

Taking Control

.....
A GUIDE FOR EARLY-STAGE
ALZHEIMER'S DISEASE

alzheimer's  association®

Massachusetts/New Hampshire Chapter

Introduction

A diagnosis of Alzheimer's disease is certainly a life-changing event. As people are diagnosed earlier and earlier with Alzheimer's or another dementia, it can be a challenge for them and members of their families to find ways to manage the disease. Taking Control is designed to help you live with Alzheimer's. We hope that it assists you in engaging in a full and healthy life now; and also plan for the future.

Hundreds of individuals with Alzheimer's disease and other dementias have participated in the Taking Control program over the years. Their recommendations and feedback have been invaluable. We are glad that you have decided to take advantage of their wisdom and insight. We hope that this manual will provide you with answers and guidance as you respond to the challenges of this disease.

This manual is not intended to be a complete source of information about Alzheimer's disease and related dementias. Taking Control is one part of a comprehensive offering of services and programs provided by the Alzheimer's Association, Massachusetts/New Hampshire Chapter to support people with dementia and their families. Our 24/7 Helpline provides information and referrals regarding diagnosis, treatment, planning, symptom management, home safety, research opportunities and more. A wide variety of educational programs and support groups are offered throughout New Hampshire and Massachusetts. The Care Consultation service provides individualized, in-depth, person-to-person assessment, education and support.

All of these services and programs are provided to families free of charge. For more information on any of these services and programs, or to access our 24/7 Helpline, please call 800.272.3900 or visit our website at www.alz.org/MANH. The Alzheimer's Association's mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

We are a private, non-profit organization supported primarily through donations. Established in 1980, we are a founding chapter of the national Alzheimer's Association, which includes more than 70 chapters nationwide.

June 2011

A LETTER FROM TAKING CONTROL PARTICIPANTS

When Charlie and I got the diagnosis of probable Alzheimer's, we were both devastated. And though he was the one with the Alzheimer's disease, we knew it would affect both of us.

My response to a situation like this is to get all the information I can to be able to cope better. Once I found the Alzheimer's Association, I attended every relevant program that was offered. Charlie and I together attended the four-part series, Taking Control. We both found it invaluable.

It was the first time we met others who were dealing with the same situation we were in. We heard other people's stories. We were able to share experiences—of recognizing these strange symptoms, of getting a diagnosis, of telling family and friends, and of starting treatment. We heard about people's difficulties and could relate to them. We realized others were on the same journey and somehow that made it more bearable.

The program provided a lot of valuable information. We got a comprehensive description of the disease—what's involved, what goes wrong, and what to expect. There was a major focus on lifestyle choices which one can do to improve the quality of life and possibly slow the progression of the disease. We learned strategies and tips to cope and to adjust to the new reality.

We got a new orientation. Suddenly we were not alone—not only were there others dealing with the same difficulties, there was the Alzheimer's Association which is there to assist us in so many ways and provides so many services. We began to understand what was happening to us, what we were dealing with and how to make the situation as manageable as possible.

SINCERELY,

Phyllis and Charlie Hersch

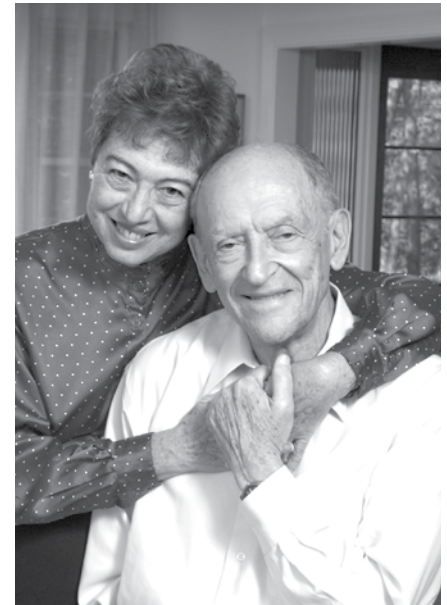


Table of Contents

CHAPTER 1 Overview of Cognitive Disorders	PAGE 5
CHAPTER 2 Diagnostic Process	PAGE 15
CHAPTER 3 Treatment and Research	PAGE 21
CHAPTER 4 Care Team and Planning for the Future	PAGE 37
CHAPTER 5 Disclosure and Changing Relationships	PAGE 45
CHAPTER 6 Practical Tips for Daily Living	PAGE 53
CHAPTER 7 Support Options	PAGE 59
CHAPTER 8 Becoming an Advocate	PAGE 63
APPENDIX	PAGE 65

Chapter 1

OVERVIEW OF COGNITIVE DISORDERS

The first chapter of this guide provides an overview of Alzheimer's disease and dementia. As you may already know, Alzheimer's disease causes a deterioration of the brain which, over time, causes many changes and significant losses. The information that we provide is an open and honest presentation of the disease progression and common symptoms that many people experience.

People with early-stage Alzheimer's disease and their care partners benefit from having a basic understanding of cognitive disorders. These topics include:

- Warning signs for Alzheimer's disease
- Diagnosis of Alzheimer's disease
- Different types of dementia
- Effects of Alzheimer's disease on the brain
- Progression of Alzheimer's disease

This knowledge validates that memory loss is more than a "senior moment" and that Alzheimer's disease is a serious medical disorder. It can help to dispel myths and negative stereotypes about Alzheimer's that contribute to embarrassment and secrecy about a diagnosis. Armed with this information, people with early-stage Alzheimer's disease and their families can stop blaming themselves for symptoms beyond their control and focus their energies on effective coping strategies.

Warning Signs for Alzheimer's Disease*

The following are 10 warning signs which are critical to detecting Alzheimer's disease:

1. *Memory loss that disrupts daily life.*

One of the most common signs of Alzheimer's is memory loss. This may include forgetting recently learned information, forgetting important dates or events, or asking for the same information over and over.

2. *Challenges in planning or solving problems.*

Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe, keeping track of monthly bills, or take much longer to do things than they did before.

3. *Difficulty completing familiar tasks at home, at work or at leisure.*

People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

4. *Confusion with time or place.*

People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

5. *Trouble understanding visual images and spatial relationships.*

For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

6. *New problems with words in speaking or writing.*

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock").

7. *Misplacing things and losing the ability to retrace steps.*

A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

8. Decreased or poor judgment.

People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

9. Withdrawal from work or social activities.

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

10. Changes in mood and personality.

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

*Taken from 10 Warning Signs of Alzheimer's Disease, Alzheimer's Association, 2009.

Remember, every person will experience these symptoms differently. During the earliest stages of the disease, you may not encounter all of the above warning signs. It is possible to receive a diagnosis even if only a few symptoms have developed.

Recent studies have indicated that people may experience subtle changes in other cognitive abilities before these symptoms are noticeable. These changes include visuospatial skills, speeded psychomotor skills, attention skills, and executive function. In laymen's terms, these changes can be described as follows:

- Visuospatial skills—Getting lost, understanding directions, reading a clock or graph
- Speeded psychomotor skills—How quickly one can do tasks requiring hand/eye coordination
- Attention skills—Ability to focus
- Executive function—Activities such as planning, strategizing, organizing, paying attention to detail, and managing space and time

New tests for diagnosing Alzheimer's disease and brain function focusing on the eye and sense of smell are being developed and examined.

What are normal changes in memory?

It is normal to experience some changes in memory as we grow older. The majority of older adults experience some of the following normal changes in cognition:

- Forgetting names more frequently
- Experiencing difficulty switching from one subject to another
- Requiring more time and concentration to learn new information

Normal age-related symptoms of memory loss result from the brain's decreased capacity for quickly and efficiently retrieving information from long-term memory. It can take more time to recall information or learn new things. These memory changes may be bothersome, but they do not significantly affect daily functioning.

For someone with Alzheimer's disease, changes in memory increasingly interfere with one's ability to complete daily tasks and activities. Memory loss in Alzheimer's disease is not the result of a retrieval problem, but rather the brain is no longer able to consistently store new information.

Risk Factors

Researchers have identified multiple risk factors that increase one's likelihood of developing Alzheimer's disease. Some are risk factors that we cannot change, while others we may be able to influence.

The most significant risk factors are those that we cannot control:

- **Age** is the greatest known risk factor. Most individuals with Alzheimer's disease are 65 and older. The likelihood of developing Alzheimer's approximately doubles every five years after age 65. After age 85, the likelihood reaches nearly 50 percent.
- **Family history and genetics** also play a significant role. Research has shown that those who have a parent, brother or sister with Alzheimer's run an increased risk of developing the disease. The risk increases if more than one family member has the illness.

Scientists have so far identified one gene (APOe) that increases the risk of Alzheimer's but does not guarantee an individual will develop the disorder. Experts believe that the vast majority of cases are caused by a complex combination of genetic and non-genetic influences.

There are some risk factors that we may be able to influence:

- ***There is a strong link between serious head injury and future risk of Alzheimer's disease.*** It's important to protect your head by buckling your seat belt, wearing your helmet when participating in sports, and "fall-proofing" your home.
- ***Overall healthy aging may offer some protection.*** These measures include eating a healthy diet; staying socially active; avoiding tobacco and excess alcohol; and exercising both body and mind.
- ***Heart health influences brain health.*** Heart disease, diabetes, stroke and high blood pressure all increase your risk of developing Alzheimer's. Work with your doctor to monitor your heart health and treat any problems that arise.

If you already have a diagnosis of Alzheimer's disease, remember that limiting the above risk factors may help you remain in the early stages of the disease for longer. For care partners, consider adapting your own lifestyle to reduce your risk of developing Alzheimer's disease.

Tip:
Remember it isn't your fault if you have been diagnosed with Alzheimer's disease.

There are factors beyond your control that influence the development of this disease. Even if you take every precaution to minimize risk factors within your control, it is still possible to develop Alzheimer's disease.

Different Types of Dementia

What's the difference between dementia and Alzheimer's disease?

Dementia is an umbrella term used to describe symptoms of memory loss and other changes in cognitive abilities severe enough to interfere with daily life.

Dementia is a condition that has many possible causes. Alzheimer's disease is the most common cause of dementia, accounting for 50 to 70 percent of all cases. Alzheimer's disease is also commonly referred to as a type of dementia, among numerous others.

These various types of dementia share many similar symptoms, but they differ in the way they affect the brain, the order in which symptoms appear, the severity of individual symptoms, and how the disease progresses.

Alzheimer's disease is a disease of the brain that is marked by a slow, progressive decline of cognitive function as brain cells are destroyed by plaques and tangles in the brain. Alzheimer's disease will be described in more detail in upcoming sections.

Although you may not have a diagnosis of Alzheimer's disease, the Alzheimer's Association can still help you. In some cases we may also be able to refer you to organizations that cater to individuals with your specific diagnosis.

In addition to Alzheimer's disease, the following disorders can also cause memory loss, confusion and other symptoms associated with dementia:

- **Vascular dementia** may be the second most common type of dementia, and refers to impairment caused by reduced blood flow to parts of the brain. Symptoms of vascular dementia can be similar to Alzheimer's disease. In some cases, impairment associated with vascular dementia can occur in "steps" rather than in the slow, steady decline usually seen in Alzheimer's disease.
- **Dementia with Lewy bodies** often begins with wide variations in attention, alertness, judgment and rational thinking. Individuals affected by this illness often experience visual hallucinations as well as muscle rigidity, tremors, falls, and balance issues similar to those associated with Parkinson's disease.
- **Parkinson's disease** affects control of movement, resulting in tremors, stiffness, and impaired speech. Many individuals with Parkinson's also develop dementia in later stages of the disease.
- **Frontotemporal dementia or Pick's disease** is another disorder that may sometimes be hard to distinguish from Alzheimer's disease. Personality changes and disorientation often occur before memory loss. Symptoms often resemble depression. There are many different subtypes of frontotemporal dementia that feature different rates of progression and prominence of specific symptoms.
- **Huntington's disease** is an inherited, progressive disorder that causes irregular movements of the arms, legs, and facial muscles; personality changes; and a decline in the ability to think clearly. Huntington's disease can cause dementia, but varies in severity.

- ***Creutzfeldt-Jakob disease (CJD)*** is a rare, rapidly fatal disorder that impairs memory and coordination and causes behavior changes. Recently, “variant Creutzfeldt-Jakob disease” was identified as the human disorder believed to be caused by eating meat from cattle affected by “mad cow disease.”
- ***Normal pressure hydrocephalus (NPH)*** is caused by a buildup of fluid in the brain. The cause in most cases is unknown. Symptoms include difficulty walking, memory loss and inability to control urine. NPH can sometimes be corrected with surgery to drain the excess brain fluid.
- ***Physical injury to the brain*** caused by an automobile accident or other trauma can damage or destroy brain cells and in some cases cause symptoms of dementia such as behavioral changes, memory loss and other cognitive difficulties.

Doctors are discovering new subtypes of dementia all of the time, so you may have received a specific diagnosis that is not listed above. Some individuals may receive a dual diagnosis (e.g., Alzheimer’s disease and dementia with Lewy Bodies).

Each of these disorders are medical conditions that cause damage to the brain.

Younger-Onset Dementia

Anyone diagnosed with Alzheimer’s disease or a related dementia before the age of 65 is considered to have younger-onset dementia. People who have younger-onset dementia essentially experience the same symptoms as older people with the disease. However, younger-onset individuals will face unique age-related issues. For instance, those under 65 are more likely to be employed or have children living at home. Issues facing families affected by younger-onset include ensuring financial security, obtaining benefits and helping children cope with the disease. Experts estimate that some 500,000 people in their 30s, 40s and 50s have Alzheimer’s disease or a related dementia.

Mild Cognitive Impairment (MCI)

Sometimes a person may have problems with memory or another thinking skill that is serious enough to show up on tests, but not severe enough to interfere with daily life. Some doctors use the term mild cognitive impairment (MCI) to describe this situation.

Research has shown that individuals with MCI have an increased risk of progressing to Alzheimer’s disease, especially when their main area of difficulty involves memory. But a diagnosis of MCI does not always mean the person will develop Alzheimer’s.

Effects of Alzheimer's Disease on the Brain

The brain has 100 billion nerve cells (neurons). Each nerve cell communicates with many others to form networks. Nerve cell networks have special jobs. Some are involved in thinking, learning and remembering. Others allow us to see, hear and smell. Still others tell our muscles when to move. In Alzheimer's disease, as in other types of dementia, increasing numbers of brain cells deteriorate and die over time.

Two abnormal structures called plaques and tangles are prime suspects in damaging and killing nerve cells.

- Plaques build up between nerve cells. They contain deposits of a protein fragment called beta-amyloid (BAY-tuh AM-uh-loyd).
- Tangles form inside dying cells. Tangles are twisted fibers of another protein called tau (rhymes with "wow").

Though most people develop some plaques and tangles as they age, those with Alzheimer's tend to develop far more. Scientists believe that the damage from Alzheimer's disease begins in an area of the brain known as the hippocampus which is responsible for recent memory and learning. In particular, the hippocampus controls the formation of new memories which is why people with early stage Alzheimer's disease experience the most trouble with short-term memory and recall but usually continue to have strong long-term memory.

Scientists are not absolutely sure what role plaques and tangles play in Alzheimer's. Most experts believe they somehow block communication among nerve cells and disrupt activities that cells need to survive.

Progression of Alzheimer's Disease

Most types of dementia, particularly Alzheimer's disease, tend to show a slow progressive decline. One exception is vascular dementia, which can show a slow progression with periods of fast decline depending upon the occurrence of additional vascular damage.

Sudden changes in a person with dementia should always be referred to a physician. Possible causes may include:

- Infection
- Dehydration
- Poor nutrition
- Lack of adequate rest

- Thyroid imbalance
- Medication side effects
- Depression
- Other health conditions

In the early stages of Alzheimer's disease, plaques and tangles begin to form in the areas of the brain involved in learning, memory, thinking and planning. You may begin to notice changes in your cognitive abilities—including forgetting names or having trouble finding the right word. You may also experience more difficulty planning and performing tasks in social or work settings. Eventually these types of symptoms will interfere more with your daily life. However, these cognitive changes will occur gradually—you may not even notice changes for some time.

As the disease progresses, more plaques and tangles build up in the regions of the brain involved with memory, thinking and planning. Your problems with memory or thinking will become severe enough to interfere with daily life. Plaques and tangles also eventually spread to portions of the brain involved in speaking, understanding, orientation, and personality.

The progression of Alzheimer's disease is highly variable. Although there are many common experiences, you can also expect to have your own unique experience. Rather than focusing on when to expect cognitive losses during the course of this disease, **try to focus your current strengths**. Even in the late stages, not all abilities are lost. For instance, our capacity for emotion and relationships remains intact throughout the course of the disease. As the disease progresses, care partners should continue to foster positive emotions and capitalize on the strengths of the individual with Alzheimer's disease.

It is important to remember that during the early stages of Alzheimer's disease, there is a great deal that you can do to **take control!**

Chapter 2

DIAGNOSTIC PROCESS

There is no single test for Alzheimer's disease, but experts estimate that a skilled physician can diagnose Alzheimer's with at least 90% accuracy. The only definitive (100%) diagnosis for Alzheimer's disease requires an autopsy to examine the brain tissue using a powerful microscope for evidence of the plaques and tangles that are hallmarks of the disease.

Why seek a diagnosis?

- To rule out a disease or condition that can cause symptoms that look like Alzheimer's disease but may be potentially treatable or even curable
- To provide an explanation for symptoms
- To ensure appropriate treatment (The earlier you receive treatment, the more effective it will be.)
- To find opportunities to participate in research
- To enable future planning

Diagnostic Components

A medical workup is designed to evaluate overall health and identify any conditions that could affect how well the mind works.

The diagnostic process may involve the following components:

- Review of personal and family medical history
- Evaluation of mood and cognitive skills
- Physical exam (including a blood test)
- Neurological exam including reflexes, coordination, eye movement, speech, sensation, and muscle strength and tone.
- Brain scan (CT, MRI, or PET). The MRI (magnetic resonance imaging) and CT (computed tomography) scans provide structural imaging about the shape, position or volume of brain tissue. The PET (positron emission tomography) scan provides a functional image which reveals how well cells in various brain regions are working by showing how actively the cells use sugar or oxygen. This test can be rather expensive. Currently, a standard medical workup for Alzheimer's disease often includes structural imaging with MRI or, less frequently, CT. These images are used primarily to detect tumors, evidence of small or large strokes, damage from severe head trauma or a buildup of fluid. The MRI cannot detect Alzheimer's disease directly but is used to rule out other causes of cognitive impairment.
- Neuropsychological exam. Neuropsychological tests are sometimes used to learn more specific information about an individual's cognitive strengths and weaknesses. Depending on the individual, a neuropsychologist may run one test or a number of tests. Neuropsychological tests are not invasive but involve interviewing of the person with memory concerns and the care partner, paper-and-pencil tests, and sometimes computerized tests.

Each of these tests is used to rule out the possibility of any reversible causes (ex. infection or medication issues). The components of the diagnostic process also help to inform a clinical diagnosis of Alzheimer's disease or related dementia.

Who can make a diagnosis?

There is no single type of doctor that specializes in diagnosing and treating Alzheimer's disease and related dementias.

A primary care physician who suspects some type of dementia may make the diagnosis or refer to one of the following types of specialists:

- **Geriatrician**—Primary care physicians who specialize in conditions unique to older adults. (MD)
- **Geriatric Psychiatrist**—Specialists in mental and emotional issues among older adults. They may also diagnoses conditions associated with dementia such as depression or anxiety. (MD)
- **Neurologist**—Specialists in diseases of the brain and nervous system and are qualified to perform extensive memory evaluations. Some, but not all neurologists, specialize in Alzheimer's. (MD)
- **Neuropsychologist**—Psychologists with specialized training in the structure and function of the brain. Typically a referral from your doctor is needed in order to meet with this type of specialist.
- **Specialized diagnostic clinic**—Group practices with different kinds of specialists (usually including a neurologist, psychiatrist, psychologist, and social worker) that each perform part of the diagnosis.

"It was almost a relief to get a diagnosis of Alzheimer's disease. I had known something was wrong for a long time and was trying to cover it up. Having a name helped me."

Principles for a Dignified Diagnosis

The Alzheimer's Association, with the assistance of a number of individuals with Alzheimer's disease created the Principles for a Dignified Diagnosis. These principles are their insights on how to make that experience better.

- Talk to me directly, the person with dementia. I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.
- Tell the truth. Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
- Test early. Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.
- Take my concerns seriously, regardless of my age. Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.
- Deliver the news in plain but sensitive language. This may be one of the most important things I ever hear. Please use language that I can understand and be sensitive to how this may make me feel.
- Coordinate with other care providers. I may be seeing more than one specialist—it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and so that I don't have to repeat any tests unnecessarily.

- Explain the purpose of different tests and what you hope to learn. Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.
- Give me tools for living with this disease. Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.
- Work with me on a plan for healthy living. Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.
- Recognize that I am an individual and the way I experience this disease is unique. This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.
- Alzheimer's is a journey, not a destination. Treatment doesn't end with the writing of a prescription. Please continue to be an advocate—not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

"My first doctor didn't give me any sense of hope. He told me to get my affairs in order. I didn't stick with that doctor. The doctor I see now has been helping me to get involved in research studies. That makes me feel like I'm doing something about Alzheimer's disease."

Visiting the Doctor after Diagnosis

Start by asking your physician how frequently you should be seeing her/him for routine appointments and ask under what circumstances you should contact the office immediately.

A general guideline is to schedule a follow-up appointment with your physician for 3 months after receiving the diagnosis. After that, schedule appointments every 6 months. Remember, this may vary by type of specialist and your own unique situation.

Whenever you visit your doctor, ask questions about the tests and procedures that he/she orders—including their intended purpose, side effects, and timeline for results.

Also, you should always bring someone with you to medical appointments. Sometimes these visits can be overwhelming, so it is helpful to have someone else present to keep track of important information.

It is a good idea for you and your care partner to start keeping a journal where you can record mood, behavior changes, and new symptoms. You should bring this journal to doctor's appointments so that you can share this valuable information and record any instructions from the doctor including what you should expect from any new medications. Without this record keeping, it can be difficult to determine the effectiveness of medications and notice subtle changes.

To assess cognitive strengths and weaknesses during the early stages of Alzheimer's disease, request a referral for neuropsychological testing if it was not part of the initial diagnosis.

If significant mood or behavior changes are occurring, discuss with your physician about involving a psychiatrist.

Chapter 3

TREATMENT AND RESEARCH

There is currently no cure for Alzheimer's disease, but there are options available that can help manage symptoms, improve quality of life and possibly slow disease progression. Traditional medicine is the source of some of these treatment options. There are also a wide range of **lifestyle choices** including diet, physical exercise, and social engagement that should be considered part of the treatment plan. Some people opt to participate in clinical research trials that offer the possibility of experimental treatment for Alzheimer's disease.

Medications to Treat Alzheimer's Disease

There are two general ways that medications are used to treat Alzheimer's disease:

1. Medications to treat the cognitive symptoms
2. Medications to treat the behavioral and emotional symptoms

Treatment of Cognitive Symptoms:

As of 2011, the U.S. Food and Drug Administration (FDA) has approved two types of medications to treat cognitive symptoms of Alzheimer's disease. These drugs affect the activity of two different chemicals involved in carrying messages between the brain's nerve cells. Note that research is continually evolving and in the future, there is the hope that more options will be available.

1. Cholinesterase (KOH-luh-NES-ter-ays) inhibitors prevent the breakdown of acetylcholine (a-SEA-til-KOH-lean), a messenger chemical important for learning and memory. These drugs support communication among nerve cells by keeping acetylcholine levels high. On average, these medications delay worsening of symptoms for 6 to 12 months for about half the people who take them. Some experts believe a small percentage of people may benefit more dramatically.

Three cholinesterase inhibitors are commonly prescribed:

- Donepezil (Aricept), approved to treat all stages of Alzheimer's disease and recently approved in a higher (23 mg) dosage
- Rivastigmine (Exelon), approved to treat mild to moderate Alzheimer's and also available in a patch form
- Galantamine (Razadyne), approved to treat mild to moderate Alzheimer's.

2. Memantine (Namenda) works by regulating the activity of glutamate, a different messenger chemical involved in learning and memory. Namenda:

- Was approved in 2003 for treatment of moderate to severe Alzheimer's disease.
- Is currently the only drug of its type approved to treat Alzheimer's disease.
- Temporarily delays worsening of symptoms for some people. Many experts consider its degree of benefit is similar to the cholinesterase inhibitors.

Side effects for both cholinesterase drugs and Namenda are mostly gastrointestinal as well as vivid dreams and nasal drip. When starting these medications, take notice of any changes you experience and discuss with your doctor.

These drugs may not be effective for everyone. Even when these drugs are effective, the results are only temporary. These drugs do not attack Alzheimer's disease or stop damage to the brain, however, they may help your brain compensate for cognitive losses caused by Alzheimer's disease. After some time, these drugs will no longer be effective in compensating for the changes happening in your brain.

You might not notice a change in your cognitive ability once you begin taking these medications. These drugs may help you maintain your current level of functioning for a longer period of time, but do not restore what has already been lost. Consult with a doctor if you are uncertain about the effectiveness of your prescription.

Treatment of Psychological Symptoms:

Treatment is also available for the psychological symptoms that **sometimes** occur with Alzheimer's disease and related disorders. In the early stages of Alzheimer's disease, the most common psychological symptoms that might be treated medically are:

1. Irritability
2. Anxiety
3. Depression

Before prescribing medications for these symptoms, it is important to rule out other possible causes for these symptoms including:

1. Drug side effects
2. Medical conditions
3. Environmental influences like overstimulation or understimulation

It is often helpful for families to consult with a geriatric psychiatrist to address serious psychological symptoms. Medications are not always the only option, or best option, for the treatment of psychological symptoms. Counseling, patient and family education, and behavioral management can also be effective both in combination with medications or on their own.

Depression and Alzheimer's Disease

20 to 40 percent of people with Alzheimer's disease experience clinically significant depression.

Symptoms may include:

- significantly depressed mood
- decreased positive feelings
- social isolation or withdrawal
- disruption in appetite

- disruption in sleep
- agitation or slowed behavior
- irritability
- fatigue
- feelings of worthlessness
- recurrent thoughts of death, suicide plans or suicide attempt

If you are concerned about depression, the first step is to pursue a thorough evaluation by a professional, possibly one skilled in geriatric psychiatry. Effective drug and non-drug therapies are available. For those with Alzheimer's disease, treating depression can improve one's sense of well-being, quality of life, and individual function—even in the presence of ongoing decline in memory and thinking.

Depression is most definitely treatable!

Change in sleep patterns is another psychological symptom that can occur with Alzheimer's disease, but medical treatment requires caution due to side effects that decrease coordination and can increase falls.

Natural Treatments for Alzheimer's Disease

There are a number of vitamins and herbs that have been suggested for the treatment and/or prevention of Alzheimer's disease.

Although many of these natural treatments have received significant media coverage, most of these natural treatments have not been thoroughly tested and are not approved by the Federal Drug Administration for the treatment of Alzheimer's disease. Use of non-FDA approved treatments brings up the following concerns:

- Effectiveness and safety are unknown.
- Purity is unknown. The FDA has no authority over supplement production.
- Bad reactions are not routinely monitored. Manufacturers are not required to report to the FDA any problems that consumers experience after taking their products.
- Dietary supplements can have serious interactions with prescribed medications.

Before starting any over-the-counter or natural treatment, ALWAYS consult with your doctor.

Here are some of the more common natural treatments for Alzheimer's disease:

- 1. *Vitamin E***—Initial research indicated that Vitamin E might help prevent or slow Alzheimer's disease, but new research suggests that Vitamin E might worsen the progression of Alzheimer's disease. It is also a blood thinner and should not be taken with certain medications.
- 2. *Huperzine-A***—Evidence from small studies shows that the effectiveness of huperzine-A may be comparable to that of the approved drugs. However, if used in combination with FDA-approved Alzheimer drugs, an individual could increase the risks of serious side effects.
- 3. *Ginkgo Biloba***—It was once thought to stimulate nerve activity in the brain while improving blood flow and preventing further cell damage. However, results of a large, multicenter Phase III study published in the *Journal of the American Medical Association* (November 19, 2008) showed that ginkgo was no better than the placebo in delaying changes in memory, thinking and personality and had no impact on the development of dementia and Alzheimer's. It is also a blood thinner and should not be taken with certain medications.
- 4. *Omega-3 fatty acids***—Research has linked high intake of omega-3s to a possible reduction in risk of dementia or cognitive decline. Theories about why omega-3s might influence dementia risk include their benefit for the heart and blood vessels; anti-inflammatory effects; and support and protection of nerve cell membranes. Research suggests that omega-3s might be more helpful when consumed in the form of omega-3 rich foods, rather than in supplemental form. In 2010, a large research study showed that omega-3s, such as those found in fish oil, does not slow the progression of Alzheimer's disease or prevent it.

Lifestyle Choices

Many lifestyle choices maximize brain function and may help prevent or delay the onset of Alzheimer's disease, or slow the progression of Alzheimer's disease. These include:

1. Good overall medical care
2. Diet
3. Exercise
4. Mental stimulation
5. Social engagement
6. Adequate rest
7. Controlling stress
8. Maintaining routine

Good Overall Medical Care

When you are diagnosed with a medical condition such as Alzheimer's disease, it is very important to take care of your entire body. Acute and chronic medical conditions, if left untreated, can also impact your brain health, worsen your cognitive functioning and hasten the progression of Alzheimer's disease.

We recommend regular check-ups with a primary care physician whom you trust. The primary care physician can treat infections and other acute medical conditions that arise and provide preventive health care such as immunizations. He/she will also help to identify and treat other chronic health conditions that might arise. Of particular concern for people with Alzheimer's disease are high blood pressure and cholesterol. Some people may continue to or be referred to see specialists for other chronic health conditions.

When you visit with your primary care physician or other specialists, make sure that they know that you have Alzheimer's disease and are aware all of prescribed medications. Medications often interact with one another and people with Alzheimer's disease sometimes react differently to certain medications.

Be sure to take all medications as prescribed.

Diet

Doctors recommend eating a heart-healthy diet that is low in fat and cholesterol. Studies show that having high cholesterol and blood pressure increase your risk of developing Alzheimer's disease and experiencing strokes. A stroke or other brain injury may cause increased damage to the brain and a worsening of dementia symptoms.

Several common spices and foods appear to be protective of the brain and heart, most notably green tea. It is difficult to recommend any one particular spice, as it is difficult to test their benefit individually since other dietary factors may interfere. The best advice may be to eat a variety of spices in the hope of obtaining some benefit.

A diet that increases sugar metabolism and decreases insulin resistance (pre-diabetes) may delay the onset of Alzheimer's disease. This kind of diet reduces sugar consumption, includes green tea, and emphasizes whole grains.

It is important to drink plenty of water. Dehydration can adversely affect memory and increase confusion.

What's good for the heart is good for the brain!

Physical Exercise

Physical exercise is essential to maintain good blood flow to the brain as well as encourage the growth of new brain cells. Research has indicated that regular physical exercise may protect against the development of Alzheimer's disease and can slow its progression. This physical exercise does not have to be especially rigorous or lengthy but it should increase heart and respiratory rates. Also, the physical exercise needs to take place consistently.

For people with Alzheimer's disease, physical exercise has the following benefits:

1. Helps prevent diseases that can worsen Alzheimer's disease like strokes, heart attacks, and diabetes
2. Helps control cholesterol levels
3. Improves mood and reduces depression
4. Can have added benefit of social interaction
5. Improves sleep patterns

TIP: Consult with a dietician. These professionals can help you make changes to your current diet. They may also help you develop and implement a specialized brain-healthy diet. Ask your physician for a referral.

TIP:
Exercise regularly and you will sleep better.
We already know exercise is important, but it has the added benefit of helping us sleep better. When you keep your body active, you may find that you are naturally more inclined to attain adequate rest.

TIP:**Take a daily walk.**

This measure does not require intense exertion, but simply gets you up and moving every day. This is a great activity for individuals with Alzheimer's disease and their care partners to pursue together. We can all benefit from regular exercise!

"I go to the gym regularly. Every time I get off the treadmill, my mind feels so much clearer. I feel better for the rest of the day."

"I walk a couple of miles a day with my dog. I have lost weight and am in better shape than ever. I meet people when I am out with my dog."

In addition to walking, other ideas for physical exercise include:

- Swimming
- Gardening
- Yoga or *tai chi*
- Biking
- Dancing
- Bowling
- Golf, especially if you walk the course
- Group exercise classes
- Personal training sessions at a gym

If physical exercise is new for you or you have concerns about whether your physical exercise is effective, you should consult with your primary care physician. A referral to a physical therapist may also be helpful.

People are usually more motivated to exercise regularly if they do their exercise at the same time each day and with other people. This is especially true when you have early-stage Alzheimer's disease which can cause trouble with planning and initiative.

Social Engagement

Social interaction has been proven to help maximize and potentially improve brain function. Socialization can provide you with the opportunity to:

1. Use communication skills, so that they are not lost
2. Improve mood
3. Develop close relationships

Families living with Alzheimer's disease are at high risk for isolation, and it is important for both the person with early-stage Alzheimer's disease and the care partner to maintain social ties. Ways to promote social interaction may include:

- Family gatherings
- Contact with friends
- Exercise at a gym
- Joining a social club such as bridge club, retired person's group, or knitting circle
- Trying a sports team or league
- Involvement with a religious organization
- Community organizations such as senior centers, libraries, and schools
- Volunteer involvement
- Professional organizations, if appropriate

This kind of social involvement may be new for some people. Even if you have never been one for organized social activities, consider giving it a try. It is okay to start small with even one activity a month at the senior center or library.

Your care partners and friends should not assume that decreased social engagement means decreased interest and ability. In many cases, people with early-stage Alzheimer's disease simply need someone else to set up and encourage the social opportunity, as loss of planning abilities and initiative are common symptoms of the disease. Remember, it is much easier to remain socially engaged if you are open about your Alzheimer's diagnosis.

"Going to my support group is my lifeline. These people have become like family."

TIP:
Make connections with others in the early stages of Alzheimer's disease.

If you are attending the *Taking Control* program, you have likely met numerous other people in a situation quite similar to your own. Take advantage of this opportunity and exchange contact information. Find time to meet again and share your experiences—or just pursue interesting activities together. Also, consider joining an early stage support group to meet others in similar circumstances.

Tip:
Combining social, mental, and physical activities is ideal.

Try to find an activity that engages you socially, mentally and physically. For instance, try a new exercise class or go hiking with friends. If you find such an activity that works for you, try to build it into your regular routine.

"I still like to read, but I tend to read shorter things like the newspaper or magazines."

Mental Stimulation

Studies indicate that mental stimulation promotes growth of new brain cells, while lack of mental stimulation reduces the number of brain cells. In simpler terms—use it or lose it!

Mentally stimulating activities include:

1. Word games such as crossword puzzles and word search
2. Computer games/exercises
3. Reading books or the newspaper
4. Attending classes and lectures
5. Mental exercises such as Sudoku, brain teasers, and logic challenges, including *The Big Brain Puzzle Book* available on [amazon.com](https://www.amazon.com)
6. Board games
7. Card games
8. Television game shows where you test your own knowledge
9. Writing in a journal
10. Arts and crafts

Many products are heavily marketed as mentally stimulating activities that will ward off Alzheimer's disease or cognitive decline—for example, computer games or puzzle books. However none of these products have been thoroughly studied nor are any endorsed by the Alzheimer's Association.

The most important features of mentally stimulating activities for a person with Alzheimer's disease are:

1. Activities should be enjoyable
2. Activities should not lessen self-esteem

Don't be afraid to try something new. It is possible that by learning something new, you are developing new connections in your brain that will help your overall cognitive performance. You might consider:

- Learning to play a musical instrument
- Taking a computer class
- Using your non-dominant hand to do routine tasks. For example, if you are right handed, try brushing your teeth with your left hand.

It is also important to continue doing the tasks that you are able to do even if they may take a little longer, need some modification, or require prompting.

Adequate Rest

Inadequate rest contributes to poor cognitive performance, especially in regards to memory, for all people.

Too much sleep can also be detrimental to a person with Alzheimer's disease and may be a sign of depression.

In order to function at your best, it is vital that a person with Alzheimer's disease get an adequate amount of rest.

"I'm very happy that I can still play the guitar and write songs."

Stress

There has been some inconclusive research on the impact of stressful events on the development of Alzheimer's disease. High stress levels can certainly impact the ability of a person with Alzheimer's disease to function to his/her highest potential. For many people with early-stage Alzheimer's, stress from family and work troubles, environmental factors, and task frustration can worsen cognitive and behavioral symptoms.

Some ideas for stress management include:

- Good communication about the changes that are happening because of Alzheimer's disease
- Making changes in work and family responsibilities
- Yoga
- Spiritual activities
- Physical exercise
- Meditation
- Time with family and friends
- Time with children and/or pets
- Participation in support groups
- Finding a counselor

Care partners of people with early-stage Alzheimer's are at high risk for stress that can cause physical, emotional, and psychological problems. It is very important that care partners pay attention to the signs of stress including:

- Sleeplessness
- Anxiety
- Social withdrawal
- Exhaustion

- Irritability
- Lack of concentration
- Anger

Care partners need to take care of themselves which can include attending a support group even if the person with Alzheimer's disease is not interested. There are support groups for care partners only.

Maintaining a Routine

People with Alzheimer's disease function best in a structured environment with regular times for meals, activities, and sleeping.

Routine reduces confusion and helps ensure that a person with Alzheimer's disease is active and engaged.

With assistance and encouragement from a care partner, keeping a routine of meals, activities, and sleeping can prevent one of the most frustrating symptoms of Alzheimer's disease—lack of initiative.

Sometimes it is helpful to write out a daily routine with input from the person with early-stage Alzheimer's and the care partner. By writing out the daily routine, you can identify areas of the day that need more activity and identify areas of treatment that are lacking. If the routine is written down and posted, it can help the family to commit to adhering to the routine.

Of course, not every minute of the day needs to be accounted for in the daily routine. Everyone needs "down time" and spontaneity in their lives.

Lifestyle changes are important, but challenging. It is important to recognize that making lifestyle changes is difficult and requires much effort and commitment. It is easier to make such changes with the support of a care partner and support group. It is a good idea to start with small and manageable changes that will give one confidence to tackle other bigger changes later. Think about a small change that you can make in the next week.

"I don't want to walk this road, but if I have to, someone else better benefit from it."

Research

With public awareness of Alzheimer's disease on the rise, there is a lot of exciting research about the causes of and treatment for Alzheimer's disease and many opportunities for people with Alzheimer's disease to participate in this research. Massachusetts is the hub of much Alzheimer's research.

90% of what we now know about Alzheimer's disease has been discovered in the last 15 years.

Current research on Alzheimer's disease is focusing on:

1. Pinpointing the cause including the genetic influence associated with the disease
2. Improving diagnostic techniques
3. Testing drugs and vaccines to prevent and slow the progression
4. Testing existing drugs for other conditions that may also affect disease development and progression
5. Studying the impact of social and community programs on care partners and people with Alzheimer's disease

The only way to put new ideas for diagnosis, treatment and care into practice is by studying people with Alzheimer's disease, those at risk for Alzheimer's disease and their care partners.

Reasons to participate in clinical trials

1. Possible benefits from experimental treatment
2. Opportunity to learn more about the disease and receive more medical care and attention at no cost
3. Support received from research team
4. Ability to contribute to knowledge about and treatment of Alzheimer's disease for future generations

Clinical trials versus other types of research

Participating in research does not necessarily mean piloting a new drug or treatment technique, but sometimes involves contributing to social research. For instance, some studies seek to better understand the experience of caregivers or the effectiveness of a driving program. Know that there are a wide variety of research opportunities available, not all medical in nature.

Things to consider regarding participation in a research trial

1. It might require frequent doctor's visits and involvement of a care partner
2. It may have uncomfortable or possibly serious complications
3. It might be assigned to the control group and receive a placebo or no treatment
4. It might require that you stop taking other medications

Research participants have certain rights that are protected by law including:

1. Assurance that the study contributes new information
2. Assurance that benefits outweigh risks
3. Option to drop out without penalty
4. Voluntary nature of participation
5. Requirement that participants be informed about risks and benefits

If you decide to participate in research, report any problems you experience to the Alzheimer's Association.

If you are interested in participating in research, there are multiple ways to learn more:

1. Contact the Alzheimer's Association for an updated list of trials in the Massachusetts/New Hampshire area
2. Ask your physician about any studies for which you might qualify
3. Use the Alzheimer's Association's online Trial Match Program at: <http://alz.org/MANH>

Chapter 4

CARE TEAM AND PLANNING FOR THE FUTURE

The Taking Control program and this manual offer many ways to help you manage a diagnosis of Alzheimer's disease or a related disorder. You should be armed with knowledge about the disease, treatment options, symptom management and coping strategies. There are also some very concrete matters to be addressed, including building your medical team, legal and financial planning, safety, and community services. This final section will provide general guidance in these areas, but for provider referrals near your location and to address your specific needs, please call our 24/7 Helpline at 800.272.3900.

Partnering With Your Doctor

Choosing a primary care doctor and developing a working relationship with him/her is one of the most important steps to managing Alzheimer's disease.

A good primary care physician can:

1. Ensure that your other chronic medical conditions and acute illnesses are treated so that you can function to the best of your ability
2. Help to coordinate referrals and recommendations on specialists, including neurologists, psychiatrists, and neuropsychologists
3. Oversee prescription and over-the-counter medications to minimize side effects and avoid interactions

In order to find a primary care physician who can best support someone with a diagnosis of Alzheimer's disease:

1. Ask friends and family to recommend someone who they trust. In particular, friends that you make through Alzheimer's support groups or education events may be able to recommend primary care physicians who are familiar with Alzheimer's disease
2. Most hospitals should be able to refer you to primary care physicians and/or geriatricians. Ask for a referral from an Alzheimer's diagnostic clinic to see if they know of any physicians with an understanding of the disease
3. Most health insurance companies have websites and/or referral lines where you can find out which physicians are available in your area and accepting new patients
4. Once you receive several referrals, call the physicians' offices and ask to speak with a staff member who can provide details about the doctor's credentials and expertise. Ask how many patients they see in your age range and if the physician has experience with Alzheimer's disease.

To prepare for a doctor's visit, see the Principles for A Dignified Diagnosis (chapter 1), and:

1. Make a list of questions
2. Take a family member or friend with you
3. Write down a list of all symptoms, both cognitive and physical, including when they began and how frequently they occur
4. Bring a list of ALL medications including prescriptions, over-the-counter medications, vitamins, and herbal supplements
5. Ask for a longer appointment if you have a lot of questions. You might want to give your care partner the opportunity to meet with the physician alone

Your time with a physician is often short, and here are some tips for making the most of the appointment:

- Review your list of medications and symptoms
- Be specific when describing changes in mood, behavior, personality, sleep cycle, and level of function, giving specific examples
- Answer all of your physician's questions thoroughly and honestly
- Ask questions about all tests and procedures that the physician orders—their intended purpose, side effects, and timeline for results
- Inquire about referrals to other helpful professionals such as speech, occupational, and physical therapies, visiting nurse services, or dieticians
- Report on care partner's health and stress level
- Take notes during the visit and ask that your physician communicate with all of your other doctors
- Ask how frequently you should be seeing the physician and under what circumstances you should contact the office immediately
- Discuss Advanced Directives and ensure that you have a Health Care Proxy. Be sure that your physician knows your wishes.

Remember to always check with your primary care physician before adding ANY medication—prescription, over-the-counter, vitamin, or herbal supplement.

Call the doctor immediately if you experience any of the following symptoms:

1. Sudden change in mental status or mood
2. Blackouts, fainting spells, or falls
3. Sudden inability to speak or move a part of your body
4. Fever
5. Sudden incontinence

Legal and Financial Planning

Taking the time to make legal and financial plans now will help ensure that your wishes are honored in the future and will lessen stress and anxiety for you and your family.

Giving thought to these issues and having conversations with your family about your wishes for long-term care is an important part of this process. Five Wishes, available on www.agingwithdignity.org, can be a useful tool for generating these discussions.

An elder law attorney can help you to draw up the following documents:

1. Durable Power of Attorney—Names a person to take care of financial matters if you are unable to do so.
2. Health Care Proxy/Durable Power of Attorney for Health Care Names a person to make medical decisions for you if you are unable to do so. In Massachusetts, the document is called Health Care Proxy. In New Hampshire, the document is called Durable Power of Attorney for Health Care.
3. Will—Describes financial estate and itemizes distribution in the event of your death.
4. Living will (Optional)—States your preferences for critical medical procedures, if you are unable to make decisions. State laws vary.
5. CPR directive (Optional)—Tells emergency personnel that you do not want to be resuscitated. Talk to your doctor if you are interested in a CPR directive. State laws vary.

Getting these documents in place now will avoid costly and complicated guardianship and/or conservatorship proceedings in the future.

The Alzheimer's Association, MA/NH Chapter offers a free program on legal and financial issues at locations throughout our region. The program is presented by elder law attorneys who volunteer their time. For a full listing of our educational programs, please visit our website, www.alz.org/MANH or call the 24/7 Helpline at 800.272.3900.

Safety Issues

Personal and Home Safety

Changes in judgment and orientation that occur with the progression of Alzheimer's disease can be dangerous to you and those you love.

Possible safety risks include:

1. Leaving appliances on and/or having cooking accidents
2. Getting lost (6 out of 10 people with Alzheimer's disease will wander or get lost, and it is impossible to predict at which point in the disease they will do so.)
3. Difficulty taking medications properly
4. Falls

Some strategies to enhance safety include:

1. Enrolling in Medic Alert® +Safe Return®
2. Using a pillbox or medication dispensing system. Keep pill bottles and over-the-counter medications in a safe place
3. Modifying cooking (for example, only use the microwave or get Meals on Wheels)
4. Getting appliances with automatic shut-off
5. Using night lights or sensor lights to reduce chance of falls at night
6. Installing smoke detectors
7. Giving two to three sets of spare keys to trusted neighbors
8. Using flood alert on sinks and tubs
9. Getting rid of dangerous weapons
10. Using sticky notes for reminders
11. Reducing the number of kitchen tools
12. Keeping cleaning supplies and other household chemicals in a safe place

If you are unsure about what safety risks your environment poses, ask your primary care physician to refer you to an occupational therapist for a home safety evaluation.

Driving

Driving is a vital link to independence and part of one's identity in American society.

Driving is a complex activity that requires quick thinking and reactions, good perceptual abilities, and split-second decision-making. Symptoms of Alzheimer's disease that affect one's ability to drive include:

1. Memory loss—How to get to places
2. Disorientation—Getting lost
3. Visual and perceptual changes—Judging distances and speeds
4. Trouble with multi-tasking and split decisions
5. Mood/behavior changes—Making drivers anxious and irritable
6. Longer reaction time

Studies show that people with Alzheimer's disease are 4 to 5 times more likely to have accidents.

The Alzheimer's Association does not believe that a diagnosis of Alzheimer's disease requires an immediate surrender of one's license, but the Alzheimer's Association does recommend monitoring the driving ability of a person with dementia often.

It is important not to wait too long to give up driving.

Most people, whether they have Alzheimer's disease or not, are not the best evaluators of their own driving ability. Discussions about how driving will be monitored, how the decision to stop driving will be made, and how transportation needs will be met should begin soon after the diagnosis. Usually both the family and the physician will be involved in this decision.

In some situations, a formal driving evaluation will be done at a specialized evaluation center, a list of which is available through Helpline. The Alzheimer's Association does not recommend getting tested at the Registry of Motor Vehicles.

People with Alzheimer's disease and their care partners need to take steps to be safe before they or someone else gets hurt. For some people who are diagnosed in the very early stages, steps can be taken to improve driving safety including:

- Limiting the area in which you drive to familiar locations
- Driving only in daylight
- Not driving in bad weather
- Restricting driving to low traffic times

Financial Safety

Personal financial management is a complex activity that is essential in securing an individual's livelihood. In the early stages of Alzheimer's disease, it is still possible to remain involved in managing ones finances; however the following precautions will help ensure your financial safety:

1. Ask a trusted person to help you manage your finances. For instance, if you are comfortable, you might wish to continue with your personal bookkeeping but need someone to review your work. This may be a good role for the person you designate as your durable power of attorney, who you have chosen to legally manage your finances when you are no longer able.
2. To ensure the timely submission of bill payments, you might consider utilizing online banking to set up automatic deposit and withdrawals of your funds.
3. Beware of solicitors that contact you over e-mail or on the phone. Some are reputable, however many are not. Never give personal identification or financial information to a stranger who asks for this information. Keep a note about this on your computer and phone to remind yourself of this risk.

Some info taken from the *By Us for Us* guides at:

http://marep.uwaterloo.ca/products/BUFU/93711_tips.strategies.pdf

Chapter 5

DISCLOSURE AND CHANGING RELATIONSHIPS

A diagnosis of Alzheimer's disease will eventually lead to changes in roles and relationships for both the person with early stage Alzheimer's disease and his/her family. Good communication is essential in managing these changes in roles and relationships. Alzheimer's disease itself can make communication challenging and language difficulties are some of the most frustrating symptoms. The previous section on coping strategies offers some advice for maximizing communication abilities. While communication may require considerable effort in the early stages of Alzheimer's disease, it is important for you, your care partner(s) and your family to have meaningful conversations about present feelings, challenges, and plans for the future.

"I just want to put it in a drawer, forget about it, and live my life."

Common Reactions to Alzheimer's Diagnosis

Before talking to other people about the diagnosis of Alzheimer's disease, you need to come to terms with the diagnosis yourself.

Common and normal feelings include:

- Shock and denial
- Anger or resentment
- Fear
- Feeling overwhelmed
- Loneliness
- Depression
- Sadness
- Frustration
- Guilt

Some people with early-stage Alzheimer's disease and their care partners will find these feelings manifesting themselves physically and will experience such issues as:

- Physical discomfort
- Sleep disturbance
- Headaches
- Weight loss or gain

These symptoms can also be the result of other pre-existing medical conditions or side effects of medications.

Both people with Alzheimer's disease and care partners need to report these feelings and physical symptoms to their doctors so that he/she can assess whether medications are required and if counseling would be helpful.

Gaining acceptance about a diagnosis of Alzheimer's disease takes time. It is a journey. Alzheimer's disease is progressive and you and your family will be confronted with many changes that can cause old feelings to resurface. Some helpful ways to reach acceptance and find hope include:

- Talking about your feelings of loss and grief with a trusted family member or friend
- Maintaining social connections
- Attending a support group
- Taking care of your physical health
- Seeking professional mental health counseling
- Drawing upon your faith or spirituality
- Staying informed
- Making long-term plans
- Finding new purpose

Denial

Denial is a popular term these days. Being "in denial" is a phrase used to describe everything from someone's inability to own up to the fact that their house is in constant disarray to refusal to recognize symptoms of a serious illness. Denial usually has negative connotations, but for people diagnosed with Alzheimer's, a certain amount of denial can help people set aside the overwhelming implications of the disease and focus on the positive aspects of the present. It is also important to recognize that what seems like denial may be impaired insight that is a direct result of the disease and beyond a person's control.

Telling Others about Alzheimer's Disease

People with early-stage Alzheimer's disease do not exhibit any changes in physical appearance and must find ways to tell others about their diagnosis. Even for those who have come to an acceptance of the diagnosis, it can be difficult to tell other people. Questions include:

1. Who do I tell?
2. Do I have to tell anyone?
3. How and when should I raise the issue?
4. How will people react to my disclosure?

The people who you need to tell include:

- People who you trust, know well, and love
- People to whom you are responsible
- People from whom you may need assistance

There is no right way to tell others that you have a diagnosis of Alzheimer's disease. Everyone has his/her own methods. Most people prefer to tell those closest to them first, and these family members and friends may be able to help you tell others in your social circle. Sometimes a face-to-face conversation is best, while at other times a telephone call, e-mail or letter will suffice. Whatever method you chose, it is important to include the following information:

- Basic information about Alzheimer's disease and where to find more information
- How Alzheimer's disease is currently affecting you, i.e. what symptoms you are experiencing
- What things you are still able to do and enjoy despite your diagnosis
- Specific ways that others can be helpful to you
- Your desire to continue to have these people in your life

Do not feel ashamed about your diagnosis of Alzheimer's disease. As discussed in the first section of Taking Control, Alzheimer's disease is a medical condition caused by changes in your brain, not personal history or behavior. If you are not honest with others about your diagnosis, you risk the following:

- Wasting precious mental energy on covering up your symptoms
- Alienating family and friends who misinterpret your symptoms as mental illness and disinterest
- Depriving family and friends the opportunity to learn about Alzheimer's disease and offer their assistance to you

Public awareness and understanding is improving in our society but some people still hold onto false stereotypes about Alzheimer's disease. If family and friends react negatively to your diagnosis, it is important to remember that their reaction is based on lack of education and understanding. The Alzheimer's Association can provide materials that you can share with them. You should not take anyone's negative reaction personally, as it may be based on misinformation.

Telling Your Employer or Supervisor

If you are still working as a paid employee or volunteer, Alzheimer's disease will eventually affect your job performance. Your decision about when and how to tell your employer or supervisor should take into consideration both personal and financial factors. Because employment can be such an important part of one's identity, it can be very difficult to control emotions in these decisions, and sometimes it is necessary to consult with an elder law attorney, financial planner or another third-party.

Some things to take into consideration when making decisions about telling your employer are:

- Has your employer already documented changes in your work performance?
- Do you think that your supervisor would be understanding about your diagnosis?
- Would it be possible for you to reduce your hours; job share; get additional support from co-workers, or change your job title to continue your employment?

In many cases, being proactive about telling your employer will afford you more control over your future.

TIP:
In American society where much emphasis is placed on independence, it can be especially difficult to ask for assistance and accept offers of assistance. Try to see an offer of help not as a sign of weakness but as an opportunity. Accepting assistance is a gift to others and will allow you to remain independent for a longer time.

Maintaining Roles in Relationships

Occupations or volunteer pursuits are just two of many important factors that help define personal identity for ourselves, our families and society. Just as Alzheimer's disease can impact the ability to fulfill job or volunteer responsibilities, it can affect other relationships in your life and your role in those relationships. While you may experience changes in your abilities, you also will retain many strengths.

If you do not proceed carefully with changes of roles, there is a risk of:

- Loss of identity
- Loss of activities enjoyed
- Isolation
- Increase in negative moods and depression

Maintaining the important roles in your life requires appraising your own abilities and prioritizing your goals in life. Some tips that will help you achieve this are:

- Be honest
- Focus on your strengths
- Act as your own advocate
- Consider the impact of changing roles on others

Sometimes there is an option to give up a role or accept an altered role. Some questions to consider are:

- Is the activity or task persistently frustrating and less enjoyable?
- If I make mistakes repeatedly, am I putting others or myself at risk for harm?
- Have I stopped doing something I enjoy because I cannot do all of the steps?

It may take some creativity and help from others to continue to maintain important roles in your life, but the benefits to self-esteem and quality of life are great.

Conversations with Family and Friends

A diagnosis of Alzheimer's disease can raise many sensitive issues that impact both the present and the future including the ability to make decisions about health care, finances, living arrangements, and changes in relationships, roles and abilities.

In organizing a family meeting, decide:

- Who will be included
- How to meet: in-person, telephone conference calling, or video-conferencing
- Topics to be covered
- Would it be beneficial to include a professional such as a Care Consultant from the Alzheimer's Association, or a counselor or clergy person to attend or assist in facilitating the meeting

It is also important to come prepared with information on available options to resolve issues that may arise during the family meeting. The 24/7 Helpline, the Alzheimer's Association, MA/NH Care Consultation program and your local Aging Services Access Point in Massachusetts or ServiceLink in New Hampshire can be helpful in compiling available resources.

Tips for a Successful Family Meeting

1. You and your care partner(s) should be included.
2. Allow equal time to everyone
3. Listen with respect
4. Stick with the issues. This is not a time for old family disagreements.
5. Keep your sense of humor.
6. Ask one person to take notes that include—how, by whom, and when things will be done.
7. Set a follow-up meeting or way to continue to the discussion.

Most families will need additional meetings as the disease progresses, and it is important for families to be in regular contact with one another.

Chapter 6

PRACTICAL TIPS FOR DAILY LIVING

Even in the early stages, Alzheimer's disease and related disorders can be a cause of frustration in the daily lives of those affected. Common problems include memory loss, disorientation to time and date, language difficulties, decreased motivation, losing things, and problems with task completion. As you have learned in previous sections of *Taking Control*, these problems are caused by damage to the brain and are not within the control of the person with Alzheimer's disease or his/her care partner. Through our work with families living with early-stage Alzheimer's disease, we have identified coping strategies to help manage these common problems and enhance quality of life. The encouragement and patience of care partners are essential in the success of these strategies.

Depression as a symptom

Remember, 20-40% of people with Alzheimer's disease experience clinically significant depression. If you suspect depression, seek treatment! Once your symptoms of depression are treated, you may find it is easier to cope effectively with your Alzheimer's disease symptoms.

- Antidepressant medications can be quite successfully for limited periods of time.
- Talking with a trained counselor familiar with the issues of dementia can also be helpful.

**ENHANCE
MEMORY**

Strategies to Enhance Memory

Place fewer demands on your short-term memory.

1. Write things down! ALWAYS CARRY A NOTEBOOK OR DAY PLANNER. These should contain:
 - List of important phone numbers, including your own
 - Names that you need to remember
 - Important health information
 - Your address and a map of how to get there
 - A record of daily activities and important information
 - Important thoughts and ideas
 - Appointments
 - Things you need to do
2. Call yourself and leave a voicemail when you have something important to remember.
3. Ask others to help provide you with reminders.
4. Ask friends to remind you with a phone call before coming over.

Use visual cues

1. Post signage, either written or graphic, for important reminder such as turning off the stove or taking medications.
2. Put up a dry-erase board or chalkboard in a prominent place, such as the kitchen, to write down important things to remember for the day or week.
3. Use a large calendar that not only includes important appointments but also routine tasks and regular activities that you want to remember. Sometimes it helps to color code the calendar.
4. Post a list of emergency numbers and description of where you live by the telephone.
5. Collect photos of important people in your life and label them.
6. Keep a pad and pen by the phone for messages. You can also tie a notebook and pen to the telephone for phone messages. Be sure to ask callers to speak slowly so that you can get the information down.
7. Consider purchasing a telephone with a picture directory for simple dialing.

8. Use post-it notes to keep you on track, or remind you about tasks.
9. Keep important items such as pills in a visible location if it is safe to do so. Sometimes just seeing these items is a reminder of what to do.
10. Post a weekly checklist of activities planned for each day of the week.

Keep a familiar routine.

(This will help with your memory and orientation.)

1. Review your calendar daily and share with your care partner(s).
2. Write down daily, weekly, and monthly schedule of activities and bring it with you.
3. Schedule activities for the best time of the day for you.
4. Slow down—do one thing at a time.

Consider electronic devices.

1. Bring a tape recorder to important meetings and appointments.
2. Use an alarm clock as a cue to take your medications first thing in the morning.
3. Set a timer to remind you to take something out of the oven, change a load of laundry, etc.
4. Set up your phone with speed dial for important phone numbers. A large button phone often allows for more room to write down the names.
5. Carry a cell phone with you so that you can call your care partner if you forget something while you are out.

Strategies to Reduce Disorientation to Time and Date

1. Post a calendar and mark off days.
2. Arrange for daily delivery of the newspaper.
3. Get up and retire at the same time each day. Keep consistent meal times.
4. Use a timer to assist you with moving through your daily schedule.
5. Hang a clock and/or wear a watch with time, day, and date.
6. Try a digital or talking clock or watch with day and date capacity.

Tip: Reserve a place in your home for a calendar, important notes, a dry-erase board, and stationary phone. You can go to this message center area whenever you need to remember what to do next.

LANGUAGE
DIFFICULTIES

Tip: The most important communication tip is to let others know that you have Alzheimer's disease or a related disorder. If your family, friends, and regular acquaintances are aware, they will be more patient and helpful. Also you will not have to use precious cognitive energy covering up the fact that you have Alzheimer's disease and can focus on what you want to say.

Strategies to Deal with Language Difficulties

1. Don't give up!
2. Keep talking—don't withdraw.
3. Find a quiet place to talk.
4. Slow down.
5. Avoid arguments.
6. Find acceptance for symptoms you cannot change (example—repeating).
7. Prompt others to remind you when you lose track of a thought.
8. Write it if you can't say it.
9. If you can't remember a word, talk around it or describe what you want.
10. If you cannot come up with a word, do not think about it, and it may come to you on its own.
11. Ask others to slow down if they are speaking too quickly for you.
12. Use gestures.
13. Focus on the main point, not the details.
14. Have a signal with care partners when you need help or a break.
15. Talk to your physician about a referral to a speech-language pathologist, or speech therapist especially if language difficulties are your primary concern. Speech-language pathologists can help you and your family evaluate your language difficulties and provide individualized suggestions on how to manage those difficulties for you and your family.
16. For interactions with unfamiliar people such as wait staff in a restaurant or a cashier at the store, the Alzheimer's Association can provide you with a laminated business card that says: "Please be patient with me. I have a memory impairment." We also have cards for care partners that say: "Please be patient. My companion has a memory impairment."

Tips for when you forget someone's name

- For recalling names—run through the alphabet
- Keep lists or cheat sheets of names to remember
- Give your name to prompt others to do the same
- Keep a photo album with labels to review
- Care partners may repeat others' names to prompt you
- Review names before an event
- Just say, "Forgive me, I don't recall your name."
- Remember—name recall is hard for everyone

Strategies to Help with Completion of Tasks

1. Give yourself enough time to complete tasks.
2. Focus on one task at a time.
3. Break tasks down into manageable segments. You might be able to do some segments of the task on your own and need assistance for other segments.
4. Try making a list of steps in the tasks that you can cross off as they go. If the list is for routine tasks, you can put the list in a plastic sleeve and use a dry erase marker so that it can be reused.
5. Investigate if there is a specific step in the task that is causing the challenge.
6. Prep supplies for tasks in advance.
7. "Prime the pump"—care partners may assist with getting started on a task.
8. Do difficult/important tasks together (example—bill paying).
9. Simplify the tasks if possible and necessary.
10. Ask the physician about a referral to an occupational therapist especially if problems with task completion are affecting activities of daily living such as bathing, dressing and grooming. An occupational therapist might be able to provide strategies that build on your specific strengths and possibly introduce assistive devices.

Care partner tips

- When your partner struggles to find the right words, you can say, "I know what you mean."
- Be patient and helpful with your partner, but avoid the tendency to speak for him/her.
- Don't interrupt your partner who may easily lose his/her train of thought.

COMPLETE TASKS**Care partner tip**

Sometimes it is not the ability to sequence the task that is the problem, but rather the motivation to start the task. Loss of initiative is a real symptom of Alzheimer's disease. This is where the encouragement from the care partner is especially important. You can help prompt your partner. Also, you may also seek out the diagnosis and, if necessary, treatment of depression.

ORGANIZATION



Strategies to Prevent Losing Things

1. Minimize clutter.
2. Organize and label drawers and cabinets with pictures and/or words.
3. Always keep important items such as glasses and keys in the same place.
4. Try a wireless locator.
5. Label important items with your name and phone number.
6. Be patient with yourself.
7. Keep a departure checklist of everything that must be completed before you leave the house.
8. Wear a document/passport lanyard that holds important items and documents.
9. Wear clothes with pockets so you have a place to keep important things.
10. Limit what you carry (example—leave extra credit cards at home).
11. Keep spare keys, glasses, etc. This way if an item is lost, the loss is less stressful.
12. Keep photocopies of your identification and credit cards (both sides) so that you know what to do if these items are lost.
13. Find out if the base to your portable phone is equipped with a locating device.

Care partner tip

Keep a list of where you have found lost items. Often lost items are in unusual, but consistent, places.

Chapter 7

SUPPORT OPTIONS

For more information on Alzheimer's disease, Support Groups, Care Consultation and educational programs, contact the Alzheimer's Association at 800.272.3900 or online at www.alz.org/MANH. The 24/7 Helpline can also provide a list of referrals and consumer education on all of the support services described.

There are a wide range of support services available for people with Alzheimer's disease and their care partners, some of which are appropriate at any stage of the disease process and others which are appropriate at a specific stage of the disease.

Information

For advice and information at any stage of Alzheimer's disease, the Alzheimer's Association offers a 24/7 Helpline, individualized Care Consultation and many educational programs at no cost.

1. 24/7 Helpline (1.800.272.3900) /www.alz.org/MANH— Advice and information available from trained staff and volunteers from the Alzheimer's Association, 24 hours a day 7 days a week. The Massachusetts/New Hampshire Chapter provides follow-up calls to those who choose to be contacted.
2. Care Consultation—In-depth, person-to-person assessment, education and support provided by appointment through the Alzheimer's Association, Massachusetts/New Hampshire Chapter.
3. Educational Programs—Education programs on many topics including coping with early memory loss, communication, safety and legal and financial issues are offered in communities throughout Massachusetts and New Hampshire.

Social Engagement

Support groups can be very helpful. Support groups can provide:

1. A place to share concerns and coping strategies
2. An opportunity for socialization
3. A source of information on Alzheimer's disease, including important research updates

Throughout the disease process, it is very important that both the early-stage person and care partner are involved in activities that provide meaning and socialization. There is a dangerous tendency among early-stage persons and care partners to self-isolate. Some opportunities for meaningful activity and socialization include:

1. Work
2. Volunteering
3. Church
4. Senior Centers/Councils on Aging—Local agencies located in all towns that provide information, programs, and services for senior citizens. Type of programs and services varies widely by town. The local senior center is a good place to ask about transportation and Meals on Wheels
5. Social or adult day health care—More structured programs for people who need more supervision and direction than offered at a senior center
6. Companion care

Please note that the person with dementia will likely need encouragement and support from the care partner to begin and continue with these sorts of activities due to the disease's impact on initiative. For a more detailed overview of the importance of socialization in Alzheimer's disease, refer back to Chapter 2, "Treatment Options."

For those living with Alzheimer's disease, you will maintain your current level of functioning longest if you regularly engage in activities that are mentally stimulating, physically active, and keep you socially engaged. However, if you no longer work, it may be difficult to structure your days on your own. For help in this regard, you might consider attending a *Supportive Day Program* which provides structure, socialization and meaningful activities in a safe environment.

These types of programs are typically located at Councils of Aging, senior centers, and other community centers. These programs are most appropriate for those in the early stages of the disease who are able to be relatively independent with some support.

As the disease progresses, and a higher level of support is needed, an Adult Day Health Care Program is an excellent resource to meet the needs of individuals with dementia. These programs are designed to support one's strengths, abilities, and independence. These centers typically have staffed activities such as music and exercise programs and discussion groups.

Transportation

As described earlier, at some point in the progression of Alzheimer's disease driving is no longer a safe option. Once you have made the decision to stop driving, you will likely need transportation services in order to remain in the community independently.

Available transportation services can vary by town, so a good place to start is with your local Council on Aging for referral information. For Massachusetts residents, you should also contact your local Aging Service Access Point (ASAP) for additional information. For New Hampshire residents, contact your local Service Link center. Call our 24/7 Helpline at 800.272.3900 to obtain the contact information for these service agencies in your town and state.

In-Home Services

At some point in the disease process, people may need some assistance in their homes to provide companionship, supervision, meal preparation, personal care, and other services. Some of these services are subsidized by the state and others are paid for privately.

1. **Aging Services Access Points**—Regional agencies that cover the entire state of Massachusetts to provide information and referral, programs and services to people 60 and over. SAPS are a good place to ask about transportation and Meals on Wheels
2. **Service Link**—A network of resource centers across the state of New Hampshire that provide information and resource referrals to older adults, adults with chronic illnesses and care partners. Service Link centers are a good place to ask about transportation and Meals on Wheels
3. **Private pay home services**—Subsidized and private pay services to assist with a wide-range of tasks including housekeeping, meal preparation, personal care, and companionship

As the disease continues to progress, some families and individuals with Alzheimer's disease will decide that an Assisted Living Facility is the best source of care. Assisted Living residences fill the gaps for those who may not require a skilled nursing facility, but who are not able to manage their personal care or remain safe in their homes. This is a place where someone with Alzheimer's disease will live 365 days per year, and will likely cost much more than the average family automobile. Careful research from the outset will allow you to achieve the best fit possible and help ensure your success in getting your needs met and preferences fulfilled.

For in-depth and ongoing assistance with planning services, there are private geriatric care managers. Geriatric care managers have diverse experience, education and backgrounds. Many geriatric care managers are nurses or social workers. They provide individualized, ongoing assessment of needs and coordination of services for a fee.

Chapter 8

BECOMING AN ADVOCATE

There are many ways to be an advocate:

1. The early-stage person can speak for him/herself to doctors, family, and others about his/her rights to respect, fair treatment, consideration from others, and having needs met
2. The care partner can advocate for him/herself as well as for the needs of the early-stage person
3. Both the early-stage person and care partner can advocate for others with Alzheimer's disease through involvement in research, the Alzheimer's Association Walk to End Alzheimer's, public speaking, and legislative involvement
4. The early-stage person can join our Early Stage Advisory Group. This group is composed of individuals in the early stages of Alzheimer's disease who help the Association provide the most appropriate services for people living with early-stage Alzheimer's and raise awareness about early-stage issues

If you are interested in learning more about how to become an advocate for Alzheimer's disease, contact our 24/7 Helpline at 800.272.3900 for information about the opportunities listed above.

Appendix

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