mental decline include the following:

- **Slower thinking and problem solving—**the speed of learning slows and short-term memory takes longer to kick in, while reaction time increases.
- **Decreased attention and concentration—**more distractedness. Interruptions make learning harder than before.
- **Slower recall—**a greater need for hints to jog memory

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Telling the difference between normal memory loss and those symptoms attached to dementia isn't an exact science by any means, but there are some clues that you can be on the lookout for. Let's look at some of the differences now:

Typical Aging

- Complains about memory loss but able to give detailed examples of forgetfulness.
- Occasionally searches for words.
- May have to pause to remember directions but doesn't get lost in familiar places.
- Remembers recent events; conversations are not hampered in any way.
- Interpersonal skills are still the same level they always have been.

Symptoms of Dementia

- May complain of memory loss only if asked; unable to recall specific instances.
- Frequent word-finding pauses, substitutions
- Gets lost in familiar places and takes longer to get back home
- Notable decline in memory for recent events as well as ability to have conversations.
- Loss of interest in social activities; may behave in socially inappropriate ways.

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So, you may have looked at all that and thought something like: "You know, that's great and all, and I'm glad you told me, but what is it that actually *causes* the dementia and its symptoms?"

If so, read on…

Speed and mass may decline during adulthood in a healthy brain, but it is still able to form important connections throughout life. When such connections get lost through such things as inflammation, disease, or injury, the neurons in the brain eventually die, and this can result in dementia. The thought of really and truly losing yourself in this way can be really scary and even traumatic, but that's where early intervention can drastically alter the outcome of the journey. Being able to understand the causes of dementia is the first step in this right direction.

Over the course of the past twenty years, scientists have pulled back the curtain on dementia, so to speak, getting rid of any mystery or uncertainty as to its origins. While it is true that genetics can play a part in increasing the risk of developing dementia, scientists also believe that a combination of heredity, environmental and lifestyle factors are all most likely to blame for the development of the disease.

Now let's take a look at some of the things that may contribute to causing dementia:

- **Medical conditions that progressively attack brain cells and connections,** most commonly found in Alzheimer's disease, as well as Parkinson's disease and Huntington's disease.
- **Medical conditions like strokes that can disrupt flow of oxygen and rob the brain of nutrients.** More strokes can be prevented by lowering high blood pressure, treating heart disease and quitting smoking.
- **Poor nutrition, dehydration, and certain substances like drugs or alcohol.** Treating conditions like insulin resistance, metabolic disorders, and vitamin deficiencies can reduce or eliminate symptoms of dementia altogether.
- **Single trauma or repeated brain injuries.** Depending on the location of the injury, things like cognitive skills or memory may be impaired.
- **Infection or illness that affects the central nervous system,** like Creutzfeldt-Jakob disease and HIV. Some conditions can be treated, like liver or kidney disease, depression-induced pseudodementia, as well as operable brain tumors.

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Since we've seen a few of the things that can be contributors to developing dementia, that leaves the question of whether or not the disease can be delayed or prevented. We've already covered the fact that there is currently no cure for the disease, but can it at least be slowed down or prevented at all? Surely there must be something, right?

Recent research on the topic suggests that practicing good health habits and mental stimulation can help to prevent dementia altogether or, at the very least, slow its progress. In the same way that physical exercise can keep you physically fit and healthy, so also can mental exercise keep you mentally healthy, no matter your age.

Strategies to help mental clarity:

- Exercise consistently
- Eat a brain-healthy diet
- Challenge your mind
- Get regular and restful sleep
- Minimize stress
- Avoid smoking and drinking

Types of Dementia

As we learned all the way back in the first chapter, dementia isn't just one specific condition that causes memory and brain impairment. Rather, it is a blanket term used to reference many conditions. Many people, when they think of memory impairment issues, often think of Alzheimer's disease first and foremost. And while it is, indeed, the most common form of dementia, there are many more. In this section, we will list some of them and take a look at each more in depth.

Like we just mentioned, there are several different types of dementia, and some of those include the following:

- Mixed dementia
- Fronto-temporal dementia (Pick's disease)
- Dementia with Lewy bodies
- Parkinson's disease dementia
- Normal pressure hydrocephalus
- Huntington's disease

Now that we've named a few of the other types, let's now take a quick look at each, including Alzheimer's, in a bit more detail:

Alzheimer's disease

Initially described by a German doctor, Alois Alzheimer, this disease causes "plaques and tangles" to develop within the brain itself. These foreign structures can block normal chemicals that send messages around the brain, which causes brain cells to die and eventually results in the overall volume of the brain shrinking.

Vascular dementia

This type of dementia is caused by issues with blood circulation within parts of the brain that don't get enough blood and oxygen, ultimately causing the death of brain cells.

Just as there are numerous types of dementia in general, there are also multiple types of vascular dementia, like stroke-related and small vessel disease related dementia. Another type is a mixture of both of those.

- **Stroke-related dementia (post-stroke dementia)** Strokes cause damage to the brain by blocking blood from going to a specific part of the brain. Symptoms are dependent on where exactly the brain is damaged. Someone may experience weakness or paralysis on one side of the body or have difficulties with communication. Stroke-related dementia may also be caused by several small strokes on the outer brain called the cortex. These may sometimes be called TIAs (transient ischaemic attacks). They can be so small that someone may not even notice them, though their effects accumulate so that mental abilities are also affected.
- **Small vessel disease related dementia** Damage to tiny blood vessels deep within the brain may lead to slow development of dementia symptoms, and may also be hard to separate Alzheimer's disease from Vascular dementia when making a diagnosis. What's more—some people may have both.

Mixed dementia

This is a condition where, normally, both Alzheimer's and Vascular dementia happen at the same time. Many experts think that Mixed dementia occurs more often that initially thought. They also noticed that it became more common with advanced age.

It's also important to take note of whether or not an individual has Mixed dementia, as the combination of the two diseases may have a greater effect on the brain than just having either by themselves.

Fronto-temporal dementia (Pick's disease)

This type of dementia was originally called Pick's disease, and it covers a wide range of conditions that are caused by damage to the frontal or temporal lobes of the brain. These are the parts of the brain that are involved with behavior, emotional responses and language, and those who suffer from Frontotemporal dementia could show early personality or communication changes, more so than memory or orientation issues, which are more prevalent in Alzheimer's disease.

Dementia with Lewy Bodies

This type of dementia is named after the person who discovered it. He found tiny, round deposits of protein, called Lewy bodies, within nerve cells in the brain. These Lewy bodies happen in other conditions as well, such as Parkinson's disease dementia.

While Dementia with Lewy bodies can show symptoms close to those found in Alzheimer's, persons with this disease may also experience the following issues as well:

- Periods of both alertness and drowsiness
- Fluctuating cognition
- Visual hallucinations
- Becoming slower with physical movements

Parkinson's disease dementia

Sometimes those with Parkinson's disease can develop dementia—normally many years after they were initially diagnosed with the disease. The symptoms can greatly mirror those present in Dementia with Lewy bodies.

Normal pressure hydrocephalus

This is a disorder of the brain where extra cerebrospinal fluid accumulates in the spaces in the brain (called the ventricles), which, in turn, puts pressure on the brain. This pressure could lead to issues with both thinking and reasoning, as well as difficulty walking and loss of bladder control.

Huntington's disease

This is a progressive, hereditary condition of the brain that is caused by a defective gene. It causes changes within the central area of the brain, that affects movement, mood, and cognition.

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Mild cognitive impairment

Now that we've looked at various other types of dementia, let's quickly take a look at Mild cognitive impairment, or MCI.

This term does not refer to any one particular medical condition or disease. Instead, it is a general term that refers to a slight but measurable change in the functioning of the brain.

Likewise, the word "cognitive" is a more general term that refers to mental processes, like memory, concentration, speed of thought, ability to use language, organization, and problem solving. MCI may also be defined as a deterioration of any of these which is more than expected for the person's age, but is not severe enough to be classified as dementia.

Dementia in younger people

A lot of people have the assumption that dementia only affects those people who are older. However, in the UK, it also affects around 18,000 younger adults as well (those between age 40 and 64). These individuals could have similar symptoms as those found in their older counterparts, but the care required for them may be different, since they are more likely to be working and have families to support. When these younger people start to have dementia, they are also more likely to be physically active than older people.

When dementia affects a person who is under age 65, doctors often describe it as "working age dementia" or "early or young onset dementia".

Alzheimer's disease is the most common form of dementia in younger adults, but there are also others who have Vascular dementia, Dementia with Lewy bodies, Fronto-temporal dementia or any other rarer types of the disease as well.

Next, we will give a summary of symptoms associated with dementia, as well as go into each in a bit more detail.

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Summary of Dementia Symptoms

There are a multitude of symptoms associated with dementia, and which ones a person develops depends upon the type of dementia that he or she has. Symptoms can and do vary from person to person as well. Some might have only one symptom at the start; others may have multiple ones. Now, let's take a look at a few of the symptoms a little more closely.

Thinking Problems

The early signs of dementia are often more mild and could get worse very slowly. Of course, this means that those with dementia may not be aware of the symptoms for quite a while. Some typical symptoms are:

- Memory loss, especially for memories with recent information, like messages or names.
- Difficulties with tasks and activities requiring organization, decision making and planning.
- Confusion in unfamiliar environments
- Difficulty finding the right words
- Difficulty with numbers and handling money in shops
- Changes in mood and personality.

Some people don't understand that they even have problems, even when said problems are more than evident to others. This is called "lack of insight."

Behavior changes

The changes that come with dementia can cause people to feel anxious, lost, confused, and frustrated. They might be aware that something isn't as it should be, but they may be unable to recognize what it is. Even though each person handles these types of feelings differently, there are certain reactions that are common among every individual:

- Repeating questions or doing an activity
- Walking and pacing up and down
- Aggression, shouting and screaming
- Becoming suspicious of other people
- Low mood
- No concept of time

Physical changes

Some types of dementia can have an effect on someone's physical abilities as well. They may have:

- Poor coordination that might make them slow and clumsy when doing everyday tasks, like washing or dressing
- Mobility issues that could lead to slow movement and walking and, later on, losing the ability to walk completely.
- Balance problems that can contribute to their risk of falling
- Loss of control of their bladder, and, in some people, bowel, which can lead to incontinence in later stages of the disease.
- Loss of appetite and difficulty swallowing can lead to weight loss

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Medication and Treatment

As we've seen previously, there is currently no official cure for dementia, though there are drugs and treatments which can work to slow the progression of the disease. There are many, and while we don't have time to go into depth on each and every one, as that would take up much more time than we have (and we must continue our journey together), let's quickly take a look at some things that can help.

Medication to slow down or relieve effects of dementia

At this time, there are currently four drugs available for those with dementia:

- Donepezil (often known as Aricept)
- Rivastigmine (Exelon)
- Galantamine (Reminyl)
- Memantine (Ebixa)

Medications like this may also be prescribed to those with Mixed dementia who also have an element of Alzheimer's. They will, likely, be prescribed initially by the Memory Clinic, with your local GP taking over any repeat prescriptions. Your doctor can also help you to find more information as well as give you more information on these medications, and can help get answers to any questions you might have.

Medication to treat underlying conditions

While there are, sadly, no treatments available for Vascular dementia, GPs might prescribe medication to treat things like high blood pressure, high cholesterol, heart problems, and diabetes. These can help to lessen the risks for strokes, which can increase the progression rate of Vascular dementia.

Individuals who have Vascular dementia might also be given some advice about how to make lifestyle changes in order to reduce risk of strokes, like quitting smoking, exercising, and eating healthy.

Medication to relieve special symptoms

Medication can also be given in order to help symptoms like low mood and anxiety, hallucinations, aggression, agitation and sleep disturbances. The range of drugs that may be prescribed include:

- Antidepressants to help treat symptoms of depression, anxiety, agitation or apathy
- Sleeping tablets or sedative antidepressants for sleep disturbance
- Anticonvulsant drugs to treat symptoms of agitation
- Antipsychotic drugs for hallucinations, delusions and sometimes even for severe agitation or aggression.

You should be aware that all these medications can have side effects, so it is very important to try non-drug treatments first. If you can discover the cause of a person's symptoms and make the necessary changes or provide the right support, medication may not be needed. A Memory Clinic or your doctor will be able to give you the advice you need in order to help reduce symptoms without relying on medication.

Antipsychotic medications are often only considered when other treatment options have proven unsuccessful. This is because the side effects include sedation, dizziness, muscle stiffness, restlessness and an increased risk of strokes.

Finally, let's take a look at some medications to relieve pain.

Medication to relieve pain

Both recognizing and treating pain is very important for a person suffering from dementia, since they may be unable to say that they are experiencing pain or understand any questions about if they are in pain. They may depend upon their caregiver to notice symptoms of pain; for example, difficulty sleeping, changes in mood or behavior, facial expressions and body language. If you suspect the person may be in pain, you should consult the doctor.

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Like we said, there are many types of treatments and medications available, but to go through each and every one of them in detail would take up far too much time. It is also important to note that this book should not be used as a substitute for advice and information given by a medical professional. They will also be better able to answer any questions or concerns you may have regarding the dementia or the medications or treatments available to you. If you are concerned that someone you love is showing symptoms of dementia, they can help put you on the path to receiving a diagnosis as well.

So far, we've covered a lot of information regarding what to do after receiving a diagnosis and how to understand the road ahead. But what about that first step? What should you do immediately after? If you've had questions about that part of the journey, stick around. We'll be looking at that in the very next chapter.

Chapter 5: First Steps to Take After Diagnosis

Both *The Wizard of Oz* and *The Lord of the Rings* are classic stories that feature main characters going on an unbelievable journey—Dorothy simply wants to find her way back home, while Frodo is charged with the seemingly insurmountable task of saving the entire world. Of course, in each case, there were opportunities for them to do just what they needed to do in order to complete their tasks soon after they arrived: Dorothy could have only clicked her heels as soon as she learned about the shoes, and Frodo could have just ridden the eagle to the volcano and dropped the ring in.

Boom. End of movie.

However, both of those stories are not about just finishing the task, but about the journey, and how each set of characters grows and changes over the course of the books and respective films. Both also feature characters who are at first unwilling to complete the tasks they are given, and yet both sets of main characters, even though they do so with great trepidation, are willing to take that first step—Dorothy down the yellow brick road, and Frodo in his first steps out of the Shire.

And thus, their journeys, their adventures into the great unknown, begin…

In the same way, receiving a diagnosis of Alzheimer's or any other form of dementia is also a journey. And just like the characters we talked about a moment ago, you also have friends that can come alongside you or your loved one to face the journey through dementia together. There were times in the stories where it seemed as though the heroes were beaten and all hope was lost, but eventually they were able to accomplish the task that had been set before them. But before they could get there, they had to be willing to take that first step in the right direction.

It all began with that first step.

In this chapter, we will discuss about just what to do, how to take that first step, after receiving the news about dementia. So, what do you do after hearing the diagnosis?

As you're no doubt aware, since you are reading this book, getting a diagnosis of dementia can often be a very difficult, highly emotional time. It may be sudden or come as a shock, or it could bring some clarity to the issues you or a loved one have been having lately. No matter what, though, it can be very tough to come to terms with the diagnosis, let alone know what to do after getting it.

First and foremost, it is important—vital even—to have a good group of support. The person with the diagnosis, as well as close family members, should certainly talk things over with different professionals. It would be good to ask any questions about the diagnosis they or you might have, as well as what the diagnosis might mean for them. It is also important to mull things over to both think about and talk about the future. Getting information on the help and support that is available is crucial, as well as looking into how to stay well both physically and mentally.

It is also important to note that receiving a diagnosis of dementia should not stop someone from trying to be in control of their lives or from doing anything that they enjoy doing. The person should be supported to stay as independent, active, and engaged, as well as fully involved in making their own decisions and choices for as long as they possibly can.

Now, let's take a look at some things you can do to better come to terms with the diagnosis.

Coming to Terms with a Diagnosis

Learning that someone you love has been diagnosed with a disease that will cause them to slowly lose themselves can be, and is, a devastating blow—both for the individual as well as his or her family members. As such, it can take quite a while to fully accept and come to terms with it. Along with the diagnosis, the person may experience a plethora of emotions, including shock, fear, anger, or possibly even relief at finally having an explanation for their symptoms. This is quite normal, and these feelings could change from one day to the next. The person's friends, family and other loved ones may also experience a variety of emotions, and may also have difficulties accepting what is going on.

Talking about the diagnosis, as well as sharing feelings with friends and family can be of great help. Discussing the diagnosis openly and with honesty will allow each one to think about how they can better support each other during this time, as well as help them to find ways for the individual to keep on living both an independent and active life, and will also help them to start thinking about the future.

The person may also wish to tell others about their diagnosis. They may want to talk to a counsellor, or a health or social care professional, or perhaps even other people who also have dementia. Knowing both you and they are not alone can be of great comfort for everyone involved. In some places, there may even be post-diagnosis support groups. This will also better help the individual and their families to come to grips with the diagnosis while also looking at different ways to live well even with dementia. Counselling may also be an option, which would open up an opportunity for them to get the weight of the diagnosis off their chest as well as talking through both it and their personal needs also. Your GP should be able to point you in the right direction and give you more information about any post-diagnosis support groups or counselling services available in your area.

However, who to tell and how much to say and when, should all be left up to the person with dementia. It is possible they could be worried about how other people around them may react to hearing the news. Some choose to tell their close family members only, while others open up to friends outside the family as well. Some may confide in neighbors or choose to tell other members of their community. But no matter what the person decides, it should be what they feel would best be beneficial to them.

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Treatments

We've already seen that there is no official cure for dementia, but let's now turn our attention to some things that individuals can do to help alleviate some of the symptoms they may experience. Since you've made it this far, you know that there are both drug and non-drug treatments available, as well as some other easy things that people with dementia can do to help with symptoms. Let's take a better look at each of these things now.

Drug Treatments

An individual who has mild to moderate Alzheimer's could be prescribed donepezil (Aricept), rivastigmine (Excelon) or galantamine (Reminyl)—all medications we briefly touched on at the end of the last chapter. These drugs are known as acetylcholinesterase inhibitors. They do not provide a cure for Alzheimer's, but have the potential to relieve memory issues and improve alertness for a short while. Someone with moderate Alzheimer's who is unable to take an acetylcholinesterase inhibitor could be offered memantine (Ebixa) instead. This drug is also given to those with severe dementia.

For someone who suffers from Vascular dementia, the doctor should give the individual medications that help deal with any underlying conditions, such as high blood pressure. This can help to slow down the progression of the disease.

If someone is diagnosed with Dementia with Lewy bodies, the doctor can prescribe one of the acetylcholinesterase inhibitors we talked about above to better deal with the symptoms of hallucinations or delusions.

Finally, an antidepressant may be prescribed for someone suffering from frontotemporal dementia.

Non-Drug Treatments

Along with drug treatments, there are also a wide variety of non-drug treatments available as well. Such things include: talking therapies like counselling which may help individuals better address and come to terms with the diagnosis. Cognitive behavioral therapies, which work to help people change the way they think and what they do (hence the "cognitive behavioral" part), could be offered to help combat depression.

It is possible that someone suffering from dementia may also find help in cognitive rehabilitation—the goal of which is to reduce the impact of poor memory on someone's quality of life—and cognitive stimulation (in activities and exercises that work to improve memory and communication skills). Other popular activities, such as life story work, art, music-based activities and aromatherapy are also helpful. Your GP, memory service or local Alzheimer's Society can give you an idea of what may be available in your area as well as giving you an idea of what may be the most beneficial for yourself or your loved one.

Living Well

Staying Healthy

Even though someone has dementia, he or she should not feel ill or unwell. Any physical illnesses can also affect someone's ability to cope, and could make them more confused or forgetful than they could already be. If the individual *does* feel ill or unwell, they should make an appointment to speak with their GP. Having regular checkups with the doctor is important, and anyone who also has any other long-term health conditions, like diabetes, needs to make sure that they are managed properly as well.

Those who have dementia are also more likely to be at risk to develop depression. If they are feel low, anxious or irritable on a regular basis, they should speak to the doctor, as there are treatments available to help combat depression.

Anyone who has a diagnosis of dementia and is also taking more than four medications needs to speak to his or her doctor to review the medications. Medications can cause side effects that can affect someone's wellbeing, like dizziness or an increase in confusion.

Dementia patients should also have regular dental checkups to help keep up their oral health. Regular sight and hearing checkups are also highly recommended, as issues in these areas may also affect how well the dementia is managed.

Also important for individuals with dementia is to eat a balanced diet and drink plenty of fluids, as these are important to keeping up both physical and mental wellbeing. Someone who has dementia will want to eat a variety of foods, and a dietician will be able to provide them with the necessary information and advice they may need on eating and drinking. If needed, the person's doctor can make a referral for them.

Exercise can be great for someone with dementia, and have a huge impact on their wellbeing too. It is good for not only physical health, but mental health as well. Exercising doesn't have to be anything drastic either, it could be as simple as walking, chair exercises, gardening or tai chi. Any of these things is able to be adapted to meet a person's specific needs. Perhaps unsurprisingly, the most effective exercises are those that the person enjoys and those they can incorporate into their daily routine.

Being able to stay involved socially is just as important also, as is remaining physically and mentally active. Keeping involved and active can help someone with dementia to maintain skills and independence, and it also serves to reduce feelings of loneliness. It could possibly help with sleep patterns and even potentially prevent depression. These activities can be anything that the person enjoys and wants to do, and they should also be brought into their everyday routines.

If someone has trouble with a particular activity, it could benefit them to have the activity adapted to better suit their needs, or find new ones that could be more enjoyable for them. It is important that the individual and his or her loved ones don't concern themselves too much with "results" from activities and instead focus on the process and enjoyment that the person receives from doing them.

Maintaining Independence

As it does with any disease, having dementia can and does make day-to-day life harder than it normally would be, and day-to-day life is often hard enough. Because of this, someone suffering from dementia may have to change how they go about doing things. There are a multitude of technologies and devices designed to assist those who need them. They can definitely help, and someone facing a diagnosis may certainly want to consider using them. Your local Alzheimer's Society or GP should be able to point you in the right direction if you'd like more information on things (like clocks, calendars and medication prompts as well as fall sensors) that may be available to you or your loved one. The individual should also be shown how to use these things properly so that they can be better taken care of.

It may also help to consider changes that can be made to the person's home environment to further enhance both independence and safety. As an example, it can be beneficial to increase light levels in the home and get rid of tripping hazards, like loose rugs. The fire department also does free home safety visits, so you can schedule one if you feel it is necessary or just as an extra precaution.

An occupational therapist (OT) can also give you additional information on how to help yourself or your loved one remain safe and independent in the home. The individual's doctor will be able to refer an OT if needed.

Planning Ahead

If someone has been diagnosed with dementia, they may wish to take some time to consider the future and any wishes they have. As things progress with the disease, it will be harder for them to make any decisions on their health, care (including end-of-life care) and finances.

Mental capacity is the ability to make one's own decisions, and those who are unable to do this are said to lack "mental capacity". Planning for the future will allow the person with dementia to make their own choices and decisions about the future care in advance, just in case there comes a time when they are no longer able to do so. These wishes should be discussed with an individual's family and others who are close to them.

Wills

This document lets someone chose who gets their money and possessions when they pass. It is still possible to create or make changes to a will even after a diagnosis of dementia, so long as the individual can show that he or she is still able to understand the decision they are making, as well as any implications that may come along with those decisions.

Lasting Power of Attorney

Creating a Lasting Power of Attorney (LPA) lets someone with dementia give someone they trust (called the attorney) the authority necessary to make certain decisions on their behalf. Usually, this is a close friend or family member, and all decisions made by the attorney must be in the individual's best interests. There are two differing types of LPA, so let's quickly take a look at each of them:

- **Health and Welfare LPA:** The attorney is able to make decisions about a person's healthcare (like medical treatment) and welfare (where they live). These powers may only be used if the individual can no longer make these decisions on their own.
- **Property and Affairs LPA:** They attorney has the power to keep track of and manage the person's money, property, and affairs on behalf of the individual. Such things could include paying bills, collecting income and benefits, accessing bank accounts and even selling a house.

They attorney will not get to take control immediately after the LPA is made. In order for this LPA to be used, it must first be registered with the Office of the Public Guardian (you can search for your area's OPG online). The attorney may only make decisions on behalf of the individual after the LPA has been registered, and when they can act might depend on how the document has been set up.

Anyone who wishes to set up an LPA will also need to have the mental capacity to do so. You may also wish to consult an attorney, who will then be able to help you set up the document as well.

Advance Statements

This is a record of a person's preferences and priorities concerning their future. It is able to cover things like where they wish to live or how they like to perform daily tasks (like whether they prefer a shower over a bath). It will then be used if the person becomes unable to make such decisions of their own accord. The document is also not legally binding, but it should still be considered when deciding on the person's best interests. If the person elects to set up an advance statement, they should tell people about it and keep it somewhere they know it will stay safe.

Advance Decisions

An advance decision allows a person to have a say when it comes to their future medical care, by letting them to refuse—in advance—any specific medical treatments or procedures. This is just in case the person becomes unable to make these decisions on their own. Such decisions may include whether the person would be resuscitated if their heart stopped. Unlike an advance statement, an Advance Decisions document **is legally binding**. Any person wishing to set one up should speak to their doctor. It is also important to review the document early and regularly, as well as to revise it as necessary, so that it will always continue to reflect the person's views and wishes.

Financial Matters

Someone who has just gotten a diagnosis of dementia might wish to see that their financial matters are in order. It is vital that all such details can be found easily. Such documents can include the following: details of bank accounts, tax, benefits, pension, mortgage or rent documents, any insurance policies as well as their will.

Getting things in order early will help the person to feel more prepared when it comes to the future. It will also mean that when things eventually become harder to manage, they know that everything is already taken care of just the way they wished.

Benefits

Someone who has been diagnosed with dementia may also be eligible for a variety of benefits. The Social Security office or Alzheimer's Association will be able to help you in finding out what benefits you or someone you love may qualify for.

Main benefits that someone may be entitled to include Attendance allowance (AA) for those 65+, or personal independent payment (PIP) for those under 65. These benefits are not based on a person's financial situation and are also tax-free. Again, the Social Security office or Alzheimer's Association can help answer any questions regarding this that you may have.

Driving

Learning that one has dementia does not mean that they must stop driving at once. However, they will want to tell the DMV of the diagnosis, and will also want to let their auto insurance company know. The DMV will also request a report from the person's doctor and ask them to take a driving assessment. These will then be used to determine whether or not the person should continue to drive. As the disease progresses, there will come a time where the person *will* need to stop driving altogether. Having to do so will be very difficult, and it can take quite a while to adjust.

Working

Someone may get a diagnosis while they are still working. This does not mean, however, that they will need to quit work right away, but there are a few things they will want to consider, so let's take a second and look at them now:

- **Talking to the employer:** It can help for the person to talk to their employer about the diagnosis. With some jobs, there could even be a legal obligation to tell them, and this will be in the person's contract, if so. Once the conversation happens, the employer is then obliged to make "reasonable adjustments" in order to support the person to keep them working if they wish to do so.

- **Thinking about the future:** The person may also wish to take some time to think about the future, and to get advice regarding their rights, pension, or any work-related benefits they may be entitled to receive as well.
- **Leaving work:** The person might decide to retire early or quit working. If they choose to leave, they should get advice regarding their pension.
- **Benefits:** Someone who is of working age could be eligible to receive a variety of benefits. This will depend on their individual circumstances, and getting a full check of their benefits will help them to know what exactly they are entitled to.

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It is quite important that someone who has a diagnosis get advice about working and dementia. They can speak to their human resources department, trade union (if they have one). Their employer should be able to point them in the right direction if they are unsure where to go.

Support and Services

After getting diagnosed with dementia, a person could be unsure as to what to do next or where to go to receive help. It can be hard to ask for help, and the individual may not feel as though he or she actually *needs* it. Even so, it would be helpful for them to see what may be available in and around their area, no matter if they need help right now or may need it in the future.

If needed, information, advice and support can be found in numerous places:

- **Health professionals**—doctors and other health professionals will be able to answer any questions you may have or point you in the direction of any help or services that may be available in your area. Others, like occupational therapists and counselors will be of help to you or your loved one as well if needed.
- **Charities and other not-for-profit organizations**—can help provide support, advice, or other information for those with dementia or their caregivers and family members. These may be either national or local, and can offer a range of local services such as dementia advisors or dementia

support worker services, support groups, activity groups and telephone helplines. Your local Alzheimer's Society can also share information about what may be available in your area.

- **Social services and social care—**these groups can help to work out the care and support needs of the individual with dementia as well as his or her caregiver. They can even arrange for care and support to be provided, if need be. If you would like to know more information regarding this, you can contact your local social services department. Anyone who would like to have their needs assessed should ask about a community care assessment, and caregivers are able to have their needs assessed as well—through a caregiver's assessment. Both information and advice from social services are, thankfully, free.
- **Private companies—**can also give care and support services at home, though there could be a charge for these services. You can find out the details of local registered companies by talking with social services, and your doctor may even be able to help in this area as well.

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Places like the memory clinic, social services or the local Alzheimer's Society office or any other local voluntary organizations will be able to provide information on what may be available in your local area. Again, some of these services may be paid, but some might also be free. If you are in need of help, it can be good to keep these places in mind.

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Services for Younger People with Dementia

As we've seen previously, it isn't just older people who suffer from dementia. And while it is certainly important to get older individuals the help and treatment they need, what about those who are younger and have dementia? Surely there is help available to them as well, right?

Someone who is under age 65 who has been diagnosed as having dementia may possibly wish to have services that have been specifically designed to help younger people who suffer from dementia. These things can include the following:

- Support groups
- Advocacy
- Counseling
- Day Centers

The individual's family could also benefit from getting specialist support as well. And speaking of that, the provision of specialist support services for younger adults with dementia isn't great, but the number of available services is increasing. The person's doctor, the memory clinic, or the local Alzheimer's Society can provide information on what services or avenues of support are available within your area.

So, until now we've been focused mainly on providing information about what the person who has been diagnosed with dementia can do for help. While we hope that this book can do exactly that, we also want to make sure and give advice for family members and friends or other loved ones as well. With that in mind, let's spend the next few minutes and end the chapter by looking at a few of the first steps available after they learn that their loved one has been diagnosed with dementia.

One of the most important first steps you can take is to get that diagnosis, so if you've done that, that's one less thing you have to worry about. Some other things you can do are:

1. **Recognize you are going through a variety of emotions**

   Getting the news of a diagnosis and the changes that will follow it can often cause a number of feelings to well up in us. These can range from: anger, denial, embarrassment, frustration, fear, sadness and guilt. It is perfectly normal to feel all these things and quite common among caregivers, and they can come and go. People sometimes even get depressed, and if you or someone else are being overwhelmed by any of these feelings, you should certainly make it a point to talk with your doctor. It is also crucial to realize that the person with the disease as well as any other family members could be feeling the same emotions.

2. **Learn about Alzheimer's and other dementias**

   It is also a good idea to learn as much as you possibly can about the disease, as well as providing care to the person. You will also want to know how the disease can affect an individual, what kinds of changes to expect, and how you can better give them help and support to maintain independence and a good quality of life. Be sure to share the information with those who are closest to the person, like other family members, co-workers, or friends, as it can help them better understand what is going on, and thus provide better support as well. Contact your local Alzheimer's Society for more help and resources.

3. Recognize the disease affects a person's abilities

Things like Alzheimer's get worse over time. It can and does affect how the person functions from one day to the next. Find out as much as you can about the disease, and the changes it will bring, so that you, as a caregiver, can have more realistic expectations of the person's abilities. Inquire how you can help them remain independent and keep a feeling of control. Above all, be patient.

4. Don't lose sight of the person

No matter how someone is affected by the disease, he or she is still a person, and still deserves to be treated with respect and dignity. Even though they will lose the ability to do certain things, their feelings and emotions stay intact, so too will the need for belonging and companionship. Give the person things to do and interactions that will bring them joy and a reason to celebrate. Instead of focusing on what they can't do, focus on what they still *can*. This can help to greatly improve quality of life and help them maintain a sense of self.

5. Explore treatment options

As mentioned multiple times already, there is currently no cure for Alzheimer's, but treatments and medications are available to help with symptoms. Talk over the risks and benefits for each with the person's doctor. Also, your local Alzheimer's Society will have up-to-date information about any new treatments that may be available through any drug trials. If the person wishes to participate, you could be asked to help.

6. Recognize that caregiving can take its toll

Caregiving is a hard job for anyone, but especially when taking care of someone with dementia. While you're busy caring for them, don't forget to also take care of yourself. Caregivers are also at risk to suffer from their own mental or emotional issues, and it is important to recognize these things and take steps to care for yourself too. After all, you can’t take care of someone else if you aren’t first caring for yourself. Keep up your physical health, stay active and make healthy choices when it comes to food. Take time out for activities you enjoy!

7. Seek out help

You can also get in touch with your local Alzheimer’s Society to see what kind of help is available in your area. Community agencies may also offer practical services, such as help with any household or caregiving tasks. You could also have a network of family members or friends who would be willing to help give support to you and your loved one. Find out exactly what you need by thinking about any strengths and weaknesses, what you need and what would also help you to become a better caregiver. It’s possible that family and friends want to help, but they may not know what to do. Figure out who can help, and then ask that person. Make yourself knowledgeable regarding the system of resources your community or local area may have. Learn how the services they provide work, what you can expect from them, and how you can get access to them when you need them.

8. Develop a support network

Find a group of friends or others you are comfortable with and share your emotions and how you’ve been feeling lately. It could be a family member, close friend, members of a support group, or even someone at the local Alzheimer’s Society. The most important thing is that you can find an outlet where you can express your feelings. Caregivers will often suffer from the effects of isolation and loneliness, so it is crucial to stay connected to those around you.

9. Plan for the future

It is also important to help the individual to plan for the future. Decisions about such things as work or any personal issues need to be taken care of while he or she is still able to be involved in the decision-making process. You could help get all the paperwork together, if it isn’t already. Be sure and see that someone has been chosen to preside over the financial and healthcare decisions when the person is unable to do so themselves, or that he or she has documented their wishes for such a time. Both legal and estate planning should also be on your list of discussion topics, and there should be a backup plan in case you or someone else would be unable to provide care.

10. Know the Alzheimer's Society is here to help

The AS can help you by:

- Giving you the necessary information so you can learn more about the disease, caregiving and any coping strategies.
- Giving support, either by telephone counselor or a support group.
- Registering the individual with the disease with the AS MedicAlert Safely Home program to help emergency responders to identify the person who is lost and bring them back to their families.
- Locating any services available in your community.

The Alzheimer's Society also has information and support programs available too, and you can contact your local chapter for more information.

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Let's next look at eight more things that your or other family members can do after you first learn of your loved one's diagnosis.

1. Let reality sink in

No matter if you have secretly suspected the diagnosis for a long time or it hits you like a brick wall, wrapping your mind around the reality of the situation can be a difficult—yet necessary—process. This is especially so if most of the burden of care falls to you. It can also be helpful to recognize early on that what lies ahead of you is nothing short of an emotional rollercoaster, and things will get more challenging as time goes on, and the experience of it all will vary greatly from person to person. Even though your main focus will be on your loved one's health, it is vital to not ignore your own and what you're experiencing too, as well as how it affects the many areas of your life. Things like disbelief, denial, grief, fear, and financial worries are some of the most common feelings you can expect, and it is important to talk with other family members to help the situation become more real to get a reality check as to how you're actually handling things.

2. Get to know the turf

Dealing with Alzheimer's is rarely a disease that those in the middle of life have very much firsthand experience with. As we've said throughout this book, it is important to know just exactly what you're dealing with, and there is loads of information out there for you. Critical issues, like stages of Alzheimer's, common caregiving issues, and any available treatments, including the medications prescribed by the doctor and any lifestyle changes that can slow the progress of the disease are very important to know.

3. Talk with a geriatric care manager or Life Care Planning Elder Law Attorney

A lot of people often skip this very important step. Those professionals who have experience with advising those with Alzheimer's as well as their families can often be a shortcut to get through the ocean of resources and questions in front of you. Geriatric care managers often typically have training in the study of aging (gerontology), social work, nursing, and/or counseling.

You can use this person to:

- Locate any good local resources
- Help to coordinate care if your parent or loved one has other medical issues
- Provide advice on how to handle the symptoms and behavioral issues
- Help to safety-proof your loved one's home or your own
- Keep track of routine care, like appointments or prescriptions
- Mediate family disagreements
- Make home visits
- Refer you to specialists

To start, you may only want a go-to person who is able to answer any initial questions, even if you hire a consultant in the long-term.

At our Elder law firm we focus on Life Care Planning. This means we have geriatric care managers on staff. This creates a holistic approach between legal, financial, and care issues.

4. Get Organized

About Money: If one hasn't already happened, be sure to have a serious talk with your loved one about his or her financials. You'll need to know any monthly resources available, as well as resources available over long-term periods as you make plans for the future care that he or she is going to require. The best time to start taking legal and practical steps to protect their assets would be during the early stages of the disease.

About Records: Establish systems for record-keeping purposes. Within designated files or binders, put your loved one's medical records, financial records, and any helpful personal information (like names and contact information of neighbors and friends, hair stylist, a pastor or rabbi, or any others). The best time to do so is now, while he or she is still able to help you gather the information, and give necessary permissions to medical professionals to share information with you. This is especially important if there are other health conditions on top of the dementia.

About Dates: Create a central calendar in your loved one's home to help them better keep track of appointments, support group meetings, and any other commitments. A lot of geriatric care providers who deal with dementia issues often recommend a portable dated diary or journal where he or she can, along with your help, begin the habit of writing down notes, details of conversations, and any other day-to-day things that he or she wants to remember.

About Help: Start your own running resource list of names and contact information of those who can help provide care, like local Alzheimer's organizations to friends and family who can run errands and help you and your loved one in other ways. Talk over with siblings and other family members a good way to keep in touch.

5. Plan ahead for care

It could be possible that nothing in the life of your loved one needs to change right after receiving the diagnosis (the only exception is driving), as most people in the early stages of Alzheimer's can stay in their own homes with sufficient checks and supports. Being able to live independently for as long as possible can be empowering for them and may even slow the rate of decline, but it's important to also be practical. As their judgement and problem-solving skills worsen, they will eventually require more elaborate help. Right now, though, with some research, you can better identify the needs that may arise in the near future—things like self-care, cooking, home maintenance, paying bills and home safety. Creating a basic outline of these issues, and the ways to deal with them, can help everyone feel better prepared to tackle them when they come. Think of any plan as a work in progress that will need updated and revised as you go along. You can get insider information on those issues you'll likely run into from the doctor, a geriatric care manager or consultant, your local Alzheimer's Associations and online support groups.

6. Encourage your loved one to share the diagnosis

In the beginning, it's best to let the person with the disease decide whom to tell and when. However, it's also important to nudge them, if you're comfortable doing it, to at least tell close friends or family so they can better offer support. If they refuse to tell anyone because of shame, you can try letting them know that Alzheimer's is a physical disease just like cancer or heart disease—and that over 4 million people in the U.S. alone share it—it's nothing to be ashamed of. If it is still an issue, consider bringing in a neutral party, like a nurse or geriatric care consultant to talk with them about the benefits to be had from sharing information about the condition, as well as any strategies as to how to make it as comfortable as possible. Though you may also find it good to tell close friends or family discreetly on your own.

7. Check out support for you and your loved one

Getting into a support group, either online or within the area, can be helpful, even if your loved one has been recently diagnosed. There are even specially-designed groups for just those individuals, as well as family members and friends. You can also learn a lot and get support by going to caregiving seminars or any classes available to you in your area. A particular type of support you may want to look into is informal caregiving training. Having regular meetings with a social worker or some other professional can help you to know how to apply Alzheimer's care within your specific situation. Confide to an inner circle of friends and family. Figure out who can best help you with day-to-day issues and caregiver responsibilities, especially if and when you're unavailable or need some rest or a listener of your own.

8. Have "the talk" about financial and legal inquiries

Take full advantage here and now of your loved one's ability to comprehend and understand, and make some good decisions now regarding any financial or legal issues, since these things affect everyone. Give your loved one some reassurance that the main goal is to help them to keep control, along with some support from you (or someone else) as needed, rather than to just take control from them. Such plans could involve asset management, wills, guardianship, and powers of attorney. If your loved one doesn't take care of such things while he or she is still able, you may need to muddle through expensive and distracting court proceedings later on to take care of financial or healthcare matters. If they are still hesitant or flat out refuse to make any concrete plans, try to meet with a qualified professional who will be able to serve as a neutral party, like a financial planner, lawyer, or social worker.

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Wow, that was a ton of information! I know it was a lot to get through, and I'm sorry, but there was so much that was important for you and your loved one, and any other family members or friends, to know. Hopefully this will help you to better take the steps necessary to not only help your loved one with the diagnosis, but yourself and your family as well.

In the next chapter, we'll focus mainly on the progression of dementia and any changes that you can expect as time goes on.

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Chapter 6: Progression of the Disease

Upon receiving the diagnosis of dementia, emotions can run rampant, and often we find ourselves caught in a limbo of disbelief or denial. We don't want to think of what will happen to our loved one as he or she makes the journey through this disease, so we push it back, to the furthest recesses of our minds to where, maybe if we just don't think about it for long enough, it will all turn out to be nothing more than a terrible nightmare. The fact of the matter is, though, that Alzheimer's *is* real, and as bad as things seem now, just hearing the diagnosis, the truth is that things will progressively get worse. I know that's really difficult to hear, but it's the truth, and something that we have to come to terms with.

So, to help us to do just that, this chapter is going to focus on the progression of the disease. Before we really dig deep into it though, let us take a few minutes and go through a general overview of its progression together, and then we'll break down each stage in a more in-depth manner.

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Overview of Disease Progression

Alzheimer's most often progresses very slowly through three general stages—mild (or early-stage), moderate (middle stage), and severe (late stage). Since the disease affects each person in different ways, each will also experience the symptoms and stages differently too.

The symptoms of Alzheimer's get worse gradually, although the rate at which they do will vary person to person. After receiving the diagnosis, an individual can live with the disease around four to eight years, but some may live as long as 20, depending on a variety of other factors.

Changes that are related to Alzheimer's happen in the brain well before any signs of the disease normally manifest. This time period, which may last for years, is often referred to as preclinical Alzheimer's disease.

The stages we'll look at below give you an overall idea of how abilities can and do change once symptoms appear, and the information below should only be used as a more general guide. As we've seen, these stages are separated into three categories: mild, moderate, and severe. You should be aware that it can be hard to place someone with Alzheimer's in a specific group since the stages might overlap.

With this in mind, let's take some time to look at each of the three stages:

Mild Alzheimer's disease (early-stage)

In the beginning stages of the disease, someone may still be able to function independently and might still drive, work and take part in social activities. In spite of this, the person may feel that they are having memory lapses, like forgetting familiar words or the location of everyday objects.

Friends, family or neighbors may also start to notice them having hard times too. By conducting a more detailed medical interview, doctors might be able to discover problems with memory or concentration. Some of the more common issues in this stage are:

- Problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having more difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object, or
- Increased trouble with planning and organization

Moderate Alzheimer's disease (middle-stage)

This is, most often, the longest stage of the illness and can last for several years. As the disease continues to progress, the individual will have a need for a greater level of care.

You might notice that the person is confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can make it hard to express thoughts or perform routine tasks.

It is likely that symptoms will be noticeable to others by this point, and such things may include:

- Forgetfulness of events or about one's own personal history

- Feeling moody or withdrawn, especially in regard to socially or mentally challenging situations
- Being unable to recall their own address or telephone number or the high school or college they graduated from
- Confusion about where they are or what day it is.
- Needing help to choose proper clothing for the seasons or the occasion
- Trouble with controlling bladder and bowels in some people
- Changes in sleep patterns, like sleeping during the day and being restless during the night
- An increase in risk of wandering or getting lost
- Personality and/or behavioral changes, like suspiciousness and delusions, or repetitive behaviors like hand-wringing or shredding tissues

Severe Alzheimer's disease (late-stage)

This is the final stage of disease, and the one where people lose their ability to respond to their surroundings, carry on a conversation and, eventually, to control their movements. They could still say words or phrases, but communicating things like pain is difficult. Memory and cognitive skills continue to worsen, and as they do, changes in personality may occur, and the person needs extra help with daily activities.

During this stage, someone might:

- Need full-time, around-the-clock help with daily personal care
- Lose awareness of any recent experiences as well as of their surroundings
- Need high levels of help with daily activities and personal care
- Experience changes in physical abilities, like walking, sitting, and even swallowing
- Have increased difficulty with communicating
- Become vulnerable to infections, like pneumonia

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Progression Step-by-Step

Now, we're going to break down the progression of the disease in a step-by-step manner and take a look at the changes a person can experience, as well as any emotions they are likely to be feeling as the disease continues its course. As with the information in the last chapter, we have a lot to cover, so let's get started.

Aggression and Anger

Aggressive behaviors can be either verbal or physical. They may present suddenly, for seemingly no reason, or may result from the individual being frustrated. While it's true that this kind of behavior can be hard to deal with, understanding that the person who is sick is not acting this way on purpose may help.

Aggressive behaviors and outbursts can be caused by a number of things, such as physical discomfort, environmental factors, and poor communication. Here are some questions to consider for each category when trying to determine the reason for the aggressive behavior:

Physical discomfort

- Is the person able to let you know that he or she is feeling physical pain? It is quite common for those with Alzheimer's or other forms of dementia to have urinary tract or other infections, but because they have lost cognitive function, the cannot articulate or identify the reason for their discomfort and may be expressing it through aggression.
- Is the person tired due to inadequate rest or sleep?
- Are there medications that are causing side effects? These are especially likely to happen when someone is taking multiple medications for many different health conditions.

Environmental factors

- Is the person being overstimulated by loud noises, an overactive environment or physical clutter? Things like large crowds and being surrounded by unfamiliar people—even in one's own house—can be overstimulating for someone with dementia.
- Does the person feel lost?
- Many people often function better at certain times of day—with mornings being typically best. Be sure to consider the time of day when making appointments or scheduling any activities. Pick a time when you know the person will be most alert and best able to process new information or surroundings.

Poor communication

- Are your instructions simple and easy to understand?
- Are you asking too many questions or making too many statements all at once?
- Is the person picking up on your own stress or irritability?

How to Respond

- **Try to identify the immediate cause.** Think about what happened right before the reaction that might have triggered their aggressive behavior.
- **Rule out pain as a source of stress.** Pain can cause someone with dementia to become aggressive.
- **Focus on feelings, not facts.** Rather than focusing just on specific details, think about the person's emotions. Look for feelings behind their words or actions.
- **Don't get upset.** Be positive and reassuring. Speak slowly in a soft tone.
- **Limit distractions.** Look at the person's surroundings, and change them to keep similar situations from happening again.
- **Try a relaxing activity.** Use things like music, massage or exercise to help soothe the person.
- **Shift the focus to another activity.** The activity or situation at hand might have accidentally caused the aggressive behavior to manifest. Try something different.
- **Decrease levels of danger.** Assess danger levels—for both yourself and the individual with Alzheimer's. Oftentimes, you can keep from harm by simply stepping away from the person. If they are headed out of the house and to the street, then be more assertive.
- **Avoid using restraint or force.** Unless you're facing a serious situation, avoid physically holding or restraining the person. He or she might get more frustrated and cause personal harm.
- **Share your experience with others.** Join ALZConnected, the Alzheimer's Association online support community and message boards, and tell others what response strategies have worked for you and get more ideas from other caregivers.

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Anxiety and Agitation

Someone with Alzheimer's might feel either anxious or agitated. He or she could become restless, which causes them to need to move around or pace, or get upset in certain places, or when focused on specific details. Following the same setup as before, let's look at some possible causes for agitation, as well as tips to help prevent it, and ways in which you can better respond to it when it happens.

Both anxiety and agitation can be caused by multiple different things, such as medical conditions, medication interactions, or any circumstances that worsen the person's ability to think properly. What is actually happening is that the person with dementia is going through a profound loss of their biological ability to be able to negotiate new information and stimuli. It is important to know that this is a direct result of the disease.

Some things that may contribute to anxiety or agitation include the following:

- Moving to a new residence or nursing home
- Changes in environment, such as travel, hospitalization or the presence of houseguests
- Changes in caregiver arrangements
- Misperceived threats
- Fear and fatigue as a result of trying to make sense out of a confusing world

Tips to Prevent Agitation

- **Create a calm environment.** Get rid of stressors. This could mean moving the person to somewhere safer or quieter, or giving them a security object, rest or privacy. You could also try soothing rituals, like limiting caffeine use.
- **Avoid environmental triggers.** Things like noise, glare and background distraction (like having the television on) can be triggers.
- **Monitor personal comfort.** Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections or skin irritation. Be sure the room is set to a comfortable temperature, and be aware of any fears, misperceived threats and frustration with expressing what is desired.
- **Simplify tasks and routines**

- **Provide an opportunity to exercise.** Go on a walk or garden together, put on music and dance. Give them a chance to get up and move.

How to Respond

- **Listen to the frustration.** Discover what may be causing the agitation, and try to understand it.
- **Give reassurance.** Use calming phrases, like: "You're safe here;" "I'm sorry that you are upset;" and "I will stay until you feel better." Let them know that you are there.
- **Involve them in activities.** Try things like art, music, or other things to help get them engaged and keep their attention away from the anxiety.
- **Modify the environment.** Lessen noise and distractions, or relocate.
- **Find outlets for their energy.** They may be bored and looking for something to do. You might go on a walk or take a car ride.
- **Check yourself.** Don't raise your voice, show alarm or offense, or corner, crowd, restrain, criticize, ignore or argue with them. Be sure not to make sudden movements out of the person's view.
- **See the doctor.** Talk to the person's primary care physician to rule out any physical causes or any side effects related to medications.
- **Share your experience with others.** Join ALZConnected, the Alzheimer's Association online support community and message boards, and tell others what response strategies have worked for you and get more ideas from other caregivers.

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Depression and Alzheimer's

It is a fact that depression is quite common among those who suffer from dementia, especially so during the early and middle stages of the disease. There is treatment available to help combat depression, and it can make quite the difference in the quality of life.

Now, let's take a few minutes to focus on the symptoms of depression, how to diagnose it with the Alzheimer's, and finally the treatments that are available.

The truth is that identifying the depression in someone who has Alzheimer's can be especially hard, as the dementia itself is able to cause some of the same symptoms. Some examples of symptoms that are common among both dementia and depression include the following:

- Apathy
- Loss of interest in activities or hobbies

- Social withdrawal
- Isolation
- Trouble concentrating
- Impaired thinking

Also, the cognitive impairments experienced by those with Alzheimer's can (and often does) make it hard for them to express or articulate their sadness, hopelessness, guilt, and the other feelings that are associated with depression. It is also important to know that depression in Alzheimer's may not look exactly like the depression seen in others without Alzheimer's. Some ways that depression with Alzheimer's can be different are as follows:

- Can be less severe
- May not last and symptoms may come and go
- Those with Alzheimer's may be less likely to talk about or attempt suicide

Being a caregiver, if you notice any signs of depression, talk it over with the primary doctor of the individual. Getting a right diagnosis and treatment can better their sense of well-being and function.

Diagnosing Depression with Alzheimer's disease

The fact of the matter is that there is no one single test or questionnaire that can diagnose depression. Achieving a proper diagnosis requires a detailed evaluation by a medical professional, especially since the side effects from medications and a few medical conditions can mimic symptoms of depression.

An evaluation for depression includes the following:

- A review of the person's medical history
- A physical and mental examination
- Interviews with family members who know the person well

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Because of all the intricacies involved in trying to diagnose depression in those who also have Alzheimer's, it could be helpful to talk with a geriatric psychiatrist who specializes in the area of recognizing and treating depression in older adults. You can talk to your doctor for a referral.

The National Institute of Mental Health made a formal set of guidelines for the diagnosing of depression in those individuals with Alzheimer's. Though the criteria are quite similar to general diagnostic standards for major depression, they put less emphasis on verbal expression, instead paying more attention to irritability and social isolation.

For someone to be diagnosed as having depression with Alzheimer's, he or she must have experienced depressed mood (sad, hopeless, discouraged or tearful) or decreased pleasure from usual activities, along with two or more of the following symptoms for a period of at least two weeks or longer:

- Social isolation or withdrawal
- Disruption in appetite not related to another medical condition
- Disruption in sleep
- Agitation or slowed behavior
- Irritability
- Fatigue or loss of energy
- Feelings of worthlessness or hopelessness, or guilt that is inappropriate or excessive
- Recurrent thoughts of death, suicide plans or an attempt of suicide

Treating Depression

Receiving the right help and treatments for depression can greatly improve a person's quality of life. The most common type of treatment involves a combination of medicine, counseling, and slowly reconnecting to activities and people that make them happy. Things like telling them to "cheer up," "snap out of it" or "try harder" are very seldom helpful at all. Those who are depressed with or without Alzheimer's are very rarely able to feel better simply by the sheer force of their will, or without a lot of support, reassurance and professional help.

Non-drug approaches

- Support groups can be a great help, especially in the early stages of the disease, with those who are aware of the diagnosis and want to be active in getting help or helping others; counseling is also good, especially if the person is uncomfortable in a group setting.
- Make up a predictable daily routine, being sure to take advantage of the person's best time of day to perform difficult tasks, such as bathing.
- Create a list of activities, people or places that the person enjoys and schedule such things more frequently.
- Help them to exercise regularly, particularly in the morning.
- Make note of and acknowledge the person's frustration or sadness, while also continuing to offer hope that he or she will feel better soon.
- Celebrate small successes and occasions.
- Look for ways the person can contribute to family life and be sure to recognize them when they happen.
- Give reassurance that the person is loved, respected and appreciated as an integral part of the family, and not just for what he or she may be able to do now.
- Nurture them with offers of favorite foods or soothing or inspirational activities.
- Let them know, often, that they will not be abandoned.

Medication to treat depression in Alzheimer's

Many different types of antidepressants are available to treat depression. Those antidepressants known as Selective Serotonin Reuptake Inhibitors (SSRIs) are most often used for those who have Alzheimer's and depression due to the lower risk than some others of causing interactions with other medications they may be taking. And just like with any other medications, be sure to ask about all of the risks and benefits, as well as any type of monitoring and follow-up that will be needed.

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Hallucinations and Alzheimer's

When someone who has Alzheimer's or another form of dementia hallucinates, he or she might see, hear, smell, taste or feel something that, in reality, is not there. Some of these could be frightening, while others may be ordinary visions of people, situations, or objects from their past. Let's spend some time now to better understand hallucinations and see some coping strategies that can help when they occur.

As you may know, hallucinations are those false perceptions of objects or events that involve the senses. These false perceptions are instigated by changes in the brain that result from Alzheimer's—normally during the later stages of the disease. The individual might see the face of a former friend in a curtain or could see insects crawling on his or her hand. In still other cases, they might even hear someone talking and might even engage in conversation with the imagined person.

Alzheimer's and dementias aren't the only causes of hallucinations though. Others can include:

- Schizophrenia
- Physical problems, like kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse
- Eyesight or hearing problems
- Medications

Coping Strategies

Be careful when it comes to responding to hallucinations. First, be sure to assess the situation to determine whether or not the hallucination is a problem for the person or for yourself. Is the hallucination upsetting? Is it leading them to do something dangerous? Is the sight of some unfamiliar face causing them to become scared? If so, you need to react calmly and quickly to reassure them. Do not argue with them about what they may see or hear. If their behavior is not dangerous, it may not be necessary for you to step in.

Offer reassurance

- Respond calmly and in a supportive manner. You could choose to respond with, "Don't worry. I'm here. I'll protect and take care of you."
- Gentle patting might turn the person's attention to you and lessen the hallucination.
- Acknowledge the feelings behind the hallucinations and try to discover what that hallucination means to the person. You may want to say something like, "It sounds like you're worried" or "I know this is frightening for you."

Use distractions

- Suggest taking a walk or moving to another room. Frightening hallucinations will often subside in areas that are well-lit and where others are present.
- Try getting the person to focus on things like music, conversation, or any other activities you normally enjoy together.

Modify the environment

- Check for any sounds that could be misinterpreted, like noise from the television or an air conditioner.
- Look for lighting that casts a shadow, reflection or distortion on surfaces of floors, walls, and furniture. Turn on the lights so as to reduce shadows.
- Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.

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Memory Loss and Confusion

During the later stages of Alzheimer's, people may not remember familiar people places or things. Situations that involve memory loss and confusion can be and are incredibly difficult to deal with as caregivers and family members, and they necessitate much more patience and understanding.

During earlier stages, the memory loss or confusion might be mild. The individual could be aware of—and frustrated by—the changes that are taking place, like difficulty recalling recent events, making decisions, or processing what was said by others.

In the later stages, memory loss often becomes much more severe. The person may not recognize family members, might forget relationships, call family members by the wrong names, or get confused about where their home is or by the passage of time. He or she could forget the purpose of common items, like a pen or fork. These changes are often some of the most difficult and painful for caregivers and families to deal with.

Such behaviors are incorrectly referred to as senility or "senile dementia" at times, which is reflective of the formerly widespread, yet incorrect belief that severe mental decline is nothing more than a normal part of aging. We know now that this is not true.

Causes

The main underlying cause of memory loss and confusion is the progression of the Alzheimer's disease, which causes continuing damage to the brain cells. And I know that it's repetitive, but it *is* worth knowing that while there may not be a cure for Alzheimer's as of yet, there are medications available that can help slow its progress.

Another cause of memory loss and confusion are certain situations—like a change in living arrangements, switching up a routine or even certain infections—each of these can cause symptoms to become worse. If there is a sudden change in behavior, at any time, it is crucial to get a medical evaluation so as to rule out any other causes that could be affecting them.

How to Respond

- **Stay Calm.** Even though it can be quite painful to be called by a different name or not be recognized altogether, do your best to keep calm and not make the hurt apparent.
- **Respond with a brief explanation.** Don't overwhelm them with any lengthy statements or reasons. Instead, clarify things using a simple explanation.
- **Show photos and other reminders.** Make use of pictures or other thought-provoking items to remind them of important relationships and places.
- **Travel with them to where he or she is in time.** If they are focused on a particular time in their life, talk with them about their recollections, while also understanding that this is his or her current reality.

- **Offer corrections as suggestions.** Stay away from explanations that come off as scolding. Try: "I thought it was a fork" or "I think this is Julie, your granddaughter."
- **Do your best not to take it personally.** Alzheimer's can cause your loved one to forget, but still having your support and understanding will always be appreciated.
- **Share your experience with others.** Join ALZConnected, the Alzheimer's Association online support community and message boards, and tell others what response strategies have worked for you and get more ideas from other caregivers.

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Repetition and Alzheimer's

Someone who has Alzheimer's might do or say something over and over again—like repeating a word, question, or activity—or undo something that they just finished. In a lot of cases, he or she is probably looking for some comfort, security and familiarity.

Causes

As we said earlier, the main causes of behavioral symptoms in Alzheimer's and any other progressive dementias is due to the breakdown of brain cells, which, in turn, causes a decline in a person's ability to understand and make sense of the world around them. With repetition, in particular, he or she may not remember that they have just asked a question or completed a task.

Environmental influences can also be to blame for specific symptoms or may make them worse. Those who have dementia and who ask questions repeatedly might be trying their best to express a specific concern, ask for help, or cope with frustration, anxiety or insecurity.

Because someone with Alzheimer's will gradually lose the ability to communicate, it is crucial to regularly monitor their comfort and anticipate any needs they may have. Now, let's take a look at some of the ways that you can respond to these situations when they happen.

How to Respond

- **Look for a reason behind the repetition.** Does it happen around certain people or surroundings, or at a certain time of day? Is the person trying to communicate something?
- **Focus on the emotion, not the behavior.** Rather than react to what they are doing, think about how they might be feeling.
- **Turn the action or behavior into an activity.** If he or she is rubbing her hand across the table, provide a cloth and ask for help with dusting.
- **Stay calm and be patient.** Be reassuring. Use a calm voice and gentle touch. Don't try to argue or use logic; Alzheimer's affects memory, so the person may not remember that he or she has asked the question already.
- **Provide an answer.** Give them the answer they may be looking for, even if you have to repeat it several times. If the individual is still able to read and comprehend, it could help to write it down and put it in a prominent location where they will see it.
- **Engage in an activity together.** It could be that the person is simply bored and wants or needs something to do. Give them some structure and get them engaged in an activity.
- **Use memory aids.** If the person is repeating the same questions time and time again, offer some reminders by using notes, clocks, calendars or photos, if such items are still meaningful to them.
- **Accept the behavior and work with it.** If their behavior isn't harmful, try not to worry about it so much. Look for ways that you can work with it.

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Sleep Issues and Sundowning

Those with Alzheimer's and dementia may have issues sleeping or increases in behavioral problems that begin at dusk and last into the night (called sundowning).

Scientists aren't exactly certain disturbances in sleep happen with Alzheimer's and dementia. Like with changes in memory and behavior, these sleep changes somehow come about as a result of the toll that Alzheimer's can take on the brain.

There are some studies that show as many as 20 percent of those with Alzheimer's will experience increased confusion, anxiety and agitation beginning late during the day. Some might experience changes in their sleep schedule and restlessness during the night. Due to the disruption of the body's normal sleep-wake cycle, it can lead to more behavioral issues.

Some factors that can contribute to sundowning and sleep disturbances include the following:

- End-of-day exhaustion (both mental and physical)
- An upset with the "internal body clock," that causes a biological mix-up between day and night.
- Reduced lighting and increased shadows making those with Alzheimer's misinterpret what they see, and become both confused and afraid.
- Reactions to nonverbal cues of frustration from exhausted caregivers.
- Disorientation due to the inability to separate dreams from reality when sleeping.
- Less need for sleep, which is common in older adults.

Coping Strategies

- **Keep the home well-lit in the evenings.** Adequate lighting might reduce the agitation that can happen when surroundings are dark or unfamiliar.
- **Make a comfortable and safe sleep environment.** The person's sleeping area should remain at a comfortable temperature. Give nightlights or other ways to keep the person safe, like appropriate door and window locks. Door sensors and motion detectors can be used to alert family members when a person begins to wander.
- **Keep a schedule.** As much as you can, as often as possible, encourage the person to stick to a schedule of regular meals, waking up and going to bed. This can make for a more restful sleep.
- **Avoid stimulants and big dinners.** Things like nicotine and alcohol you should avoid. You should also limit sweets and caffeine consumption to the morning hours. Have a large meal at lunch to keep the evening meal simpler.
- **Plan more active days.** Someone who rests during the day is more likely to be active during the night. Discourage afternoon napping and choose and plan more challenging activities like doctor appointments, trips, and bathing in the morning or early afternoon. You should also encourage regular daily exercise, but no later than four hours before going to bed.
- **Try to identify triggers.** Limit the environmental distractions particularly during evening hours (TV, kids arriving, chores, loud music, etc.)

- **Be mindful of your own mental health and exhaustion.** If you feel stressed yourself, the person might pick up on it and become agitated or confused. Be sure to try and get lots of rest at night so that you can have more energy to do your best during the day.

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Suspicion, Delusions and Alzheimer's

Someone who has Alzheimer's could become suspicious of those around them, even going so far as accusing others of stealing, infidelity or other improper behavior. While such accusations can be hurtful, remember that it is the disease, not the person, who is responsible for these behaviors and try not to be offended if and when they happen.

What to Expect

Delusions (that is a firmly held belief in things that are not real) might happen in the middle- to late-stage of the disease. Contributing to these untrue beliefs are the confusion and memory loss—like the inability to remember certain people or things—that can also occur during the progression of the disease. Someone with Alzheimer's may believe a family member is stealing his or her possessions or that he or she is being followed by law enforcement. Although it is not true, the situation is, in fact, quite real to the person with dementia. Bear in mind that the person is only trying to make sense of his or her surroundings with a decline in their cognitive abilities.

It should also be known that a delusion and a hallucination are **not** one and the same. Whereas delusions involve false beliefs, hallucinations are false perceptions of objects or events that are more sensory in their nature. When people with Alzheimer's experience a hallucination, they can see, hear, smell, taste or feel something that isn't really there.

How to Respond

- **Don't take offense.** Listen to what is troubling the person, and then try to understand their reality. Then reassure them and let them know that you care about what's going on.
- **Don't argue or try to convince.** Allow the person to express ideas and acknowledge his or her opinions.

- **Offer a simple answer.** Share your own thoughts with the person, but stay simple. Make sure not to overwhelm them with lengthy explanations or reasons.
- **Switch focus to another activity.** Get them engaged in an activity, or ask them for help with a household chore.
- **Duplicate any lost items.** If he or she is searching for something in particular, have several of that item available. As an example, if the person is always looking for their wallet, purchase two of the same kind.

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Wandering and Getting Lost

Out of every ten people, six of them will wander. Someone suffering from Alzheimer's might not remember his or her name or address, and can easily become disoriented, even in places that are ordinarily familiar. Wandering is especially problematic and dangerous in those with dementia, but there are also strategies and services available to you to help prevent it. Let's take a look at those things now.

Anyone who suffers from memory issues and is still able to walk is also at risk for wandering. Even during the disease's early stages, someone can become disoriented or confused for a while. It is, then, incredibly important to plan ahead just in case the situation happens to present itself. Be sure to watch for the following warning signs:

- Comes back from a regular walk or drive later than normal.
- Tries to fulfill former obligations, such as going to work.
- Tries or wants to "go home" even when they are at home.
- Is restless, paces or makes repetitive movements.
- Has difficulty locating familiar places, like the bathroom, bedroom or dining room.
- Asks whereabouts for current or past friends and family members.
- Acts as if he or she is doing a hobby or chore, but nothing gets done (e.g. moves around pots and dirt without actually planting anything).
- Appears lost in a new or changed environment.

Tips to Prevent Wandering

Wandering can occur in spite of your diligence. The following strategies and tips can help to lower the chances of it happening:

- **Carry out daily activities.** Having a routine can give them some structure.
- **Identify the most likely times during the day that wandering may happen.** Plan out some activities at that time. Both activity and exercise can lower anxiety, agitation or restlessness.
- **Reassure them if they feel lost, abandoned or disoriented.** If he or she wants to leave to "go home" or "go to work," communicate using words focused on exploration and validation. Keep from correcting the person. As an example, "We are staying here tonight. We are safe and I'll be with you. We'll go home in the morning after a good night of sleep."
- **Ensure all basic needs are met.** Has the person gone to the bathroom? Is he or she thirsty or hungry?
- **Avoid busy places that are confusing and may cause disorientation.** This might be a shopping mall, grocery store, or any other busy venue.
- **Place locks out of line of sight.** Install them either high or low on exterior doors, and think about placing side bolts at the top or bottom.
- **Camouflage doors and door knobs.** Paint doors the same color as the walls, or cover them with removable curtains or screens. Cover knobs with cloth the same color as the door or use childproof knobs.
- **Use devices that signal when doors or windows are opened.** This may be as simple as a bell placed above a door or as sophisticated as an electronic house alarm.
- **Provide supervision.** Never lock them in at home alone or leave them in a car without supervision.
- **Keep car keys out of sight.** Someone with dementia may drive off or be at risk of potential harm to themselves or others.
- **If night wandering is an issue:** Make sure he or she has restricted fluids two hours before bedtime and has gone to the bathroom just before bed. Also, use nightlights throughout the house.

Make a Plan

There is significant stress to families and caregivers when someone who has dementia goes missing. That's why it is so important to have a plan in place, so that you and your family know exactly what to do next in case you come face to face with an emergency.

- **Keep a list of people to call on for help.** Have telephone numbers easily accessible.
- **Ask neighbors, friends and family to call if they see the person alone.**
- **Keep a recent, close-up photo as well as updated medical information on hand to give to the police.**
- **Know your neighborhood.** Pinpoint any dangerous areas near the house, like bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- **Is the person right or left-handed?** Wandering most generally follows the direction of the dominant hand.
- **Keep a list of places where the person may go.** This might be past jobs, former homes, places of worship or restaurants.
- **Give the person ID jewelry.** Enroll them in MedicAlert+ Alzheimer's Association Safe Return.

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Abuse

Abuse can happen anywhere, even within the home and in care settings. Those who suffer with dementia are most vulnerable since the disease can keep them from reporting or recognizing the abuse when it happens. They could also fall victim to strangers who would seek to take advantage of their cognitive impairments.

Types of Abuse

Abuse can come in many forms:

- **Physical:** Causing physical pain or injury.
- **Emotional:** Verbal assaults, threats of abuse, harassment and intimidation.
- **Neglect:** Failure to provide necessities, like food, clothing, shelter, medical care or a safe environment.

- **Confinement:** Restraining or isolating the person.
- **Financial:** The misuse or withholding of the person's financial resources, like money or property, to his or her disadvantage or the advantage of someone else.
- **Sexual abuse:** Touching, fondling or any sexual activity when the person is unable to understand, unwilling to give consent, threatened or physically forced.
- **Willful deprivation:** Willfully denying the person medication, medical care, food, shelter or physical assistance, and thereby exposing him or her to the risk of physical, mental, or emotional harm.
- **Self-neglect:** Because of a lack of insight and the cognitive changes that occur, someone with Alzheimer's could be unable to safely and adequately provide for day-to-day needs, and might be at risk for harm, falls, wandering and/or malnutrition.

Signs of Abuse

It is important to note that while a singular sign doesn't always indicate abuse, the following signs could point to a problem:

- Bruises, pressure marks, broken bones, abrasions and burns could indicate physical abuse, neglect or mistreatment.
- Unexplained withdrawal from normal activities, sudden changes in alertness or unexpected depression could indicate emotional abuse.
- Bruises around the breasts or genital area could be a sign of sexual abuse.
- Any sudden changes in financial situations could be the result of exploitation.
- Bedsores or unattended medical needs, poor hygiene and unusual weight loss might point to neglect.
- Belittling, threats or other uses of power by spouses, family members or others may be a sign of verbal or emotional abuse.
- Strained or tense relationships, frequent arguments between the caregiver and the person with dementia could be a sign of abuse as well. It may come from either a caregiver or someone with dementia. Someone suffering from the disease might exhibit more aggressive behaviors as the disease goes on and their cognitive function and ability to reason decline. Absolutely no one should live in threat of harm or danger to themselves or anyone else.

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Abuse can and does happen, even when we would like to think it doesn't. If you suspect abuse and want to report an incident or concern, you can call the Alzheimer's Association (1.800.272.3900) or Eldercare Locator (1.800.677.1116). You'll then be connected with your state or local adult protective services division or to a long-term care ombudsman. You are not required to prove abuse is actually happening—it's up to the professionals to investigate any suspicions.

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Now that we've taken a more in-depth look at the progression of the disease and the issues that may come along with it, we will next turn our attention toward the treatments available to help combat the disease.

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Chapter 7: Treatments and Other Resources

Before we get deep into talking about heavy things, let me take a second and congratulate you for getting to the halfway point of the book. We hope that it has been not only an informative read thus far, not only providing you with vital information, but also an enjoyable read as well.

So, at this point, we've talked off and on throughout the previous chapters about treatments available. You've likely gotten to the point where you could recite it from memory that there is no official cure for Alzheimer's or other forms of dementia, but there are treatments available to help with the symptoms.

In this chapter, we will focus more specifically on the person with dementia, and the treatments and some other resources that can be used to combat the disease. However, the information is beneficial for all parties, not just those who are facing the diagnosis. Again, we will go over drug treatments and non-drug treatments, and we will also see some treatments and medications designed to help with changes in behavior, memory loss, and sleep changes that are associated with dementia.

It should be noted that the information contained within this chapter and the book overall should not be used as a substitute for, nor does it replace advice that doctors, pharmacists, nurses or other medical professionals can give to you and your family.

With all this in mind, let us now continue on our journey through dementia together…

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Treatments Available

Drug Treatments for Dementia

If you find yourself or a loved one facing a diagnosis of dementia, there are several medications and drugs that can help. We will review some of them again, as well as how they work and their effects, below.

You may also speak with your doctor about any of the treatments available and can discuss together which ones may be best suited to the specific situation you are facing. It may also be beneficial to have a caregiver or other member of your family be involved in these decisions as well.

If you are prescribed a drug to help with dementia, the treatment usually is initiated via a specialist doctor. These kinds of doctors who see dementia patients include the following: psychiatrists, geriatricians and neurologists. Once the treatment begins, it can be continued and monitored by the specialist or by your own GP.

If you have any concerns about medicines you take, or if you experience any unexpected side effects, be sure to speak to your doctor, nurse or pharmacist.

Cholinesterase Inhibitors

Someone suffering from Alzheimer's may benefit from taking a cholinesterase inhibitor. These are not a cure, but they can be used to treat symptoms in some people. They may provide an improvement in thinking, memory, communication, or day-to-day activities. Others may see their condition remain the same as it is, when they may have expected to become less able as the condition goes on. Still some may not notice any difference whatsoever.

During the course of Alzheimer's disease, a person's nerve cells get damaged and thus lose the ability to communicate. Cholinesterase inhibitors affect a chemical that is involved in the communication of nerve cells, allowing it to keep working for longer. This may improve the way the signals are sent within the brain, lessening the symptoms of Alzheimer's for a short period. Since these drugs do not keep the disease from spreading, though, the symptoms can continue to worsen as time goes on. However, they may help some individuals to function at a slightly higher level than they would be able to without the drug.

Three cholinesterase inhibitors are licensed to treat Alzheimer's, and we've looked at them briefly before: donepezil (Aricept), rivastigmine (Excelon) and galantamine (Reminyl). All three work similarly to each other, and thus far, no difference in effectiveness of the three has been shown, though some individuals could respond better to one drug than another, or they may have fewer side effects.

These drugs have been licensed and are recommended specifically for those with mild to moderate Alzheimer's, and doctors could keep prescribing one of them for longer if they believe it to still be beneficial to the person with dementia.

Treatments are normally given via tablets or capsules, and donepezil is also available as a tablet that dissolves on the tongue, while galantamine may be given in liquid form. Rivastigmine is available either in liquid form or in patches, where the drug is absorbed through the skin. Your doctor will discuss with you which would be most suitable for your situation.

It is important to note that cholinesterase inhibitors are not normally beneficial for those individuals suffering from vascular dementia, though they may be helpful to those with both Alzheimer's **and** vascular dementia—also known as 'mixed dementia'.

There is also evidence that cholinesterase inhibitors could help improve some symptoms of dementia with Lewy bodies, like thinking skills and visual hallucinations.

The most common side effects associated with cholinesterase inhibitors include: feeling or being sick, diarrhea, trouble sleeping, muscle cramps, and tiredness. These effects are normally mild and, for the most part, only temporary. What's more—not everyone will experience side effects from the drugs.

Memantine

Memantine (also known as Ebixa or Axura) is recommended normally for those who suffer with severe Alzheimer's disease, and for those who have moderate Alzheimer's if the cholinesterase inhibitors did not help or are not suitable treatment for them. The memantine is usually given in tablet form, but it is also available in liquid form. Your doctor can talk with you about which option would be best for you. And just like the cholinesterase inhibitors, memantine is also not a cure, but it may help with some symptoms, however, which is always a positive.

Some of the people who take memantine may not notice any effect whatsoever. Others might find their condition remains the same as it was, when they may have expected it to get worse.

Some people taking the drug also experience side effects while doing so. The most common of these is headaches, but others also report dizziness, drowsiness and constipation as fairly common as well. These effects are normally just temporary.

Memantine is currently only recommended for those who have Alzheimer's, but research is currently being conducted to ascertain if it would prove beneficial to those with other forms of dementia.

Memantine is also beneficial to the nerve cells in the brain, as it helps them to communicate with each other. It also helps in the receiving of messages as well and can improve the sending of signals within the brain as well—which works to reduce the symptoms of Alzheimer's for a short time.

Non-drug Treatments for Dementia

Along with medications, there are also a variety of cognitive therapies available that may benefit those with all types of dementia. Cognitive skills may be described as thinking skills, and cognition is a word that is used to describe the thought process.

Cognitive stimulation activities re ones that are designed to both stimulate thinking skills and engage people who have dementia. They are most often group-based activities and may include games, with an emphasis on being enjoyable to participants. Cognitive stimulation may be given by health or social care staff with the appropriate training.

The benefits of cognitive stimulation for those with dementia could be an improvement in their memory, thinking skills, and overall quality of life.

Other types of cognitive therapy are currently in the testing phase to see if they may also prove beneficial to people with dementia. Such therapies include reminiscence therapy—where past activities and experiences are talked about, usually with photographs and other familiar objects from the past.

Cognitive rehabilitation is also undergoing testing to see if it can help those who have dementia as well. This goal of this particular technique is to improve how individuals manage their everyday tasks by setting personal goals and then finding ways to achieve them. The main focus, then, is on developing the person's strengths and helping them to successfully overcome their own individual challenges.

On the flip side, it would be best to be wary of "herbal", "alternative" or "complementary" products that make the claim of being beneficial to those with dementia, or that claim to better their memory. High quality research in this area and of these types of products has been scarce, and there may be some which are unsafe for those with dementia. To give you an example, despite anecdotal reports, there is little right now in the way of evidence obtained from studies that coconut oil can be beneficial for those with dementia.

However, the most important thing when you consider taking a complementary therapy that makes claims of helping with dementia is to talk first with a doctor. Some of these products interact with normal medications, so doctors need to know about anything that is being taken, and such products should never be taken as a substitute for any prescribed medications.

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Treatment for Other Symptoms of Dementia

Some people who have dementia may suffer from agitation, aggression, delusions (which are negative or mistaken beliefs), severe anxiety, hallucinations, sleep disturbances or other symptoms that can affect their behavior. We covered all of those in the previous chapter, so if you need a refresher at any point, you can refer back to chapter six.

Those symptoms that we mentioned can pose problems for caregivers and can often be difficult to manage because of that. In more medical terminology, such challenging behaviors are known as neuropsychiatric symptoms or behavioral and psychological symptoms of dementia (or BPSD).

While these symptoms can indeed be difficult to handle, there are some simple things that may be able to help. It could be possible to reveal the trigger to some of the troubling behavior, or the cause of the aggression or agitation. Someone's physical health may be affecting their behavior—just like how, when we don't feel *our* best, we can sometimes lash out due to the frustration of not feeling well. In the same way (although on a greater scale), the same is true here. Surroundings can also be a catalyst for a behavioral change, as well as any feelings toward a specific situation.

Discovering any possible triggers that contribute to the aggressive or agitated behavior also means it may be possible to rid the person of it, treat it or simply avoid it altogether. Most mild behavioral symptoms can normally be helped with simple adjustments to physical surroundings, calm reassurance or even changes to daily routines. Some possible triggers may include the following:

- Undetected pain or discomfort
- Infection
- Depression
- Social situations
- Environmental factors
- Disruption to routine

Non-drug treatments

To aid someone who is dealing with agitation, a doctor or other healthcare worker might think of offering the person a non-drug therapy. What things are considered are dependent upon the person's individual preferences, skills, and abilities. It also depends on what may be locally available to them. Such things might include:

- Aromatherapy
- Therapeutic use of music or dancing
- Animal-assisted therapy
- Massage
- Multi-sensory stimulation

Someone's response to these therapies should be monitored closely, and the approach should be changed if necessary. Such therapies may be given by a health or social care worker with the appropriate training and supervision.

Some people with dementia could find that one of these therapies is helpful, and there has also been some research that indicates they may be beneficial. However, thus far, the research that has been done has been fairly small, so more is needed.

Drug treatments

If the non-drug options do not work and a person is quite distressed, he or she may be offered treatment via an antipsychotic drug.

These types of drugs should be offered only in the event there is severe distress or an immediate risk of harm, either to the person themselves or anyone else around them. While they may indeed be helpful within certain situations, antipsychotics also bring with them the possibility of serious side effects, so all other options should be explored prior to the prescription of any such medications.

Anyone who has been prescribed such a drug needs to be monitored closely and at regular intervals by a doctor. If you have any questions or concerns about these medications or any others that are being used, be sure to bring it up with your doctor.

There are many different types of antipsychotic drugs. One, which is called risperidone (Risperdal), is for the treatment of severe agitation, aggression and behavioral changes in those who have dementia. Short-term treatments may help to lessen and relieve these symptoms.

On some occasions, other such antipsychotic drugs may be taken into consideration as well, but only at a low dose and only if someone is extremely aggressive. Haloperidol (Hadol, Serenance) is yet another antipsychotic that could be considered for a very short term of one week. Lorazepam (Ativan, Temesta), which is a type of drug known as a benzodiazepine, is *not* an antipsychotic, but might still be used in a similar way for a short time to help in the reduction of aggressive behavior.

As with any medications, antipsychotic drugs can have side effects, though the ones associated with these types of drugs can often be very serious. Extended use of antipsychotic drugs is most often associated with an increased risk of stroke and could also make memory and thinking worse in those who have Alzheimer’s. Because of this, these types of drugs should not normally be used for any longer than three months, and the benefits for their prescription should be carefully weighed against the individual risks for each person.

It is also worth mentioning that antipsychotic drugs can be particularly harmful to those people who have dementia with Lewy bodies, and as such, should only prescribed in the most severe of circumstances. There is the potential for them to cause worsening symptoms or even sudden death in some cases.

In the past, different types of antipsychotic drugs have been used for the treatment of dementia symptoms, but often they are not recommended or licensed for this use. You can (and really should) discuss with your doctor about the type of medication that is being prescribed and why.

A cholinesterase inhibitor could be prescribed for someone with Alzheimer's who also has behavioral symptoms that are the cause of significant stress. It is possible they could be a viable option if a non-drug approach would be inappropriate for the situation or has been ineffective, and if antipsychotic drugs are unsuitable or have not helped the situation.

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Treatments for Depression

Depression is quite common in every form of dementia, and your doctor might choose to recommend cognitive behavioral therapy (CBT) to help with it. CBT gives people the opportunity to voice any worries or concerns with a specialized practitioner. Its goal is to help those people develop some different ways of thinking and behaving.

There might also be some other therapies offered in your area that may be helpful; such things might include exercise or group activities.

It is possible you may be offered an antidepressant drug, either as an alternative to the CBT or in conjunction with it. As with most drugs, there are different types (aka classes) of antidepressant; some are not suitable for those with dementia, and your doctor will best be able to determine whether or not an antidepressant would help your specific situation, and if so, which type would work best.

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Treatments for Sleep Changes

Now that we've taken a more overall approach to looking at treatment options, let us now shift our focus to a few things in particular. Next, we will look at treatments that are available to help with changes in sleep, medications for memory loss, and finally, treatments for changes in a person's behavior. Now that you know, let's continue on.

While most everyone has had issues with sleep throughout their lives at one point or another, people with Alzheimer's experience it to a different degree. However, scientists aren't exactly sure why disturbances in sleep or changes in their sleep schedule happen. Just as in the changes in both memory and behavior, changes in sleep somehow occur as a result from the impact that Alzheimer's has on the person's brain. When looking to better manage these sleep changes, any non-drug coping strategies should be tried before anything else.

Common Sleep Changes

A lot of people who have Alzheimer's go through changes in their sleeping patterns, though many older persons who do not have dementia also become aware of changes in their sleep. However, any such changes or disturbances are often magnified when coupled with dementia. There is also evidence that these changes in sleep are more common in the later stages of the disease, but some studies have also found them in the earlier stages as well.

Sleep changes can include the following:

- **Difficulty Sleeping.** A lot of people who have Alzheimer's often wake up more and stay awake longer in the nighttime hours. Studies of brain waves show decreases in both dreaming and non-dreaming stages of sleep. Those who are unable to sleep may wander, be unable to keep still, or yell or call out, often disrupting the sleep of their caregivers.
- **Daytime napping and other shifts in the sleep-wake cycle.** Someone might feel quite drowsy during daytime hours and be unable to sleep at night. He or she could get restless or agitated in late afternoon or early evening—an experience known as "sundowning." Experts have estimated that during the late stages of Alzheimer's, a person spends about 40 percent of their time in bed awake at night and a majority of time sleeping during the day. In more extreme cases, the usual wake-sleep pattern can be completely reversed.

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Contributing Medical Factors

Someone who is experiencing disturbances in their sleep patterns should participate in a thorough medical examination to identify any treatable illnesses that may be the cause of or contributing to the problem. Some examples of things that can cause worsening sleep problems include:

- **Depression**
- Restless legs syndrome, which is a disorder that causes unpleasant “crawling” or “tingling” sensations in the legs, which causes an overwhelming urge to move them.
- Sleep apnea, an abnormal breathing pattern in which people will stop breathing for a short time many times a night, resulting in poor quality of sleep.

Unfortunately, there are no non-drug or drug approaches to treating sleep changes caused largely by Alzheimer’s. A great many experts, as well as the National Institutes of Health (NIH) often recommend and encourage using non-drug measures rather than simply relying on medication.

Some studies show that these sleep medications do not often improve the overall quality of sleep for older adults. Use of these medications is associated with a greater risk of falling and other risks that can outweigh the benefits of such treatments.

Non-drug Treatments for Sleep Changes

The aim of non-drug treatments is to improve both sleep routine and the sleeping environment as well as to reduce napping during the daytime hours. Non-drug strategies should always be tested before relying on medications, since some of these sleep medications can be the cause of some serious side effects. To both create an inviting sleep environment and promote better rest for someone with Alzheimer’s:

- Keep regular times for meals and for going to bed and getting up
- Seek morning sunlight exposure
- Encourage regular daily exercise, though no later than four hours before bedtime
- Steer clear of alcohol caffeine and nicotine
- Treat any pain they may have

- If the person takes a cholinesterase inhibitor, like tacrine, donepezil, rivastigmine or galantamine, avoid giving it to them before bed
- Make sure bedroom temperature is comfortable
- Provide nightlights and security objects
- If he or she wakes up, discourage staying in bed while awake; use the bed only for sleeping
- Discourage watching TV during wakeful periods

Medication for Sleep Changes

In a few cases, non-drug approaches can fail to work or the sleep changes can be accompanied by nighttime behaviors that are disruptive. For anyone who *does* require medication, many experts recommend treatment "begins low and goes slow."

The risks that come with sleep-inducing medications for older, cognitively-impaired individuals are great. They can include increased risk of falling and fractures, confusion and decline in ability to care for oneself. If any sleep medications are used, you should try to discontinue them after the person has established a regular sleep pattern.

Which medication is prescribed by a doctor is often influenced by the behaviors that may come along with changes in sleep. Coming to the conclusion to use an antipsychotic drug should be approached with extreme caution. There has been research to show that such drugs are often associated with an increased risk for stroke and death in those older adults suffering from dementia. The FDA has ordered drug manufacturers to label such things with a "black box" warning about risks as well as a reminder that they have not been approved to treat symptoms of dementia.

Examples of medications that are used to treat sleep changes include the following:

- Tricyclic antidepressants, like nortriptyline and trazodone
- Benzodiazepines, like lorazepam, oxazepam and temazepam
- "Sleeping pills" like zolpidem, zaleplon, and chloral hydrate
- "Atypical" antipsychotics, such as risperidone, onlanzapine, and quetiapine
- Older "classical" antipsychotics like haloperidol

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Here are some questions you will want to pose to your health care team each time you are given a new medication:

- What are the benefits of the medication?
- What are the risks of the medication?
- What other treatment options may be available?

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Any treatment goals are quite likely to change during the journey through Alzheimer's disease. It is important that you understand any and all available options, as well as the benefits and risks of each choice as your treatment plan continues to change.

Medications for Memory Loss

The United States Food and Drug Administration (FDA) has approved two types of medications to treat cognitive symptoms associated with Alzheimer's disease: cholinesterase inhibitors (like Aricept, Exelon, and Razadyne) and memantine (Namenda).

We have seen and discussed previously that when brain cells die and connections are lost, cognitive symptoms like memory loss, confusion, and issues with thinking or reasoning can get worse as the disease progresses. And while current medications are not able to stop the damage that is caused to brain cells by Alzheimer's, they can lessen or stabilize the symptoms for a limited period of time. They do so by affecting certain chemicals that are involved with carrying messages throughout the nerve cells in the brain. Doctors will sometimes prescribe both of the aforementioned medications together, while some will also prescribe high doses of Vitamin E to help with any cognitive changes caused by Alzheimer's.

Now, let's take a look at the medications available during the early to moderate stages of the disease.

Medications for Early to Moderate Stages

Every medication that is currently approved to treat symptoms of Alzheimer's in their early and moderate stages are called cholinesterase inhibitors, which we've spoken about at length already. They are most often prescribed in order to treat symptoms related to memory, thinking, language, judgement or other thought processes.

But what can they actually *do*? That's a good question, and I'm glad you asked. Here's a handy list of things for you to look over. Cholinesterase inhibitors can:

- Prevent the breakdown of acetylcholine, which is a chemical messenger that is important for learning and for memory. This helps to support the communication among nerve cells by keeping the acetylcholine levels high.
- Delay the worsening of symptoms for an average of 6-12 months, in around half of the individuals who take them.
- Cholinesterase inhibitors are most generally well tolerated. If side effects do happen, however, they will commonly include nausea, vomiting, loss of appetite and an increased frequency in bowel movements.

As we've mentioned previously, the three most commonly prescribed cholinesterase inhibitors are Donepezil, Rivastigmine, and Galantamine—with the first being approved to treat all stages, while the latter two are approved for mild to moderate Alzheimer's only.

Medication for Moderate to Severe Stages

For those individuals in the moderate to severe stages of the disease, there is a second type of medication, known as memantine (Namenda), that is approved to treat symptoms associated with those later stages. Memantine is prescribed in order to help improve memory, attention, reason, language and the ability to perform simple tasks. It may be used alone or in conjunction with other Alzheimer's treatments, and there is also some evidence that those with moderate to severe Alzheimer's who are also taking a cholinesterase inhibitor could benefit by taking memantine as well. Of those we just mentioned, only Donepezil is approved to treat all stages of dementia, as we said.

Here is a list of things that memantine can do. It:

- Regulates the activity of glutamate, which is a different messenger chemical involved in learning and memory.

- Delays worsening symptoms for some individuals for a while. Many experts think of its benefits as being similar to those of cholinesterase inhibitors.
- Can cause side effects, such as headaches, constipation, confusion and dizziness.

Tomorrow's Treatments

When all is said and done, the pathway to finding effective new treatments to combat Alzheimer's lies in clinical trials. These trials are recruiting people who have Alzheimer's and mild cognitive impairment (MCI), as well as healthy volunteers to serve as controls.

You can find out more about participating in clinical studies through the Alzheimer's Association TrialMatch service—a free tool for those with Alzheimer's, their caregivers, families and physicians to find clinical trials based on personal criteria, like diagnosis, stage of disease, and location.

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Treatments at a Glance

Generic	Brand	Approved For
Donepezil	Aricept	All Stages
Galantamine	Razadyne	Mild to Moderate
Memantine	Namenda	Moderate to Severe
Rivastigmine	Exelon	Mild to Moderate
Memantine and Donepezil	Namzaric	Moderate to Severe

Side Effects

Donepezil: nausea, vomiting, loss of appetite and increased frequency of bowel movements

Galantamine: nausea, vomiting, loss of appetite and increased frequency of bowel movements

Memantine: headache, constipation, confusion and dizziness

Rivastigmine: nausea, vomiting, loss of appetite and increased frequency of bowel movements

Memantine and Donepezil: headache, diarrhea, dizziness, loss of appetite, vomiting nausea, and bruising

Treatments for Behavior

Let's finish out the chapter by next taking a look at treatments that can be used to help behavioral changes associated with Alzheimer's. When it comes to the disease, there are a variety of changes that can and do affect a person's behavior, and many people often say that this aspect is the most challenging and distressing part of the disease. The major cause behind the change in behavior is, in fact, the deterioration of brain cells, though things like medication, environmental influences and some medical conditions can also initiate or worsen symptoms.

During the early stages of the disease, someone might experience behavior and personality changes like:

- Irritability
- Anxiety
- Depression

In later stages, symptoms can include:

- Anger
- Agitation
- Aggression
- General emotional distress
- Physical or verbal outbursts
- Restlessness, pacing, shredding paper or tissues
- Hallucinations (seeing, hearing or feeling things that aren't truly there)
- Delusions (firmly held beliefs in those things that are not true)
- Sleep disturbances

Triggering Situations

Both events and changes in a person's surroundings can contribute to triggering behavioral symptoms. Going through change can be a stressful time for anyone, but even more so for someone struggling through Alzheimer's disease. It can increase fear and fatigue from trying to make sense of things that don't make sense.

Some things that can affect behavior include:

- Moving to a new residence or nursing home
- Changes to a familiar environment or caregiver arrangements
- Misperceived threats
- Admission to the hospital
- Being asked to bathe or change clothes

Being able to correctly identify what caused the behavior can really help you to select the approach best suited to deal with it.

Medical Evaluation for Contributing Factors

Each person who develops behavioral changes should get a thorough medical evaluation, especially if the symptoms manifest without warning. Although the main cause of these behavioral symptoms is due to the Alzheimer's progressing through the brain, getting an examination could reveal some other treatable conditions that are also adding to the behavior as well. Such conditions may include:

- **Drug side effects.** A lot of people with Alzheimer's take prescription medications for other health problems. Side effects from the drugs or interactions among them can affect behavior.
- **Discomfort due to infection or other conditions.** As the disease continues to get worse, individuals may have more and more difficulty communicating with others about what they are experiencing. Because of this, they might be unable to report symptoms of common illnesses. Having pain due to infections of the urinary tract, ear or sinuses could lead to restlessness or agitation. Discomfort from a full bladder, constipation, or feeling either too hot or too cold can also be expressed through behavioral changes.

- **Uncorrected problems with hearing or vision.** These may also contribute to any confusion or frustration they may experience and can lead to a sense of isolation for the individual.

Non-drug Approaches

A lot of the strategies we've discussed up to this point seek to identify and then take care of any needs the person with Alzheimer's may have a hard time expressing as the disease goes on. As we mentioned before, any non-drug approaches should be considered first before turning to medication.

Some steps you can take to creating successful non-drug treatments include the following:

- Recognizing that the person isn't just acting mean or ornery, but is experiencing more symptoms of the disease.
- Identifying the cause of the problem and how the particular symptoms could relate to that issue the person is experiencing.
- Changing up the environment in order to resolve any obstacles to the person's comfort, and to add to his or her peace of mind.

Coping Tips

- **Keep track of personal comfort.** Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections or skin irritation. Keep the temperature of the room at a comfortable level.
- **Avoid being confrontational** or arguing facts. As an example, if someone wishes to visit a parent who died several years ago, don't just blurt out that the person is dead. Instead, you could say something like, "Your mom is a wonderful person, I'd like to see her too."
- **Redirect the person's attention.** Be flexible, patient and supportive by responding to the emotion they are displaying, not the behavior.
- **Create a calm environment.** Avoid noise, glare, insecure space and too much in the way of background distractions, like television.
- **Allow adequate rest** between stimulating events.
- **Provide a security object.**
- **Acknowledge requests,** and respond to them.
- **Look for reasons behind each behavior.** Talk with a physician to discover any causes that might be related to medications or illnesses.
- **Explore various solutions.**

- **Don’t take the behavior personally,** and share your experiences with others.

Medications for Behavioral Symptoms

It may be appropriate to turn to medications if, after several attempts, the non-drug approaches fail consistently. However, this should be done for those persons with severe symptoms or if the potential is there that they might harm either themselves or others. While prescription medications can be effective in some instances, they have to be used with caution and are the most effective when they are combined with non-drug approaches to treating the symptoms.

When considering using medications, it is very important that you understand that no drugs have been specifically approved by the Food and Drug Administration (FDA) to treat the behavioral and psychiatric symptoms that come along with dementia. A few of the examples we will see below represent an “off label” use—that is, a medical practice in which a doctor could prescribe a drug for a different purpose than the one for which it has been approved.

Guiding Principles

The general principles that follow can help to guide the appropriate use of any medications:

- **Know the risks and benefits.** It is very important that you understand any potential risks or benefits of a medication before making any decisions about treatment.
- **Target a specific symptom.** Effective treatment of a core symptom could work to relieve other symptoms as well. As an example, some antidepressants could help the person to sleep better.
- **Start with a low dose of a singular drug and monitor closely to watch for any side effects.** Side effects can be a serious issue, and drugs can serve to worsen the symptom being treated at times. **Do NOT** increase dosage without first getting evaluated by a healthcare professional.

Medication Examples

Now, let's look at some medications that are most commonly used to treat behavioral and psychiatric symptoms. These medications are listed in alphabetical order via generic name, and they include the following:

Antidepressants for low mood or irritability:

- Citalopram (Celexa)
- Fluoxetine (Prozac)
- Paroxeine (Paxil)
- Sertraline (Zoloft)
- Trazodone (Desyrel)

Anxiolytics for anxiety, restlessness, verbally disruptive behavior and resistance:

- Lorazepam (Ativan)
- Oxazepam (Serax)

Antipsychotic medications for hallucinations, delusions, aggression, agitation, hostility and uncooperativeness:

- Aripiprazole (Abilify)
- Clozapine (Clozaril)
- Haloperidol (Haldol)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)
- Risperidone (Risperdal)
- Ziprasidone (Geodon)

Antipsychotic Medications

Coming to the decision to use an antipsychotic drug has to be considered only with extreme caution. Research has been done that has shown these drugs are associated with an increased risk of stroke and death in older individuals with dementia. The FDA has ordered manufacturers to label any such drugs with a “black box” warning about the risks as well as a reminder that such things are not approved to treat any dementia symptoms.

According to scientific evidence, as well as governmental warnings and guidance from care oversight bodies, people with dementia should only use antipsychotic drugs under one of the following conditions:

1. Behavioral symptoms are due to mania or psychosis
2. The symptoms present a danger to the person or others
3. The person is experiencing inconsolable or persistent distress, a significant decline in function or great difficulty in receiving any needed care.

Antipsychotic medicines shouldn’t be used to either sedate or restrain those with dementia. The absolute minimum dosage should be used for the minimum amount of time possible. Any adverse side effects will require very careful monitoring.

Although antipsychotics are, in fact, the most commonly used medications for agitation, some physicians could prescribe a seizure medication or mood stabilizer, like Carbamazepine (Tegretol).

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To close out the chapter, let us finally take a look at some of the risk factors for dementia and how to best prevent them.

Some of the risk factors of the disease, like age or genetics, can’t be helped. But research is being done continuously to further explore the impact of other risk factors on the health of the brain and the prevention of dementia. Some of the more actively researched areas in risk reduction and prevention include cardiovascular factors, physical fitness, and diet, so those are the three areas that we will focus on ourselves.

Cardiovascular risk factors: The brain is nourished by one of the body’s richest networks of blood vessels. As such, anything that causes damage to blood vessels anywhere in your body can hurt those in your brain, which, in turn, deprives the brain cells of vital food and oxygen. Changes to blood vessels in the brain are liked to vascular dementia. Most often, they are found along with changes that are caused by other forms of dementia, like Alzheimer’s disease and dementia with Lewy bodies. Such changes can interact to cause a quicker decline or to make any existing impairments that much more severe. You can help to protect your brain with a few of the same strategies you use to protect your heart—don’t smoke; take steps to keep your blood pressure, cholesterol and blood sugar within the recommended limits; and maintain a healthy weight.

Physical Exercise: Exercising regularly could help to lower the risk of some types of dementia. There is evidence to suggest that exercise may also directly benefit brain cells by increasing blood and oxygen flow to the brain.

Diet: The things you eat could have the greatest impact on the health of your brain through its effect on the health of your heart. The best current evidence available suggests that heart-healthy eating patterns, like the Mediterranean diet, can also help to protect the brain. A Mediterranean diet includes very little in the way of red meat, instead placing emphasis on whole grains, fruits, and vegetables, fish and shellfish, and nuts, olive oil and other healthy fats.

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Well, that’s another chapter down! Look at you go! In the next chapter, we’ll take a look at a few tips on how to better connect with and help someone with dementia. We will also briefly look at some ways that you can connect with other caregivers to receive help and advice as well.

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Chapter 8: Connecting with Others

For all intents and purposes, the world has gotten smaller. Yes, it's still a huge blue marble hanging out in the middle of space, but over the last thirty years or so, or even earlier than that, perhaps, the world has gotten significantly smaller than it once was.

The reason?

The people of today live in a culture with an "always on" mentality. Another way you can look at it is that people of today—especially young people—are always connected. They're always looking down at their phones, always talking or browsing or watching, doing whatever they wish. That's because the modern cell phone is more computer and less phone these days. Think about it for a second. When you boil it down, cell phones these days are basically computers you can hold in the palm of your hand. They can do most anything a desktop computer or laptop can do, *plus* you have the ability to talk on the phone too. What's more—you can even do most of these things simultaneously!

It seems crazy at first, and no doubt you might have thought exactly that at one point. I think we all have. But there's a bit of truth in there somewhere isn't there? I mean, we all want to feel connected to something or someone, right? It's quite a sad thing to think about, feeling like there's a whole great big world to explore and we're stuck here in our pitiful little corner of it, resigned to only dream of what else might be out there, what else we might be missing out on.

If *we* feel this way—those of us who are not suffering with a disease like dementia—imagine how much more so those who *are* must feel. As the dementia progresses, they lose their ability to communicate, and thus their main ability to connect disappears as well. That's why it is so important that we let them know that we still want to connect, and they still have ways to do so.

However, it can seem a rather daunting task learning how to connect to someone whose ability to communicate may be nonexistent. It can be both daunting *and* frightening, and so many of us may be more than a little apprehensive at the thought of doing it, and that's why this chapter is so important.

In this chapter, we will take a look at 10 tips on how to connect with someone who has dementia, and how to help our spouse or partner, our children or grandchildren, or friends to help *us* if we're the ones facing the diagnosis. Hopefully, by the end of it, you'll feel (and be) better equipped to help those around you during their greatest time of need.

There's more good news too, as this chapter should be a bit shorter than the past few, so I know you've got to be excited at that prospect. So, let's not waste any more time and get right into it.

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When a baby is born, it doesn't know how to communicate and must learn how to do so over time. Gradually, as the child grows up, he or she will get better and learn how to communicate their wants and needs more effectively than when they first started.

In the same way, we too must learn how to effectively communicate with someone who has dementia. It is not an inherited trait to be able to do so, and it can take time to properly learn. But the more that you do it, the easier it will then become. Having good communication skills will also allow you to better handle difficult and stressful behaviors that often come along with the illness as well.

So, let's see some tips!

10 Tips for Connecting with Someone with Dementia

1. **Set a positive mood for interaction.** Both your attitude as well as your body language communicate how you're feeling and what you're thinking much stronger than your words do. Be sure to set a positive mood by using a pleasant and respectful manner when speaking to your loved one. Use a combination of facial expressions, tone of voice, and physical touch to help you better get the message across and show feelings of affection.
2. **Get the person's attention.** Be sure to limit distractions and noise—turn off the television or radio, close any curtains or shut the door, or simply move to some quieter surroundings. Before you speak, make sure you have his or her attention, address him or her by name, identify yourself by name

and relation, and make use of nonverbal cues as well as touch to keep them focused. If he or she is seated, get down to their level and keep eye contact with them.

3. **State your message clearly.** Use words and sentences that are simple. Speak slowly when you talk, and speak distinctly and in reassuring tones. Keep from raising your voice any higher or louder; instead, go a bit lower. If he or she is unable to understand the first time, use the same words to repeat your message or question. If he or she still does not understand, wait a few minutes and then rephrase the question. Be sure to use names of people and places instead of pronouns or any abbreviations.
4. **Ask simple, answerable questions.** Only ask one question at a time; those that have yes or no answers often work the best. Do not ask open-ended questions or giving them too many choices. As an example, ask, "Would you like to wear the blue or red shirt?" Even better still, show him or her the clothes, as visual prompts and clues can help to clarify your question and to guide the response you are looking for.
5. **Listen with your ears, eyes and heart.** While you wait for them to respond, be patient. If you see that he or she is struggling to find the words, you can suggest words if needed. Watch for any nonverbal cues and body language, and make the appropriate response. Always try your best to see the meaning and feelings behind the things they say.
6. **Break down activities into a series of steps.** Doing so will make a lot of different tasks much more manageable. You can still encourage your loved one to do what they are able, while also gently reminding them of any steps they may forget, and helping with the steps they are no longer able to do on their own. Making use of visual cues, like showing with your hand where the dinner plate is to go, can be very helpful as well.
7. **When things get tough, distract and redirect.** If and when your loved one gets upset, you could try changing up the subject or the environment for them. For example, you may ask if he or she would help you with a task, or if he or she would like to go for a walk. It's very important to connect with the person on what he or she is currently feeling before you redirect. Acknowledge the fact that they are upset, by saying something like, "I see you're sad, and I'm sorry you're upset. How about we go get something to eat?" Don't brush off how they're feeling before suggesting an alternative activity.
8. **Respond with affection and reassurance.** Those people with dementia often feel confused, anxious and very unsure of themselves. What's more—they can often get reality confused and might remember things that never happened. Try and stop yourself from convincing them they are

wrong. Instead, stay focused on what they are feeling at the moment, and how they are demonstrating those feelings, and respond with both verbal and physical expressions of comfort, support and reassurance. Doing things like holding hands, touching, hugging and praising will elicit a response from the person if all else fails.

9. **Remember the good old days.** Taking time to remember the past is often a soothing and affirming type of activity. A great number of people with dementia can't often remember what happened only 45 minutes ago, but may remember what happened 45 years ago with great clarity. As such, you should avoid posing questions that are reliant on short-term memory—such as asking what they had for lunch, and instead asking more general questions about the distant past, since this information is more likely to be retained.
10. **Keep your sense of humor.** Whenever you can, use humor, though never at the person's expense. Those with dementia tend to retain any social skills and are quite usually delighted to share in a laugh with you.

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So, we just finished looking at some ways for you to connect with someone who has Alzheimer's or another form of dementia, and how important that is. But what if that person is you? How can you help friends and family members you love better be able to adjust to the new "normal" along with you? It's hard enough adjusting to that fact on your own, so let's look at some things that you can do with those you love to help them get and stay connected with you as you make this journey together.

Helping Your Spouse or Partner

Getting news of your diagnosis may or may not come as a surprise. As both individuals strive to come to terms with the enormous change in your life together, your spouse or partner could be feeling a sense of loss or loneliness as a result of the diagnosis.

Here are some things you can do to help your spouse or partner:

- **Continue participating in as many activities together as possible.** Adapt favorite activities as needed in order to make them more comfortable and enjoyable for both of you.
- **Find new activities you can do together.** Also, keep doing things that you have always enjoyed doing together.

- **Talk with your spouse or partner about the kind of help you would like from them now.** Also, be sure to talk about what you can still do on your own.
- **Work with them to get information you might later need regarding caregiver services and costs.** Organize any needed documents into a file. When thinking of future services, make sure to include housekeeping and respite (caregiver relief) care. You can search for local services, resources and programs by using the Community Resource Finder on the Alzheimer's Association website.
- **Talk about any role changes in the relationship with a professional counselor or clergy member.** Include changes in your sexual feelings or ways of connecting.
- **Share the Caregiver Center website on the Alzheimer's Association webpage.** It is an online resource where your spouse or partner can learn more about any caregiving issues and get some tips too.
- **Attend early-stage and/or caregiver support groups through your local Alzheimer's Association chapter.** Sometimes it can help to befriend another couple who is currently facing the same situation, as it opens up new possibilities for support.
- **Connect with others.** Both you and your spouse or partner can connect with others on the Alzheimer's Association message boards, ALZConnected, as well as keep in touch with family and friends.

Helping Children or Grandchildren

Children who are younger may be afraid of getting the disease themselves, or that they have inadvertently done something to cause it. Teenagers may become resentful at the thought of having to take on more responsibilities at home, or they could be embarrassed that their parent or grandparent is "different." Those young adults who are college-bound may feel a sense of reluctance to leave home to go to school, or may create some occasions to be angry in order to make it easier to separate themselves and gain some independence.

- **Talk openly about the changes you are experiencing because of your disease.**
- **Identify their emotional needs.** Find ways you can support them, like meeting with a counselor who specializes in treating families dealing with chronic illnesses.

- **Notify school social workers and teachers about the situation.** Give them information about the disease. You can direct them to the Alzheimer's Association website, alz.org, or give them some educational brochures from your local chapter (you can find your local chapter on the AA website as well).
- **Don't pull away.** Try your best to find some activities you can still enjoy together. If driving isn't possible, you could plan a hike or bike ride. Check out your local public transportation. You can use the Community Resource Finder on the AA website to search for any local transportation services.
- **Remember to make it okay to laugh.** Sometimes humor can really help to lighten the mood and make it easier to cope.
- **Record your thoughts, feelings and wisdom in writing, audio or video.** The children in your life will come to appreciate this when they get older.
- **Share the Alzheimer's Association Kids & Teens website.** This is somewhere that young people can go to learn about Alzheimer's.

Helping Friends

Friends, co-workers or neighbors might not really understand what's going on with you at first. They probably won't know what to do or say, or they may try to distance themselves or resist the urge to keep in touch. However, it is important to remember that many people do not do this on purpose. You have to remember that they are likely just as confused by the weight of it all as you were initially (or may still be). It's also entirely possible that they may simply be waiting for you to reach out to them.

Some things you can do to help your friends include:

- Sharing your experiences living with Alzheimer's.
- Telling them what you're still comfortable doing.
- Inviting them to Alzheimer's Association educational programs and events.
- Letting them know when you need help and support—and then what they can do to help. And when they offer, take them up on it! They want to help, they just may not know how.

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Getting Stuck

There might be some times when it could feel like your family members or friends are disconnecting from you—those times when your relationship feels stuck. During these times, it could be that the person or your connection with each other is going through a challenge that could feel very emotionally overwhelming. Below, you'll see some ways that you can use if things get stuck to help to move things along and help them adjust.

- **Speak honestly and frankly about your feelings.** Be sure to acknowledge how important the relationship is to you as well as your desire to face this difficult time together.
- **Take time to listen to the other person's feelings.** Respond as much as possible while saving your own concerns for another time. It is very important that the both of you feel heard by the other, as well as taking turns being the "listener." It can really help!
- **Focus on the positive changes you can make that can help you to regain a sense of closeness.**
- **Take action.** Make plans to do something that you both enjoy.
- **If friends and family get stuck in the adjustment process,** help them by directing them to the programs and services portion of the Alzheimer's Association website.
- **Consider bringing in a third party for help.** Discussing the situation with an experienced professional who works to help those facing chronic illness can help one or both of you to come to terms with the impact of the disease. You can ask your local Alzheimer's Association chapter for help finding professionals in this area.
- **If either you or a family member is going through depression or anxiety that seems to go beyond what feels normal, remember that these are treatable conditions.** There are professionals who can help, and you can also see symptoms of depression on the Alzheimer's Association website.

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To finish up the main portion of the chapter, we'll take a look at one more resource that is there to provide support to you, your family members or other loved ones—the 24/7 Alzheimer's Association Helpline (**1.800.272.3900**).

The Helpline gives both reliable information and support to those who need some help, and you can call anytime of the day or night, and serves those with memory loss, their caregivers, health care professionals, and the general public.

Highly trained and knowledgeable staff members can assist you in the following areas:

- Understanding memory loss, dementia and Alzheimer's
- Medications or other treatment options that are available
- General information regarding aging and brain health
- Skills to give quality care and to find the best care from professionals
- Legal, financial and living-arrangement decisions

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The 24/7 Helpline also features:

- Confidential care consultation given by master's level clinicians who can assist with decision-making support, crisis assistance and education on issues that families face daily
- Help in the caller's preferred language using Alzheimer's Association translation services that feature more than 200 languages and dialects
- Referrals to local community programs, services and ongoing support

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We've reached the end of another chapter, and with it, we are now two-thirds of the way through our journey together. The next chapter will be a little different from the norm, as we'll be taking a look at some reflections and statistics about dementia. It's sure to be interesting and perhaps even enlightening, so stick around.

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Chapter 9: Statistics on Dementia

Welcome back. As we continue on our journey together, we'll be taking a detour of sorts. This chapter will be the most different in style compared to the ones that came before it and the ones to come after. Like the title suggests, we'll be spending some time diving into a number of surprising statistics and facts regarding dementia—both in the United States and the United Kingdom. With that said, let's get started:

Alzheimer's Statistics in the United States

- Alzheimer's disease is the **6th leading cause of death** in the United States
- Over **5 MILLION** Americans are currently living with Alzheimer's disease
- **1 in 3** seniors will die with Alzheimer's or another form of dementia
- In 2015, over 15 million caregivers provided an estimated **18.1 BILLION HOURS** of unpaid care
- Someone in the United States develops Alzheimer's every **66 seconds**
- Last year, Alzheimer's and other forms of dementia cost the nation **$236 billion**
- Family caregivers spend over **$5,000/year** caring for someone with Alzheimer's. For some families, they miss vacations, but for others, it may mean going hungry.
- Alzheimer's kills more than **breast and prostate cancer combined**

Prevalence

The number of Americans living with Alzheimer's is growing—and fast. An estimated 5.4 million Americans of all ages had Alzheimer's in 2016.

- Of that number, an estimated **5.2 million** were aged 65 or older, and approximately **200,000** people were under age 65 (younger-onset Alzheimer's)
- **One in nine** people has Alzheimer's by age 65
- By the middle of the century someone in the United States will develop the disease **every 33 seconds**

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These numbers will grow quickly in the coming years, as the baby boomer generation reaches the age of 65 and beyond. By 2050, those people aged 65 and older who have Alzheimer's could almost triple, from 5.2 million people to a projected 13.8 million, barring development of some medical breakthroughs to either prevent or cure the disease. Previous estimates based on high range projections of the population growth given by U.S. Census says that this number could be as high as 16 million.

Let's look at some more facts:

- Among people age 70, **61 percent** of those who have Alzheimer's are expected to die before age 80. Compare those numbers to the 30 percent of those without Alzheimer's.

Caregivers

- Those 18.1 billion hours of unpaid care we mentioned previously translates to an estimated economic value of **221.3 BILLION dollars**
- Approximately **two-thirds** of caregivers are women, with 34 percent of that number being age 65 or above
- **41 percent** of caregivers have a household income of **$50,000 or less**
- Care contributors, on average, lose more than **$15,000** in annual income as a result of lessening or quitting work altogether to meet caregiving demands
- A whopping **60 percent** of caregivers rate the emotional stress that comes with it as high or very high; around **40 percent suffer from depression. 1 in 5** cut back on their own doctor visits because of their care responsibilities, and around **74 percent are "somewhat" to "very" concerned about maintaining their own health.**

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Cost to Nation

- Alzheimer's is one of the costliest chronic diseases to society and is helping to **bankrupt Medicare**
- Medicare and Medicaid are expected to cover **$160 billion, or 68%**, of total health care and long-term care payments for those with Alzheimer's or other forms of dementia.

- Nearly **one in every five Medicaid dollars** is spent on those with Alzheimer's and other forms of dementia. In 2050, it will be **one in every three dollars**
- In 2050, Alzheimer's is estimated to cost more than **$1 TRILLION** (in 2016 dollars), and costs to Medicare will rise by 360 percent. Such a dramatic rise includes a nearly five-fold increase in government spending under Medicare and Medicaid and an almost five-fold increase in out-of-pocket spending.

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Financial Impact on Families

It is important to note that Alzheimer's takes a big toll on not only the person with the disease, but families as a whole.

How much of their own money do families spend to get care for the needs of the person with the disease? Are they prepared to take on the financial impact of the disease? Studies dealing with this specific topic are quite rare, so the Alzheimer's Association commissioned a nationwide scientific survey of over 3,500 Americans who were posed these questions and others.

Frighteningly, the survey showed that a lot of care contributors found it necessary to cut back on their basic necessities—like food and medical care for themselves and their families. They are 28 percent more likely than other adults to eat less or go hungry simply because they cannot afford to pay for food. At the same time, many participants in the survey had various misconceptions about what kinds of expenses Medicare and Medicaid cover, meaning these individuals were left unprepared to be able to face the tremendous costs that are associated with Alzheimer's or other forms of dementia. When looked at as a whole, the survey results show significant financial troubles placed on families simply because their friend or family member who has Alzheimer's can't afford to take care of themselves anymore.

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Now that we've seen some statistics for the United States, let's turn our focus to the other side of the Atlantic and look at some numbers for the United Kingdom. According to the Alzheimer's Society:

- There are 850,000 people suffering with dementia in the UK, with numbers looking to climb above 1 million by 2025. This number will then grow to 2 million by 2051.
- 225,000 will develop dementia this year. This equals one person every three minutes.
- 1 in 6 people aged 80+ have dementia.
- A whopping 70% of people in care facilities have dementia or severe memory problems
- There are more than 40,000 people under the age of 65 who have dementia in the UK.
- More than 25,000 people from black, Asian, and minority ethnic groups in the UK are affected by Alzheimer's or dementia.
- Two-thirds of the cost of dementia is paid by the those with dementia and their families.
- Unpaid careers supporting someone with dementia save the economy £11billion a year.
- Dementia is one of the main causes of disability in later life—putting it ahead of cancer, cardiovascular disease and stroke. As a country, the UK spends much less on dementia than any of these other conditions.
- There are an estimated 35.6 million people living with dementia, and those numbers will double every 20 years, ballooning to 115.4 million people in 2050.
- There is no cure for Alzheimer's or other dementias, but delaying the onset of the disease by five years would cut the number of deaths in half, and save 30,000 people a year.
- Research in the dementia field is severely underfunded. For every one person dealing with dementia, then annual cost to the UK economy is more than £30,000 and still only £90 is spent on researching the disease each year.
- There are five times **fewer** researchers who choose to work on dementia than those who choose to research cancer.
- The Alzheimer's Society is committed to spending at least £150 million throughout the next decade on dementia research to give people better care today and work toward finding a cure for tomorrow. This also includes £50 million to help develop the UK's first dedicated Dementia Research Institute.

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We are hopeful that you found this brief chapter enlightening, and perhaps it brought attention to a few things you may not have thought much about before. And while some of those statistics are, in fact, quite alarming, it doesn't mean that we can’t work together to bring about a positive change and turn things around.

Moving along, we know that being a caregiver can be (and usually is) a daunting task, especially for those who have never had to deal with such a big issue as dementia before. As such, our focus in the next chapter will be a caregiver boot camp of sorts, and we’ll look at some tips and strategies to help caregivers deal with various issues they may encounter as they care for their loved one.

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Chapter 10: Boot Camp for Caregivers

Caring for someone who is sick takes a very special person, perhaps that is why so many moms seem to be pretty good at it. Even more so, caring for someone who has a completely life-altering disease like Alzheimer's or another form of dementia is a whole different ball game. However, those who bear the brunt of the disease, at least in terms of the area of care, are not the medical professionals—though they are certainly still a vital part of the process.

Rather, it is the ordinary folks, the common folks, who have to step up, take charge, and help their loved one battle through a disease that is, seemingly, insurmountable. That's part of the reason why it can be so scary upon learning that you or your other family members must now shoulder the responsibility of caregivers. After all, you are not trained. Perhaps you didn't even go to medical school at all, and the worst health issue you've treated in your life was the common cold or an earache.

What does one do when faced with this David and Goliath-type scenario? The first thing—just breathe. You might be freaking out right now, so why don't you take a few slow, deep breaths to steady yourself, and then we'll continue…

Ready?

If you find yourself currently in this type of position, fear not. This chapter is here to help you better understand and deal with the sometimes trouble types of behavior that often come along with the Alzheimer's disease or some other form of dementia. As we begin, we'll take a look at the aspect of communication.

Communication

The fact of the matter is that communicating is important. No matter if we would rather hole up in our homes and not go into work, or not deal with the outside world for a few days, we still have the need to communicate. It is a vital part of daily life, and we need to be able to tell other people a variety of different things, like our needs, wishes or feelings. On top of that, how well we do at communicating these things can and does affect our quality of life, as well as how much of our individuality and sense of identity we retain.

If communicating is *that* important for those of us who are well, imagine how much more so it must be for those who, because of the disease, may not be able to communicate verbally at all! After all, just because someone has dementia does not mean they no longer have needs, desires or preferences—certainly not! It just means that we, as caregivers, must dig a little deeper and be willing to work a little harder to decipher these things. And that's what this chapter is aiming to assist you with.

As we've seen, dementia can make it quite hard for someone to communicate properly, and this can prove to be especially upsetting or frustrating for them and the people around them. However, there are still a lot of ways that you can support and communicate with one another.

Someone suffering from dementia might have some trouble trying to find the right word, they could repeat certain words or phrases, or they may get "stuck" on certain sounds. What's more—those who have dementia are also quite likely to have other sensory impairments (like issues with their sight or hearing), and these can also make it much more difficult for them to communicate with others. If someone cannot express themselves properly, this can create in them a lack of confidence, feelings of anxiousness or depression, or it could cause them to become withdrawn. They could also display odd behaviors, since they are doing their best to communicate what they are no longer able to say with words.

If someone with dementia is living in a hospital or other care setting, having issues with communication can also affect the care and support they receive at the facility.

Dementia and Language

Issues with language can crop up in every form of dementia. This is due to the fact that the diseases that bring about the dementia can affect the areas of the brain that are responsible for language. How and when the language problems manifest is dependent on the individual, as well as the type of dementia and the stage it is currently in. Such issues will also vary day by day, and in some forms of dementia—like frontotemporal dementia—it is quite likely to be one of the initial symptoms that you or your loved ones notice.

One way you may be able to tell that someone's language has been affected by dementia is that they won't be able to, because they cannot, find the right words. The cause of this is the dementia, which can affect. They might use a related word (like saying "book" for "newspaper"), they could use substitutes for words ("thing to sit on" instead of saying "chair"), or may be unable to find any word at all. Yet another sign that language is being affected by the dementia is the fact that their speech may be fluent, but it could be made up of gibberish, or jumbled up words and grammar. Dementia can also leave the person unable to make an appropriate response, because he or she may not understand what you have said or meant.

As the disease worsens, there might come a time when the person may be almost completely unable to communicate using language at all. This can, understandably, be a time of significant distress for them and their caregivers, but there will always be ways to keep up communication and to give them the support they need to express themselves.

Another area that dementia can have an effect on is a person's cognitive abilities. Someone with dementia may have a slower thought speed or might not be able to understand more complex ideas. It can also affect the ability to communicate. As an example, they might take a little longer to process things and words and work out how to best respond to what was said.

There are other things that can affect communication as well—like pain, discomfort, illness or side-effects from medication. If you think this might be occurring, you can speak with their doctor.

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Communicating with Someone with Dementia: Some Tips

Now, let's see some more tips for communicating!

Before you speak:

- Make sure you're in an appropriate place to hold a conversation—somewhere quiet, with good lighting, and with few distractions (no radio or TV on in the background).
- Get the person's full attention before you begin.
- Position yourself where the person can see you as clearly as possible, with your face well-lit, and be sure to be on the same level as they are, rather than standing over them.
- Sit close to the person (though not in their personal space) and make eye contact.
- Make certain your body language is open and relaxed.
- Make sure to have enough time to spend with the person. If you are feeling rushed or stressed, take some time to calm yourself down again.
- Think about what you would like to talk about. It could prove helpful to have some ideas on particular topics. You can also use the person's environment to help stimulate topics.
- If there is a certain time of day that he or she is better able to communicate (like in the morning), try to make sure and use this time to ask questions or talk about any necessary topics first. Make the most of their "good" days and find different ways to adapt their "bad" ones.
- Be sure that all the person's other needs are met before you begin the conversation (make sure they aren't in pain or hungry).

How to speak:

- Speak both clearly and calmly.
- Speak slightly slower than normal, and give them time between sentences to process the information and respond. The pause may seem uncomfortable to you, but it is vital to helping them communicate.
- Avoid speaking sharply or raising your voice.
- Use short and simple sentences.
- Try to talk with them in a conversational way. It's not an interrogation; you don't have to ask question after question.

- **Do NOT** talk about the person as if they are not there, or talk to them like you would a child. Have some patience and respect for them.
- Try and find humor in misunderstandings and mistakes—it can definitely help. Humor can bring you closer together, and could relieve pressure. However, show sensitivity and don't laugh *at* them.
- Be sure and include the person in any conversations with others. This could be easier if you slightly adapt what you're saying. Being included can help the person to keep their sense of identity and feel as though they are valued. It can also serve to reduce any feelings of being excluded or isolated.

What to say:

- Try to keep from asking too many questions, or complicated questions. Those with dementia can become frustrated or withdrawn if they cannot find the answer.
- Keep to one idea at a time. Giving someone a choice is quite important, but too many choices can be confusing and frustrating.
- If he or she is finding it difficult to understand, try breaking down what you're saying into smaller pieces so it's easier for them to understand.
- Ask questions one at a time, and phrase them in a way that allows the person a "yes" or "no" answer, or in a way that gives them a choice between a couple things.
- Rephrase questions rather than repeat them if the person is unable to understand what you're saying. Make use of non-verbal communication to help, if needed (like pointing at a picture of someone you're talking about).
- If the person gets tired rather easily, it could be better to try for short, regular conversations. As the disease progresses, he or she could become confused about what is and isn't true. If something is said that you know is not true, try and look for ways to steer the conversation around the subject and try to discover the meaning behind what they are saying, rather than outright contradicting them. As an example, if they are saying they need to go it work, is it because they want to feel useful or find a way of being involved and like they're contributing? Could it be they need more stimulation?

Listening:

- Be an active listener and listen carefully to what the person is saying.
- If you do not fully understand, rephrase what you *have* understood and check if you are right. Both the person's reaction and their body language can be a rather good indicator as to what they've understood and how they're feeling.
- If he or she has issues finding the correct word or finishing a sentence, ask them to explain it in a different way. Watch for clues. Be sure to pay attention to body language. Their expression and the way they carry themselves can provide clear signs as to how they're feeling.
- Give the person plenty of time to respond. It could take them longer to process information and work out a response. Don't interrupt them either, since this can break the pattern of communication.
- If he or she is feeling sad, let them express those feelings. Don't just brush off their worries. Sometimes the best thing—the only thing—they need from us is for us to just listen, and show that we are there to support them.

Body language and physical contact:

- For those with dementia, non-verbal communication is vital, and as the disease worsens, it will become one of the main ways they communicate. Learn to recognize what is being communicated through body language and support them so they can keep being engaged, and you can help contribute to their quality of life.
- Someone with dementia can read body language. Any sudden movements or a tense facial expression could cause them to become upset or distressed, and make communicating harder.
- See that your body language and facial expressions match your words.
- Never stand too close to someone or stand over them when speaking, as it can cause them to be intimidated. Instead, respect their personal space and drop to or below their own eye level. This can help them feel more control in the situation.
- Communicate interest and give reassurance through physical contact. Don't discount the reassurance that comes from holding someone's hand or putting your arm around them, if it feels appropriate to you to do so.

Sensory Impairment

Some people with dementia will often have a form of sensory impairment as well—like sight or hearing loss or both. People who have both sensory impairments as well as dementia are more likely to face additional hardships when it comes to communication. Nonetheless, there are still many things that you can do to help them to communicate. Let's take a look at some of these things below:

Hearing Loss

A great number of people over the age of 70 will have some degree of hearing loss. They might consider themselves to be deaf, hard of hearing, or as having acquired hearing loss. This could be because of age-related damage or other causes, like noise damage, infection, diseases or injuries.

By comparison, those who are born deaf or who become deaf at a young age are considered to have "profound deafness." That could consider themselves Deaf, use sign language as their first language or identify with the Deaf community.

How someone with hearing loss chooses to communicate will depend on several factors:

- The type of hearing loss they have
- Whether or not they use a hearing aid, sign language, lip-reading or some combination of all of them
- Personal preference and life history

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There are certainly links between dementia and hearing loss that can suggest it is likelier for someone with hearing loss to develop dementia. Those who have hearing loss are likely to have more difficulties because of the dementia, or they may already find it harder to communicate, and being unable to hear what's going on around them or hear other people speak can pile more onto their already existing confusion. Having both dementia and hearing loss can make individuals feel socially isolated, and this makes good communication that much more important.

Tips for Communicating with Someone with Hearing Loss

- If he or she uses a hearing aid, check that it fits and is working properly. If you think it isn't working or need help checking it, talk to your doctor or make an appointment with the audiology department at the hospital.
- Ask the person if they would like to lip-read.
- Turn to face the person and ensure that your face is well-lit so he or she can easily see your lip movements.
- Do not shout or overexaggerate words or lip movements, as this can make it more difficult for the person to understand you.
- Speak clearly and slightly slower, but keep natural rhythms when you speak.
- Don't cover your mouth.
- Consider using visual clues like objects or pictures to help them.
- It could help to check and see if the person has too much ear wax, since this can make any hearing loss and difficulties communicating even harder.

Sight Loss

A lot of people experience some form of sight loss as they age. In the U.K., there is an estimated 1.6 million people over age 65 living with sight loss. It's possible that it is age-related, or it could be because of a condition like cataracts or age-related macular degeneration. Most people with sight loss need glasses to help them see.

Those with sight loss are more likely to have difficulties because of dementia. Not being able to properly see their surroundings can give them a greater sense of disorientation and make them more distressed, as well as adding to decreased mobility and risk of falling. As with hearing loss, having both dementia and sight loss can add more feelings of isolation, and this makes it so important to be able to properly communicate in some form or another.

However, communicating with someone with sight loss and dementia can be hard, since they may have trouble picking up on visual clues or be unable to follow a conversation properly. Be that as it may, there are still a number of things that you can do to help.

Tips for Communicating with Someone with Sight Loss

- Make sure the person is wearing their glasses, if necessary, and that they are clean and have the up-to-date prescription.
- If a person has more than one pair of glasses, make sure they are either labelled or marked for the activity they need to be used for—like reading glasses, for instance.
- Introduce yourself and try to get the person's attention before beginning or ending a conversation. If you don't, they could get confused about who is talking, be unsure if they are being spoken to, and may not be aware if someone enters or leaves the room.
- If you are assisting them with a task, let them know what you are going to do before and during it.
- Make use of references when describing where something is—like their water is on the table on the right, for example. It could also be helpful to use imaginary hands on a clock face to describe where something is, especially if he or she has lived with sight loss for a long time.
- Make the most of the physical environment—as an example, see that there is good lightning, which is consistent and may be adjusted as needed. Try to reduce shadows, since the person can mistake them for obstacles.
- He or she may not be able to read non-verbal communication, like body language. Keep this in mind when speaking with them.
- If you are communicating through writing, like sending a letter, think about the color of paper and the font size (black font on white or yellow paper is often easier to read, as is larger text).
- Those with learning disabilities are 10 times more likely to have sight problems than other people. They are also at greater risk to develop dementia at a younger age, especially those with Down's syndrome. Make sure someone with learning disabilities and dementia has a communication passport—a special tool that gives information about someone's complex difficulties communicating, including the best ways to communicate with them.

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In the same way that parents sometimes just have to wing it when trying to raise children, caregivers can face the same sort of thing in their own line of work. They will often rely on intuition to aid them in making the right caregiving decisions—and sometimes, relying on gut instinct may be the only decision you have. After all, there is no be-all, end-all dementia handbook to consult. No one has gotten lessons from a professional on how to best deal with situations involving someone with memory loss, and sometimes the right thing to do may be the complete opposite of what it normally would be, or what we think it *should* be.

Such is the nature of Alzheimer's and other dementias.

With that said, let us next take a look at a few more practical strategies that we can use in some real-life situations in our caregiving lives:

1. Being Reasonable, Rational and Logical Will Just Get You into Trouble

If someone is acting in such a way that doesn't make sense, we will often try to explain the situation with care, and appeal to their sense of what is appropriate to elicit the compliance we desire. However, someone who suffers from dementia doesn't work like that, since their mind is no longer their own, so they cannot respond to logic. Instead, using simple, straightforward sentences about what will happen due to their behavior is usually the best route.

2. People with Dementia Do Not Need to Be Grounded in Reality

If someone suffers from memory loss, he or she will often not remember important things, like the fact a parent is deceased. When reminding them of the loss, we're also bringing up all the pain that comes along with it. Telling someone who *is* home that they *are* home will only lead to arguments if they want to go home. Instead, redirect them and ask them to talk about the person they've asked about or about their home. It's a much better way of calming them down.

3. You Cannot be a Perfect Caregiver

In the same way that there is no such thing as a perfect parent, there is also no such thing as a perfect caregiver. So, don't be surprised if there's ever a time you're not the absolute best caregiver who's ever lived. Any emotions you feel are valid, and you're allowed to feel the full range of them as you go on your caregiving journey. After all, you're only human—you're going to feel impatient and frustrated, and learning how to forgive yourself is just as important as forgiving your loved one.

4. Therapeutic Lying Reduces Stress

We do our best to be as honest as possible with people around us. But when someone has dementia being honest can just lead to more stress for them and us. Is it okay to tell your loved one you're going to have lunch together and then "coincidentally" stop by the doctor's office to pick something up when going home as a way to get them to the doctor?

5. Arguing Doesn't Work

Simply asking someone with dementia to never do something again, or to *remember* to do something isn't going to work; it will soon be forgotten. For those who have early-stage Alzheimer's, leaving them notes or reminders can help, but won't always as the disease worsens. Instead, a more successful approach would be to take action and rearrange things in the environment. As an example, giving someone a teakettle that automatically shuts off is much better than simply warning them of the dangers of leaving the stove on.

6. Doctors Often Need Educated by You

Letting the doctor know what happens at home is crucial. An examination cannot tell the doctor that your loved one has spent the entire night pacing. Sometimes, the doctor needs to tell therapeutic lies too, such as telling the patient that an antidepressant being something to help with memory rather than depression.

7. You Can't Do It Alone. It's Okay to Ask for Help.

The answer should always be an emphatic YES when people offer to give us help. You're only human, and there's only one of you. Be sure to keep a list of things that people can do to provide help for you—such as providing a meal, picking prescriptions, helping keep up the garden or simply staying with your loved one while you run an errand. This can work to reinforce offers of help. After all, it's much harder to ask for help than to accept it, so make sure not to wait until you "really need help" to get it.

8. It's Easy to Overestimate and Underestimate Yourself and Your Loved One

More often than not, it's easier to do something *for* our loved one than to let them do it on their own. However, doing something for them will deprive them of their ability and independence with that skill. In the same way, simply insisting that someone do something for themselves can sometimes lead to frustration for the individual, agitation for ourselves, and we lessen their ability to perform whatever task it was. It is a constant juggling act, not only to find the right balance, but to also be aware that the balance could shift daily.

9. Tell, Don't Ask

Just asking what someone would like for dinner might have worked before, but when someone has dementia they might not have words for what they want, might not be hungry, and may not want the food we give them after all, even if they answer. Instead, letting them know that "we are going to eat now" takes away the pressure of having to respond while also encouraging them to eat.

10. It's Perfectly Normal to Question a Diagnosis When Someone is Lucid

One of the most difficult things we can do as caregivers is to remember that we are talking to the disease, not the person who used to be there. All dementia patients have those times they make perfect sense and can give the appropriate responses to things. During such times, it can be easy to think the person has been faking it or that we've simply exaggerated the issue. It is important to remember that we are not imagining things—they are simply having a moment of clarity, and it should be treasured when it happens.

Handling Troubling Behavior

When caring for a loved one who is dealing with dementia, it can bring about a lot of challenges for families and caregivers. People suffering from dementia that comes from Alzheimer's or related diseases or conditions have what's known as a progressive biological brain disorder. What this means is that it is harder for them to remember things, think clearly, communicate with others, or take care of themselves. What's more—dementia can cause sudden changes in mood as well as personality and behavior.

Now, we'll take a look at some ways to help you as a caregiver better deal with such troubling issues and difficulties when they present themselves.

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Some of the biggest challenges caregivers face are changes to personality and behavior. However, you can rise to the occasion and face these challenges by being creative, flexible, patient and compassionate. It can also help to not take things personally, and to keep your sense of humor. As we begin, consider the following:

We cannot change the individual. The person you care for is suffering from a brain disorder that shapes who they have turned into. If you try to control or change any behaviors, it is highly unlikely you'll be successful, and you'll generally be met with resistance. That's what it is important to:

- *Try to accommodate the behavior, not control it.* If, for example, the person insists on sleeping on the floor, put the mattress on the floor to make them more comfortable.
- *Remember that we* ***can change our behavior*** *or the physical environment.* By changing our own behavior, we will often see a change in our loved one's behavior as well.

Check with the doctor first. Most behavioral issues might have an underlying medical cause: the person may be in pain or might be experiencing some sort of side effect from medications. In some cases, like incontinence or hallucinations, there may be medications that can help treat issues related to those symptoms.

Behavior has a purpose. Those with dementia most often are unable to tell us what they need or want. They could do something that seems random—like taking all the clothes out of the closet—leaving us confused. It's quite likely that the person is trying to keep busy or feel productive. You should always try and consider what the person may be trying to accomplish with their behavior, and try to accommodate them when possible.

Behavior is triggered. It is critical to remember that all behavior is triggered by something. It could be something someone did or said that triggered the behavior, or it may be a change in the physical environment. In order to change behaviors, we must disrupt the patterns we create. Try approaching something differently or try a different consequence.

What works today may not work tomorrow. There are many different things that can influence any troubling behaviors, and with the natural progression of the disease, the solutions we have today may not be the solutions we have tomorrow. This is why it is so important to be creative and flexible when coming up with strategies to deal with problems.

Get support from others. It may feel like it initially, but you certainly aren't alone in your struggles. Find your nearest Agency on Aging, the local chapter of the Alzheimer's Association, or visit the Family Care Navigator by going to www.caregiver.org/family-care-navigator to get in touch with a variety of support groups, organizations and services that can help when you need it. You should also expect to have both good and bad days, just like your loved one does. The aforementioned resources can help you come up with strategies to better deal with those bad days when they come.

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Overview of Common Behaviors

Now that we've taken a more general look at some ways to handle behaviors, let's switch gears for a bit and check out some ways at dealing with more specific dementia-related behaviors.

Wandering

Those who have dementia will sometimes walk seemingly aimlessly, for a number of different reasons, like boredom, side effects from medication, or to look for something or someone. It is also possible that they may be trying to meet a need more physical in nature, like thirst, hunger, or a need to use the bathroom or even exercise. Finding out what triggers the wandering isn't always simple, but they can help you figure out how to better deal with the behavior. Some things you can do:

- Make time for regular exercise in an effort to minimize restlessness
- Think about installing locks that require a key. Put these locks high or low on the door, as many with dementia won't think of looking beyond eye level. Also, be mindful of fire and safety concerns for all family members; the lock(s) must be accessible to others and take no longer than a few seconds to open.
- Put up a barrier, such as a curtain or colored streamer to mask the door. A "stop" sign or "do not enter" sign may also prove helpful.
- Place a black mat or paint a black space on your front porch. This could appear to be an impassable hole to the person with dementia.
- Add "child-safe" plastic covers to any doorknobs.
- Consider putting in a new home security system or monitoring system that is designed to keep watch over someone who has dementia. There are also some new digital devices that can be worn like a watch or clipped onto a belt that use GPS or another technology to track someone's whereabouts or find them if they wander off.
- Put away any essential items like the person's coat, glasses, or purse. Some people won't leave home without these items.
- Have the person wear an ID bracelet and sew some ID labels into their clothes. Make sure to always have a current photo available if you need to report the person as missing. Think about leaving a copy on file at the police department or registering the individual with the Alzheimer's Association Safe Return program or some other emergency tracking service.
- Inform neighbors of the person's wandering behavior and see that they have your phone number.

Incontinence

Losing bladder or bowel control often occurs as the disease worsens. Accidents can sometimes result from environmental factors, like not remembering where the bathroom is or not reaching it in time. If a situation occurs, providing the person with understanding and reassurance can help them to keep their dignity and minimize any sense of embarrassment.

- Keep to a routine for using the toilet. Try reminding them or helping them to the bathroom every couple of hours.
- Schedule any intake of fluids to see that the person doesn't get dehydrated. Be aware that some drinks (like coffee, tea, cola or beer) often have more of a diuretic effect than others. Limit their intake of fluids in the evening before bed.
- Use signs with illustrations to indicate how to get to the bathroom.
- A toilet, found at any medical supply store, can be left in the bedroom at night for easy access.
- Incontinence pads and products can be bought at the pharmacy or supermarket. A urologist could be able to prescribe a special product or treatment, if needed.
- Use easy-to-remove clothing with elastic waistbands or Velcro closures, and give them clothes that can be washed easily.

Agitation

This refers to a variety of behaviors associated with dementia, such as irritability, sleeplessness, and verbal or physical aggression. Most often, such issues will worsen as the disease progresses—from mild to more severe. It could be triggered by a number of things, like environmental factors, fear and fatigue. However, the most common trigger for agitation comes when the person feels that "control" is being taken from them.

- Keep noise, clutter, or people in the room to a minimum.
- Keep structure by following the same routines. Leave both household objects and furniture in the same places. Familiar objects and photos give a sense of security and may bring back pleasant memories.
- Lower caffeine intake, sugar or other foods that can cause an energy spike.

- Deal with agitation by using a gentle touch, soothing music, reading or walks. Talk in a reassuring voice. Do not try and restrain them during an agitated period.
- Keep dangerous objects out of reach.
- Allow them to be as independent as possible.
- Acknowledge their anger over the loss of control in their life and let them know you understand their frustration.
- Keep them busy with a snack or activity. Let them forget about what was troubling them. Confronting them may simply increase their anxiety.

Repetitive Speech or Actions (Perseveration)

Those with dementia are likely to repeat words, statements, questions or activities again and again. Normally, such behavior is harmless for the individual, but it can prove annoying and stressful to their caregiver(s). Such behavior is sometimes triggered by anxiety, boredom, fear or environmental factors.

- Give them plenty of reassurance and comfort, both through words and touch.
- Provide a distraction in the form of a snack or activity.
- Keep from reminding them that they just asked the same question. Instead, ignore the behavior or question and try to refocus them into doing an activity like singing or "helping" with a chore.
- Don't talk about plans with them until right before an event.
- Try placing a sign on the kitchen table, like "Dinner is at 6:30" or "____ comes home at 5:00" to get rid of anxiety or uncertainty about any anticipated events.
- Learn to recognize certain behaviors. Being in an agitated state or pulling at clothing may signal a need to use the bathroom.

Paranoia

Watching a loved one suddenly become suspicious, jealous or accusatory can be scary and worrisome. However, it is important to remember that what the person is experiencing is quite real to them. It is often best not to argue or disagree, as this, too, is part of the disease. You should try your best not to take it personally.

- If he or she suspects that money is “missing,” let the person keep small amounts of money in a pocket or handbag to easily inspect.
- Help them locate the thing that is “missing” and then redirect them to another activity. Try and keep track of their favorite hiding places for things, which they mistakenly assume are “lost.” Avoid getting into an argument.
- Take the time to explain the situation to other family members or caregivers, and that suspicious accusations are just simply a part of the disease.
- Try giving them some nonverbal reassurances, such as a gentle touch or hug. Respond to the feeling behind the accusation and then provide reassurance for the person.

Sleeplessness/Sundowning

Behaviors like restlessness, agitation, and disorientation, as well as a lot of others that are really troubling get worse and become more pronounced near the end of the day, and may sometimes even continue on into the night. Many experts believe that this behavior, called “sundowning,” is due to a combination of factors, like exhaustion from the events of the day and changes to the person’s biological clock that confuse night and day.

- Increase activities during the day, like exercise. Discourage inactivity and napping during daylight hours.
- Look out for dietary culprits, like sugar, caffeine, and various junk foods. Get rid of them or restrict such foods and drinks to earlier in the day, and plan smaller meals throughout the day, including a rather light meal, like half a sandwich, before bed.
- Plan out the afternoon and evening hours so that they are quiet and calm. It is important, though, to have structured, quiet activities. You could go on a walk outdoors, play a card game, or listen to quiet music together.
- Turn on lights well before sunset and keep curtains closed at dusk. This will minimize shadows and might help lessen their confusion. At a minimum, keep a nightlight in the person’s room, the hallway and bathroom.
- Make sure the house is safe: block off the stairs with gates, lock the kitchen door and/or put away any dangerous items.
- Consider speaking with the doctor about medication that can help the person to relax and sleep, though only as a last result. You should also know that sleeping pills and tranquilizers could solve one issue while

simultaneously creating another, like sleeping at night but being more confused the following day.

- It is so important that you, as the caregiver, get enough rest as well. If your loved one's activities at nighttime keep you awake, you might want to ask a friend or relative, or hire someone, to take a turn so that you can sleep. Taking catnaps during the day may also prove helpful.

Eating/Nutrition

Be sure that your loved one is getting enough nutritious foods and fluids. However, this can prove to be quite the challenge. Those who have dementia literally start to forget it is necessary to eat and drink. Also, dental issues could be making things worse. Such behavior could also be attributed to medications that decrease appetite or make food taste "funny." There are a number of consequences to poor nutrition, like weight loss, irritability, sleeplessness, bladder or bowel issues and disorientation.

- Make both meal and snack times a normal part of their daily routine, and schedule them during the same times each day. Try to give them five or six smaller meals throughout the day instead of three big ones.
- Make mealtimes into a special time. You could try things like flowers or soft music. Be sure to turn off loud radio or television programs or any other distractions.
- Eating independently should come before eating neatly or with the proper table manners. Finger foods help support this. Be sure to pre-cut and season the food, and try using a straw or a child's sippy cup if it is too hard for them to hold a glass. Give assistance only when it's necessary and give them plenty of time for meals.
- Sit down with them and eat together. They will most often mimic your own actions, and it simply makes it more pleasant to share a meal with someone.
- Make food with your loved one in mind. If they wear dentures or have issues with chewing or swallowing, make use of soft foods or cut the food into bite-sized pieces.
- If he or she has difficulty chewing or swallowing, try moving his or her chin in a chewing motion or lightly stroke their throat to encourage them to swallow.
- If weight loss is an issue, give them some nutritious, high-calorie snacks between mealtimes. Breakfast foods that are high in carbohydrates are desirable. In the same way, if weight gain is a problem, turn to fresh fruits, vegetable trays and other healthy low-calorie snacks.

Bathing

A person who has dementia will often find it difficult to remember to practice good hygiene, like brushing teeth, toileting, bathing and changing their clothes regularly. We are taught early on that these are both highly private and personal activities, as such, to be undressed and cleaned by someone else can be frightening, humiliating and embarrassing. Because of this, bathing is often the cause of stress for both caregivers and their loved ones.

- Did the person prefer baths or showers in the past? Did they prefer morning or evening bathing times? Did he or she have their hair washed at the salon/barber or did they do it themselves at home? As much as you can, you should try to incorporate the person's past bathing routines, as this can provide them with some form of comfort. It may also not be necessary to bathe every day. Twice a week could be enough most weeks.
- If the person has always been rather modest, make sure that all doors and curtains are closed. Whether in the shower or bath, always keep them covered except to wash as needed. Have towels and a robe or their clothes ready when they are finished.
- Be aware of the environment—like temperature of the room or water—as older adults are more sensitive to heat and cold, and adequacy of lighting. It would be good to use safety equipment, like non-slip floor bath mats, grab-bars, and bath or shower seats. A handheld shower could also be good to install. Keep in mind that people are generally afraid of falling, so it's important to help them feel secure when bathing or showering.
- Never leave someone with dementia unattended in the bath or shower. Have all necessary things laid out and ready beforehand. If you're giving a bath, draw the water first. Reassure them that the water is warm, and you can even pour a cup of water over their hands before helping them in.
- Make washing hair a separate activity if it is especially troublesome, or you can use a dry shampoo.
- If bathing or showering is consistently worrisome, a towel or bed bath can help alleviate some problems.

Additional Problem Areas

- Dressing is normally hard for someone with dementia. See that they have loose-fitting and comfortable clothing with easy zippers or snaps and few buttons. Lessen choices by getting any rarely-worn clothes out of the closet. It is quite common for those with dementia to keep layering on clothes, even when fully dressed. To allow for changing and support independence, lay out a single article of clothing at a time, in the order it should be worn. Get any soiled clothing out of the room, and do not argue if he or she wants to wear the same thing again.

- Both hallucinations and delusions could happen as the disease gets worse. If this happens, you should simply and calmly explain your perception of the situation, but keep from arguing or telling them their perception is wrong. See that rooms are well-lit to decrease shadows, and give reassurance and a simple explanation of what that particular noise was they heard. Distractions could also help, as could medications if symptoms are severe enough.
- Sexually inappropriate behavior could also happen with the disease. It is important to remember that this is not the person's fault; this is the fault of the disease. Come up with a plan of action before such behavior happens so you can know exactly what you want to say and how to respond to such a situation if it occurs. If possible, try to identify what triggered the behavior.
- Verbal outbursts can also be an issue. Things like threats, cursing and arguing are often expressions of anger or stress. You should react by keeping calm and giving them some reassurance. Validate their feelings and then do your best to distract or redirect their attention to something else.
- "Shadowing" is when someone with dementia imitates and follows the caregiver, or talks constantly, asks questions and interrupts. As with sundowning, this can happen late in the day and be very irritating to caregivers. Provide comfort via physical and verbal reassurance. Distractions may also help. Giving them something to do, like folding laundry might help them to feel needed and useful.
- Those who have dementia may become resistant to daily activities like bathing, dressing or eating. More often than not, it is a response to feeling out of control, rushed, afraid or confused by what you may be asking of them. Break down each task into steps and explain each step in a calm voice before you do it. Give them plenty of time and look for ways they can help in the process or follow up with an activity they can perform.
- Even though they can present great challenge, it is vital to remember that the things we've listed above are often simply coping tactics to they try and use to help them deal with what they're going through.

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While everything we just talked about was certainly a lot of information to take in, the truth is that we could spend several more hours just on this chapter (or any other) alone. But this was not meant to be a be-all, end-all handbook. Rather, its purpose is to provide you with a springboard of sorts and relay information in such a way that you don’t feel like you’re simply drowning in it.

We certainly hope it’s proven useful to you so far.

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Chapter 11: Is Dementia Hereditary?

When children are young, they can often be made fun of for showing interest in the opposite sex. After all, why would they do that? The opposite sex is weird and has cooties. Why would they want to hang around someone that can give them something weird? Of course, as they grow older they realize that there isn't such a thing as cooties, and they realize how silly it was to ever be afraid of something like that.

But the point still stands. Their fears were unfounded.

In the same way, however, many adults often seem reluctant to be around someone who has a disease. We are wired to be sociable with one another, yes, but it can sometimes make us uncomfortable to be in the same room with someone who is sick. But why is that? Didn't we outgrow our childish fear of things long ago?

The answer is quite simple: something like dementia is very real compared to the nonexistent cooties from the opposite sex. And since it *is* real and not imagined, all of these fears swim around in our heads, and we wonder if we may be next in line or if we'll experience it a little later down the road. With that in mind, we will try to answer the question posed at the top of the page, and we'll take a look at some of the risk factors associated with developing the disease.

After the huge previous chapter, this one should be a bit shorter, so you can breathe a sigh of relief!

Genetics of Dementia

As we mentioned, a lot of people often worry about whether or not dementia can be passed down from a relative who is affected by the disease to someone who is not. Someone who has dementia may worry that he or she has inherited it, and as such, worry that there is a risk of passing it to his or her children. So, let's talk a while about genetics.

Genes are the basic way that familial characteristics are passed down through the generations. So, if you have your uncle's nose or the females in your family seem rather vertically challenged, blame it on your genes. It *is* true that genes can play a part in the development of dementia, but the effects they bring with them are quite complicated and both how and whether the dementia is passed down—called the "patterns of inheritance"—vary significantly from one to another.

It is vital to remember that genes are only a small part of the whole, bigger picture. No matter what genes you might have inherited, a great number of people can lessen their chances of getting dementia through simply changing some things in their lifestyle choices. Such things include not smoking, exercising regularly, eating a healthy diet, and drinking alcohol only in moderation (if at all).

Now, you might be thinking something like, "That information is great and all, and I'm glad you shared, but *is* dementia really inherited?" That's a fair question, and it's what you came here for, right? So, let's answer it right now.

Is Dementia Inherited?

The majority of dementia is **NOT** inherited, but this is dependent on the very particular cause of the disease. Some of the rarer causes are clearly 'inherited', such as Huntington's disease. This is because Huntington's is what's known as an 'autosomal dominant' disease. What this means is that you only need one faulty copy of the gene to inherit the disease.

If you have managed to inherit that particular gene, then you will get the disease if you live long enough, as it does not skip a generation. A few other types of dementia have both inherited and non-inherited forms. For example, in frontotemporal dementia, around 30 to 50 percent of all cases are inherited, while a majority of the cases of Alzheimer's disease are not inherited.

Is Alzheimer's Inherited?

Even knowing that a majority of Alzheimer's cases are not inherited, many people are still afraid that if Alzheimer's is in the family, it could be passed down to children and grandchildren. So, let's talk about it for a little while. As we said, a very large number of Alzheimer's cases (99 percent) are not inherited. As it is with many conditions, having a family history of Alzheimer's increases the chances of those in later generations getting the disease only very slightly.

The most common risk factor for developing Alzheimer's is, in fact, age. Alzheimer's is quite common in those who are in their late 70s and 80s, having a grandparent who is at that age does not change your risk in any way compared to the rest of the population.

In a small number of families, Alzheimer's *can* be inherited, however. This was first discovered over 100 years ago, and such cases make up less than one percent of all Alzheimer's cases. However, for the individuals in those families it does affect, that can be quite a legacy to leave behind. In such cases, the disease normally develops much earlier than it would usually—with many people being affected as early as their thirties. There are three genes that have been identified as the cause of this early-onset inherited form of Alzheimer's: APP, PS1 and PS2, and defects in these genes are now able to be tested. If the particular gene is known, a person may opt to have predictive testing, though this is always preceded by careful genetic counseling.

Knowing this may lead to yet another question. You may be curious if there is ongoing research into inherited dementia. If so, you should know that inherited dementias have given great insight into what causes a variety of dementias, most often through members of affected families who have agreed to participate in research studies.

In 2008, a consortium known as DIAN—that is, Dominantly Inherited Alzheimer's Network—was set up to study Alzheimer's passed down through families and to try and understand the causes and earliest features of the disease sooner.

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Risk Factors for Dementia

Now that we've answered the main question we came here to answer, let's next turn our attention elsewhere and take a look at some of the risk factors for developing the disease.

Put simply, dementia is the one condition that those aged 50 and over are most afraid of. Most often, it is a concern for those individuals over the age of 55 (about 1 in 4 people) who already have a close family member with the disease. However, it needs to be known that developing dementia is not inevitable, and there are quite a few things that you can do to lower your risk of developing it. Before we get into that, though, it would be best to define the difference between what we're talking about when we say "risk" versus what we mean when we say "risk factor."

Risk vs. Risk Factor

Someone who has a **risk** of developing a certain disease or condition has a chance that said disease or condition will eventually affect them over a certain period of time. For example, all of us have some level of risk to develop dementia, though some of us have a higher or lower risk than others. To put it another way, an 80-year-old woman is significantly more likely to develop dementia within five years than a typical 30-year-old woman.

A **risk factor** is any such thing that contributes to a person's risk of developing dementia or another condition. When talking about dementia specifically, there are a variety of factors—some that can be avoided and others we cannot control. Though it doesn't mean that someone having any of the risk factors will develop dementia in the future. In the same way, just because we avoid risk factors, that doesn't mean that we will stay healthy, but it does make our chances much more likely to stay healthy.

A great number of risk factors have been found from looking at and studying big groups of people and finding the different things that those who have dementia have in common with one another. It is important to remember, though, that just because something may be linked to dementia, it does not mean that it causes the disease to happen. It could be that the link is the other way around—that is, the dementia increases the chances an individual has of having the apparent risk factor, like depression, for example. It could also be possible they may share an underlying cause as well.

Something is much more likely to genuinely be a risk factor if there is, in fact, a plausible way it could make developing dementia much more likely, based on the understanding of how the disease develops. To use an example, because high blood pressure can cause strokes, and strokes can cause vascular dementia, it would be correct, then, to say that high blood pressure is a genuine risk factor for developing vascular dementia.

All in all, the best evidence for identifying risk factors comes in the form of clinical trials. These will look at what happens over the course of time when some in the trial are given a medicine (for example, to lower blood pressure) or adopt different behaviors (like various diets). Any such “prevention” trials are increasing but are still uncommon. In order to be proven, they normally need to run for a great number of years and involve hundreds or thousands of people. Even those trials which look at smaller changes—by testing mental abilities, for example, can be quite complicated to organize and very expensive to carry out.

Very few studies that focus on dementia risk factors look specifically at the less common dementias, like frontotemporal dementia or dementia with Lewy Bodies. What we’ll take a look at now, and what we’ve already seen, deals more with the more common types of dementia—Alzheimer’s, vascular dementia and mixed dementia (that is, when someone has more than one type of dementia, most often Alzheimer’s and vascular dementia).

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Risk Factors for Dementia

Researchers have found that there are several important factors that contribute to our risk of developing dementia. These can include age and genetics, but also things like medical conditions and our lifestyle choices. Someone’s risk of developing dementia also depends on a combination of all these things. Some of them we cannot change, such as age or the genes we get from our parents. Others, like lifestyle choices, we can influence directly

It is quite natural and acceptable to question why either someone you know or you yourself has developed dementia. Normally, it’s not possible to determine the exact reason why it happened, but a doctor may be able to determine which factor(s) may have contributed to its development. In a great many cases, it is a mixture of factors that is responsible—some avoidable, some not.

Different risk factors for dementia can also be important at different parts of our lives. To see another example, there have been many studies done to show that continuing education beyond age 16 may contribute to lessening your risk of developing dementia later on in life.

In the same way, if a person stops smoking, even at age 60, they are likely contributing to lowering their risk of getting dementia later on. However, as I’m sure you’re aware, it’s better to quit smoking sooner (or to not start at all), if possible. With that said, a lot of the risk factors that are avoidable and the most important (i.e. High blood pressure and type 2 diabetes) often seem to appear in mid-life, around ages 40 and 64. This may be due to the changes in the brain that cause dementia starting in middle age. So the mid-life is a principally important time to begin choosing healthy behaviors if you haven't done so already.

Aging

This is the best-known risk factor for developing dementia. While it is indeed possible to develop it earlier (at least 1 in 20 people get it under age 65), the chances of developing it grow exponentially as we age. Beyond age 65, someone's risk of developing Alzheimer's or vascular dementia doubles around every five years. It is estimated that one in 14 people over age 65 and one in six in those over 80 are affected by dementia. It could be due to the factors that are associated with aging, things like:

- Higher blood pressure
- Increased risk of cardiovascular diseases (heart disease and stroke)
- Changes to nerve cells, DNA and cell structure
- Loss of sex hormones after mid-life changes
- The weakening of the body's natural repair systems
- Changes in the immune system

Gender

Even though women generally live longer than men, they are more likely to develop Alzheimer's than men are. The reasons for this are still unknown, though it has been suggested that Alzheimer's in women is linked to the lack of a hormone known as oestrogen after menopause. Although, controlled trials of hormone replacement therapy (HRT) have not shown any lowering of the risk of developing Alzheimer's. The age at which HRT begins, however, could affect the outcome. HRT, which is predominately prescribed to help with symptoms of menopause, is **NOT** recommended as a way that women can reduce their risk of dementia.

For most of the dementias other than Alzheimer's, men and women are at much the same risk of developing them. With vascular dementia, men are actually slightly more likely to develop it than women. The reason is because men have a higher chance of heart disease and stroke, which are contributors to vascular and mixed dementia.

Ethnicity

There is also evidence that those people within certain ethnic communities are more at risk for dementia than others. Those from South Asia, for example (those from countries like India and Pakistan), seem more likely to develop dementia—vascular dementia in particular—more often than white Europeans. South Asians are also at higher risk of developing strokes, heart disease and diabetes, and this is often the thought behind why they have a higher risk for dementia.

Those people of African or African-Caribbean origins also seem to develop dementia more often. It is known that they are more likely to have diabetes or strokes. All of these things boil down to what is likely a difference in diet, smoking habits, exercise habits and genes.

Genetics

Scientists have known for quite a while that genes we get from our parents can affect whether or not we will also develop certain diseases. While the role that genes play in the development of things like dementia is still not fully clear, researchers have made a number of advances in this area of the last few years.

Over 20 genes have been found that do not cause dementia directly, but they can affect a person's risk of getting it later on. For example, inheriting certain variants of the gene apolipoprotein E (APOE) heightens a person's risk of developing Alzheimer's. Having a close relative (like a parent or sibling) who has Alzheimer's increases your own chances of getting the disease, although just slightly, when compared to someone who has no family history of the disease. However, it doesn't mean that you getting dementia is inevitable.

It's also quite possible to get the genes that cause dementia directly, though these are much rarer than risk genes like APOE. In families who are affected there is also a clear pattern of dementia that passes from one generation to the next. Such a pattern is seen in those families with familial Alzheimer's disease—an extremely rare form of Alzheimer's that appears most generally well before age 60) and genetic frontotemporal dementia If someone has the faulty gene, then each child also has a 50 percent chance of inheriting it as well.

Medical Conditions and Diseases

Cardiovascular factors

There is also some good evidence that points to conditions that damage the heart, arteries or blood circulation can and do significantly affect someone's chances of developing dementia. Such things are known as cardiovascular risk factors. The main ones contributing to dementia are:

- Type 2 diabetes -in midlife or later life
- High blood pressure -in midlife
- High total blood cholesterol levels -in midlife
- Obesity -in midlife

All of these conditions are risk factors that can be avoided -both for dementia but also for cardiovascular diseases (like stroke and heart disease—such as abnormal heart rhythm) as well. Having cardiovascular disease or type 2 diabetes increases a person's risk for developing dementia by up to two times.

These conditions are most often linked to vascular dementia. The reason for this is because vascular dementia is caused by issues with blood supply to the brain.

Some recent research suggests that a great number of those with dementia have mixed dementia, or they have Alzheimer's along with some vascular damage within the brain. The cardiovascular risk factors and diseases should be considered risk factors for mixed dementia as well, not just vascular dementia. In some instances, such as diabetes or high midlife cholesterol, they are also known risk factors for Alzheimer's disease too.

Depression

Those individuals who have gone through periods of depression—be it in midlife or later life—generally also seem to be at risk for increased rates of dementia. Whether or not depression is a risk factor that partially contributes to dementia is not clear, and it's likely the answer will differ with age. There is, however, some evidence that experiencing depression in middle age can and does lead to a higher risk of dementia in older age. By contrast, depression in later life (in the 60s) could be an early symptom of dementia rather than a risk factor for it.

Other conditions

There are other medical conditions that can contribute to the development of dementia, and those include:

- Parkinson's disease
- Multiple sclerosis
- And HIV

Down's syndrome and other types of learning disabilities also increase an individual's risk of dementia.

A variety of other conditions have also been linked to dementia according to some studies, but there is evidence on them that is still coming to light. These conditions include the following:

- Chronic kidney disease
- Hearing loss
- Anxiety
- Sleep apnea

There is also evidence to suggest that both loneliness and social isolation could also increase the risk of dementia, but in a lot of these cases, more research is required to show the strength of the link and what causes what in that link.

Lifestyle factors

There is an overabundance of evidence that our daily lifestyle choices can also affect our risk of developing dementia. It is especially true of activities that are linked to cardiovascular health, so what's good for your heart is also good for the rest of you too, including your brain.

Studies done within large groups show that risk of dementia is lowest in those individuals who have several healthy behaviors in their midlife. Such behaviors include regular physical exercise, not smoking, drinking alcohol only in moderation, if at all, and keeping up a healthy diet and weight. The risk for dementia is lowest in those persons who do three or more of these, not just one or two. Trials also seem to point out that practicing healthy behaviors in combination seems to work better than simply taking on one or two.

- **Physical inactivity:** one of the highest risk factors for developing dementia is being physically inactive. It is also closely related to an increased risk in heart disease, stroke and type 2 diabetes. These cardiovascular and metabolic effects from being inactive are well-known, but physical activity can and does also directly affect both the functioning and structure of the brain.
- **Smoking:** Smoking tobacco is extremely bad on the heart, lungs and vascular system, and this also includes the blood vessels in the brain. Smoking also significantly increases a person's risk of developing dementia later on in life, especially Alzheimer's (along with type 2 diabetes, stroke and heart disease).
- **Unhealthy diet:** Having an unhealthy diet can also affect someone's risk of developing a great many illnesses, including dementia, but it can also lead to cardiovascular disease and type 2 diabetes. A poor diet is any one that contains too much in the way of saturated fats, which can raise cholesterol, narrow the arteries, and can lead to weight gain. An unhealthy diet is also one that contains too much salt—which is a contributor to both high blood pressure and stroke—and also too much sugar.
- **Excessive alcohol:** Drinking above the recommended levels of alcohol consumption puts a person at greater risk for developing dementias like Alzheimer's disease and vascular dementia. Excessive consumption of alcohol over an extended period of time also increases the risk for Korsakoff's syndrome and alcoholic dementia. A number of specialists used to believe that low-to-moderate levels of drinking reduced the risk of dementia (as it may help to keep the heart healthy), but the "protective effect" is still controversial, and many experts no longer believe that low-to-moderate levels of alcohol consumption reduce the risk for dementia.
- **Head injuries:** Getting a severe blow to the head—especially being knocked out—increases the risk of dementia, like Alzheimer's, later in life. Around a fifth of professional boxers wind up developing a different form of dementia. It used to be known as dementia pugilistica, but is now known as chronic traumatic encephalopathy, which is thought to be caused by protein deposits that form in the brain as a result of head injury. There is recent evidence to suggest that professional American footballers could also be at risk for chronic traumatic encephalopathy, as they generally receive repeat mild head injuries.

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Tips to Reduce the Risk of Developing Dementia

So, now we've seen some of the risk factors for developing dementia, and it's good to know those things. But it's also good to see what things we can do to help prevent or reduce the risk of developing dementia altogether. The good news is that you can start to develop a healthier lifestyle at any time; you don't have to wait until you're sick to do so. If you haven't done so already, beginning those changes in midlife is a good starting point. Many people often use significant, big changes in life as a launch pad to living a healthier lifestyle.

It's also much easier to live a healthier lifestyle if you can find ways to incorporate it into your already existing daily routine. Having friends and family to support you, or even join you, if possible, can be a great source of motivation and fun, and therefore, make it more likely for you to continue down a better path.

Let's look at some of the things we can do to help ourselves now:

- **Be physically active:** Getting regular moderate physical exercise is one of the best ways that you can reduce the risk to develop dementia, raise cardiovascular health, and better your mental wellbeing. "Regular" simply means exercising five times a week for 30 minutes at a time. But don't freak out if that seems like too much; you can build yourself up to it gradually. "Moderate" exercise means doing an activity that leaves you just a little out of breath, raises your heart rate and might make you slightly sweaty. Even if you don't lose weight, this type of exercise is good for you. Such activities can include brisk walking, cycling, swimming or dancing.
- **Quit smoking:** If you do smoke, stop. It's better to stop sooner, but it's never too late to quit. Even if you decide to stop smoking in later life, it can still benefit your overall health and could reduce your risk for dementia. You can talk to your GP or your pharmacy for advice and information on how to quit.
- **Eat healthy:** A balanced and healthy diet is one that includes lots of fruits and vegetables. You should aim for having around five portions a day, and fresh, frozen and canned fruit and vegetables all count. A healthy diet also includes fish at least twice a week, including oily fish like mackerel, salmon and sardines—all of which have a healthy polyunsaturated fatty acid and vitamin D. Adding in starchy foods—like potatoes, brown rice, pasta and bread—as well as proteins, like meat, fish, eggs and beans can help you keep a balanced diet. Keeping to a Mediterranean kind of diet can also be good for your cardiovascular health and could reduce risk of dementia. You can speak

to your doctor to get more information on this kind of diet or if you have any questions or concerns.

- **Maintain a healthy weight:** Staying at a healthy weight will also lower your risk for type 2 diabetes, stroke and heart disease, and likely dementia as well. Along with weight, watch your waistline, since fat around the middle of the body is particularly unhealthy. A good place to start is to follow the advice on physical exercise and keep up a healthy diet. Keep a food and exercise diary for each day, as you are more likely to lose weight if you burn off what you eat. You could also consider joining a local weight loss group, or speak with your doctor if you need more advice.
- **Drink alcohol within recommended levels:** If you drink at all, do so within the recommended levels or below. These levels changed in 2016, and now the maximum is 14 units each week for both men and women, spread across three or more days. This equals around four or five large glasses of wine during the week, or seven pints of beer or lager with a lower alcohol content. If you're looking to cut down, set yourself limits for each time you drink (and stick to them). Also, try smaller glasses, drinks with lower alcohol content, drinking with food, or alternating soft and alcoholic drinks. If you're really struggling, speak with your doctor about what support services may be available in your area.
- **Keep mentally active:** You are more likely to lower your risk of dementia if you can keep your mind stimulated. Having regular mental activity during a person's lifetime generally seems to increase the brain's ability. This can help to build a "cognitive reserve" and allows the brain to better deal with disease. Keeping mentally active may also help to delay the symptoms of dementia by many years, and may even mean that you never develop it at all. You could try learning a new language, doing puzzles, such as word searches and crosswords, playing cards, reading challenging books or writing letters. Find something you enjoy that also stimulates your mind, and then do it regularly and keep at it.
- **Be social:** There is new evidence to suggest that keeping socially engaged as well as having a supportive network of support could reduce your risk for developing dementia. It can also lessen the likelihood of depression and make you more resilient. Try to visit with family and friends, look after grandchildren, travel or volunteer. You may also like to try joining a social/activity club or a group at a place of worship.
- **Take control of your health:** Managing your health will also reduce your risk of dementia. You can speak with your doctor about the things that you have noticed or would like to do, and then come up with a game plan together of things that you can do to help lower your risk of developing the disease. It is important to remember that if you feel yourself getting depressed at any time, seek treatment early.

- It is also vitally important that you keep any pre-existing long-term conditions, like diabetes, heart disease, or high blood pressure, in check and under control. Always follow professional advice about taking medications, even if you feel well, and on lifestyle choices like diet and exercise.

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Well, we have reached the end of yet another chapter, and that means that there is only one chapter left. For our final chapter, we’ll be taking a look at some of the myths and truths surrounding the disease, which is sure to be interesting and hopefully informative to you, your friends and loved ones.

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Chapter 12: Myths and Facts About the Disease

Greek mythology is chock full of stories of heroic exploits, lost loves, and gods who seem to be no better than the average human. They were meant to explain some of life's greatest mysteries to the ancient Greeks, and perhaps even inspire them to accomplish some form of greatness themselves. While some of them seem too good to be any sort of true, if you spend enough time and dig deep enough, you'll often find some nugget of truth buried deep within. This is because if there wasn't, we'd be left with this story that was so amazing and fantastic, there would be no way we'd be able to experience something like that for ourselves.

After all, we want our heroes—whether real-life or mythological—to be larger than life, certainly, but we also want them to have an air of humanity about them. We want to know that those same heroes face some of the same problems that we ourselves do. If they struggle and fight and can make it out alive, then can't we also do the same? We certainly can if we see that they are the same as we are.

In today's society, we are faced with a number of problems and seemingly insurmountable issues each and every day. If we were living in Ancient Greece, perhaps even some of those problems would have been passed down as myths through the generations. Health crises, financial issues and much more plague our society so much that we can block these things out so they become less real.

The truth, however, is something like a health crisis is, indeed, quite real and needs to be dealt with, no matter how much we may push it to the back of our minds and wish it otherwise. To do that, we must learn to separate reality from fiction and find the truths that are buried in the myths that surround the sicknesses and diseases of today.

With this in mind, let us now take a look at some myths and facts regarding dementia.

- **Myth 1: Memory Loss is a Normal Part of Aging**

Reality: As people get older, it's quite normal for them to have memory issues, like forgetting the name of someone they met recently. Alzheimer's, however, is much more than just occasional memory loss. It's a disease that makes brain cells malfunction and die. When this happens, someone could forget the name of a longtime friend or what roads to take that lead them somewhere they've lived for years.

It can't be quite hard to separate normal memory issues from something more serious like Alzheimer's. The Alzheimer's Association has come up with some information to help you tell the difference. So, if you or someone you love has memory issues or other problems with thinking and learning that are troubling you, contact a physician. Sometimes these issues are caused by side effects from medications, vitamin deficiencies or other things that can be helped or reversed with treatment. Memory and thinking problems may also be caused by a different form of dementia.

- **Myth 2: Alzheimer's Disease is Not Fatal.**

Reality: Alzheimer's disease **leaves no survivors**. It destroys brain cells and causes changes in a person's memory, erratic behaviors and loss of bodily functions. A person will both slowly and painfully lose their sense of identity, their ability to connect with others around them, and the ability to think, eat, talk, walk and find their way home.

- **Myth 3: Only Older People Can Get Alzheimer's.**

Reality: Alzheimer's can affect people in their 30s, 40s, and even 50s, in what is known as younger-onset Alzheimer's. It is thought that there are over 5 million people living with Alzheimer's disease in the United States alone. This includes 5.2 million people aged 65 or older and 200,000 people under the age of 65 who have younger-onset Alzheimer's disease.

- **Myth 4: Drinking Out of Aluminum Cans or Cooking with Aluminum Pots and Pans Can Lead to Alzheimer's.**

Reality: Throughout the 1960s and 1970s, aluminum became a possible suspect as a contributor to Alzheimer's. Such a suspicion lead to a concern that exposure to aluminum through everyday objects like pots and pans, beverage cans, antacids and antiperspirants. Since that time, studies have failed to confirm any role that aluminum has in causing Alzheimer's. Today's experts instead focus on other areas of research, and few believe that any everyday sources of aluminum pose any sort of threat.

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- **Myth 5: Aspartame Causes Memory Loss.**

Reality: This artificial sweetener, better known under brand names Nutrasweet and Equal, was approved for use in all foods and beverages by the U.S. Food and Drug Administration (FDA) in 1996. Since its approval, concerns have been raised regarding Aspartame's effects on health. According to the FDA, as of May 2006, the agency had not been presented any scientific evidence to suggest a change to its conclusions regarding the safety of aspartame for most people. They say that conclusions are based on over 100 clinical and laboratory studies.

- **Myth 6: Flu Shots Increase Risk of Alzheimer's.**

Reality: A theory suggesting a link between flu shots and an increased risk of Alzheimer's has been posed by a U.S. doctor whose license has been suspended by the South Carolina Board of Medical Examiners. Many mainstream studies link flu shots and other vaccines to a **reduced** risk of Alzheimer's disease and better overall health.

The November 27, 2001 issue of *Canadian Medical Journal* contains a report that suggests that those older adults who were vaccinated against diphtheria and tetanus, polio and influenza seemed to be at a lower risk for developing Alzheimer's than those who did not receive vaccinations against these diseases.

Also, a report in the November 3, 2004 *JAMA* discovered that annual flu shots for older adults were associated with a lower risk of death from all causes, not just Alzheimer's.

- **Myth 7: Silver Dental Fillings Increase Risk for Alzheimer's.**

Reality: According to the best scientific evidence available, there is no relationship between silver dental fillings and Alzheimer's. Such a concern originally arose because "silver" dental fillings are made of a mixture that contains around 50% mercury, 35% silver and 15% tin. Mercury is a heavy metal that, in certain forms, is known to be toxic both to the brain and other vital organs.

A lot of scientists consider the dental mixture to not be a major risk factor in the development of Alzheimer's. Public health agencies, like the FDA, the U.S. Public Health Service and the World Health Organization, all endorse the continued use of this mixture as safe, strong and inexpensive material for dental restorations.

- The Dental Devices Panel of the FDA concluded in March 1991 that there was no current evidence that the mixture poses any danger.
- National Institutes of Health (NIH) funded a study at the University of Kentucky in 1991 to look into the relationship between amalgam fillings and Alzheimer's disease. Analysis from University statisticians found no significant association between silver fillings and Alzheimer's.
- On October 30, 2003, an article in the *New England Journal of Medicine* found that current evidence shows no connection between dental fillings that contain mercury and Alzheimer's or any other neurological diseases.

- **Myth 8: Treatments Are Available to Stop Progression of Alzheimer's.**

Reality: Currently, there is no treatment to cure, delay or stop the progression of Alzheimer's disease. Drugs that have been FDA-approved only slow the disease's symptoms for about 6-12 months, and only then temporarily, for around half of the people who take them.

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More and more is learned about Alzheimer's each and every year, and some of the information is quite surprising indeed. So, let's spend some time looking at ten facts regarding Alzheimer's that people will certainly want to know.

10 Facts About Alzheimer's Disease

1. Nearly half of adults aged 85 and over have Alzheimer's disease.

According to the 2012 Alzheimer's Disease Facts and Figures report from the Alzheimer's Association, around 45% of those American seniors who are 85 and over suffer from the disease, and one in eight people aged 65 and over (or 13%) has Alzheimer's. It is the most common cause of dementia in older adults.

2. Out of approximately 5.4 million Americans with Alzheimer's, more than half may not be aware they have it.

This is partially because of the difficulty with detecting early-stage Alzheimer's or mild cognitive impairment (MCI), so many of those with Alzheimer's stay undiagnosed. As the ability to find early-stage Alzheimer's gets better, the number of people known to have the disease will grow.

3. More women than men have Alzheimer's.

The Alzheimer's Association has shown that almost two-thirds of people suffering with the disease are women. Although, it is important to know that this doesn't mean there is any sort of gender predisposition for the disease; the main reason for this statistic is that women generally live longer than men.

4. Early-onset Alzheimer's can happen has early as age 30.

Normally, Alzheimer's is generally thought of as a disease that affects older adults, but the truth is that up to 5% of Americans with Alzheimer's (or around 200,000) have early-onset Alzheimer's, which normally occurs in one's 40s or 50s, but can start to show visible symptoms as early as a person's 30s. The cause for this is still not well understood, but some of these cases have a genetic component.

5. In the U.S., a new case of Alzheimer's occurs every 68 seconds; by 2050, that will increase to every 33 seconds.

As scary as it is already, the rate at which someone is diagnosed with Alzheimer's is expected to double by the middle of the century due to the growing population over the age of 65. The amount of people living into their 80s and 90s is also expected to increase, and the likelihood of developing Alzheimer's increases with age.

6. Alzheimer's is the sixth leading cause of death in the United States, and the fifth leading cause of death in those adults 65 and up.

The Alzheimer's Association states that Alzheimer's is becoming more and more common as a cause of death in the United States as the population there and in other countries continues to age. This is partially due to the fact that we are experiencing more success in reducing the death rate from other causes like heart disease, while the rate of death from Alzheimer's continues to climb.

7. More than 15 million Americans are unpaid caregivers for someone with Alzheimer's or another form of dementia.

Family caregivers to Alzheimer's patients give a whopping 80% of care provided to those patients at home, while a meager 10% of those seniors get all their care from a paid healthcare professional. A majority of these caregivers (70%) are women, according to the Alzheimer's Association.

8. Alzheimer's caregivers are at an increased risk of experiencing physical strain, mental and emotional stress, depression, financial problems, and familial/interpersonal issues.

Thanks to the difficulties with communication and the personality changes that come with Alzheimer's, an increased amount of pressure and strain can be placed on caregivers. Due to the nature of the relationship between caregiver and patient—one involving shared emotions, experiences and memories—this puts caregivers at risk for both psychological and physical illness. Therapeutic and social support has been shown to lower the risk.

9. In 2012, the average annual cost of health care and long-term care services for someone with Alzheimer's was $43,847.

More than $9,000 of that amount was paid out of pocket, and about $30,000 (or around 70%) was paid by Medicare and Medicaid. Having Medicaid coverage is especially important for those Medicare beneficiaries who have both very low income and assets but who need long-term care or skilled nursing.

10. An estimated 800,000 Americans with Alzheimer's are living alone.

For all those who suffer from Alzheimer's and are getting care from family caregivers or who are living in an Alzheimer's or dementia care facility, there are as many as 15% of Americans who are suffering with the disease alone. Many of those people have no identifiable caregiver, which is something that can and does put them at greater risk of being socially isolated, having poor self-care, falls, and other medical emergencies, wandering, malnutrition and a variety of other issues as well.

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We've talked about a lot of different things on our journey together thus far—a lot of heavy issues, and perhaps a lot of surprising ones—and our time together has nearly finished. To close out the chapter, let's take a look at ten more things that you should definitely know about dementia as a sort of review of what we've covered thus far.

10 More Things You Should Know About Dementia

1. **Dementia itself is not a disease.**

   It actually results from a variety of different diseases. The word 'dementia' is simply an umbrella term for those symptoms that are caused by those diseases, like memory loss, confusion and a change in personality. Alzheimer's disease is the most common cause, but other dementias include the following: vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

2. **Dementia is NOT a normal part of aging.**

   Although it's true that a majority of those with dementia are over age 65, it is certainly not an inevitable part of getting older. The likelihood of developing the disease increases with age, but it's not simply a given that someone will develop the disease. In the U.K., there are over 40,000 people under the age of 65 who have the disease.

3. **Dementia is more than just memory loss.**

   A majority of people often associate dementia with memory loss, but the disease can affect different people in many different ways. This could include things like a change in behavior, confusion and disorientation, delusions, hallucinations, difficulty communicating, problems judging speeds and distances, as well as cravings for particular foods. Everyone experiences it differently.

4. **It's possible to live independently and actively with dementia.**

   There are a number of people in the U.K. and throughout the world who are living with dementia and developing some support mechanisms and strategies to live better with the disease. This can be anything from taking up new hobbies to making new friends or taking part in researching the disease.

5. **Dementia has a bigger impact on women.**

   As more and more women are living well into their 80s, half a million U.K. women are living with dementia right now. As such, it is the leading cause of death to women in the U.K, and women are also more likely to take on an unpaid caring role for others who have dementia, and are more than twice as likely as men to give intensive, 24-hour care.

6. **Dementia is a global problem.**

   It is a common myth that dementia only affects the western world. However, the biggest increases in the disease, expected over the next 20 years, are actually in eastern places like China, India, and even Sub-Saharan Africa. It is, indeed, a global health issue—one that affect 46.8 million people worldwide.

7. **Dementia doesn't discriminate.**

   It is a condition that can affect anyone, regardless of their background, education, lifestyle or status.

8. **There are no treatments to stop the diseases that cause dementia.**

   While there are some treatments out there that can help people to better cope with the symptoms of the disease, there are not currently any treatments available to slow down or stop diseases like Alzheimer's. What this means is that the diseases will continue to worsen over time unless new treatments can be found quickly.

9. **Investment into researching dementia is still low.**

   Even though the government has focused more on dementia over the past three years, research into the disease still only receives about 3% of the government's total medical research budget in the U.K. Combined government and charity investment in dementia research is 6.4 times lower than cancer research. Raising investment in dementia research to a similar level will help to make progress toward a cure.

10. **You can help.**

    Dementia research is in desperate need of volunteers. A lack in the number of volunteers is slowing any efforts to discover any new preventions or treatments. If you or someone you know are willing to help, you can speak with your doctor who may better be able to point you in the right direction.

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With this last bit of information, we have now come to the end of our journey together. While receiving that diagnosis of dementia and learning how to live with it is very hard to do, it is my hope that the information in this book has been able to provide you not only with things you need to know going forward, but also with a greater sense of comfort than perhaps you had when you first started reading.

With that, let me leave you with a gentle reminder that, no matter how dark the road ahead may seem, no matter how hopeless you may feel going into and through the disease, it is very important that you remember this one, very important thing:

You are not alone.

Dementia is a terrible disease.

However, with professional help you can minimize the emotional impact this disease has on your family. When the diagnosis is Dementia, you need an experienced elder law attorney to help plan for the individual's long-term care. You also need to work with a firm that can address other health issues that come up along the way.

My life's work is to help seniors, the elderly, and disabled find ways to afford a better quality of life than they ever thought possible. When you are caring for someone else, you shouldn't feel like you have to go it alone.

My sincere hope is that this dreaded disease will one day be cured and that this book will no longer be needed. Until then, I am here to help you and your family through this challenging journey. Feel free to contact me for help or guidance.

Warmly,

Justin L. Scott, Esquire

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