

TOOLKIT FOR MALE CAREGIVERS:



ALZHEIMER'S

The Men's Health Network Advisory Board

Educating ■ Empowering ■ Supporting

MHN Men's Health Network™
www.menshealthnetwork.org

MEN'S HEALTH NETWORK™

Men's Health Network (MHN) is a national non-profit organization whose mission is to reach men and their families where they live, work, play, and pray with health awareness messages and tools, screening programs, educational materials, advocacy opportunities, and patient navigation. MHN partners with both private and public entities to achieve these goals. MHN also sponsors conferences and promotes awareness periods such as National Men's Health Week. With a network of chapters, affiliates, and health partners, MHN has a presence in every state and over 30 countries.



Building Healthy Families One Man at a Time™

The information provided here is a public service of Men's Health Network and is not intended to constitute medical advice. Please consult your healthcare provider for personalized medical, dietary, and/or exercise advice. Any medications or supplements should only be taken under medical supervision. Men's Health Network does not endorse any medical products or therapies.

FOREWORDS

There is a lot of good news these days on the health front. Americans are living longer than ever. The number of people over 65 has increased tenfold over the last century. Great strides are being made in reducing death rates from heart disease, cancer, and other major health threats.

However, there is a saying that “new solutions bring new problems.” As the aged segment of the population continues to increase, some of the more daunting problems associated with aging become increasingly common. Of these, few are as challenging as Alzheimer’s disease.

In a society that places great value on intellect, performance, and self-sufficiency, the gradual loss of one’s basic mental faculties is particularly unsettling. Alzheimer’s patients often find themselves abruptly unable to do simple things they had taken for granted not long before. Caregivers may find that people they’ve known and loved all their lives can no longer recognize them. Patients commonly lose even the awareness that anything is wrong with them, unknowingly becoming a danger to themselves.

Many people think that Alzheimer’s disease is uncommon. It would be great if that were true, but according to the Alzheimer’s Association, as many as one in nine Americans will face the diagnosis. Above the age of 85, almost two out of five show signs of this disease. Alzheimer’s is considered the most common cause of major loss of mental function in the elderly, accounting for two out of three cases. At this time, almost two thirds of those diagnosed with Alzheimer’s are women.

So why create a toolkit aimed at men? With an aging population and a preponderance of cases among women, many men may find themselves called upon to assist in the care of an Alzheimer’s patient. Many men may even find themselves in the role of the primary caregiver. Anyone caring for an Alzheimer’s patient will need knowledge and skill, not only to care for the patient effectively, but to care for themselves in the process of coping with this demanding affliction. Thus far, men have been an underused resource for caregiving. Let’s all get ready to change that.

Jean Bonhomme, MD, MPH

Board of Directors, Men’s Health Network

Founder of National Black Men’s Health Network

FOREWORDS

“Cruel,” “devastating,” “soul robbing,” and “unforgiving” are just some of the terms that have been used to describe Alzheimer’s dementia, a disease that impacts an increasing number of people and their families, especially the caretakers. There are so many emotions that family members go through, sometimes all at once. Anger, frustration, guilt, and sheer exhaustion. While there is no “script” that families can follow when dealing with Alzheimer’s, Men’s Health Network has developed a toolkit meant to educate, support, and offer useful resources to anyone affected by this illness.

This easy-to-use toolkit is especially helpful to men who are serving as caretakers. It is no secret that in our society, women do the majority of the caretaking over the course of their lives. Whether raising children or balancing a career and a home life, women have developed more skills and coping strategies, and have larger social networks that can offer key support. It is more difficult for men for a variety of reasons that include feeling overwhelmed, as any caretaker knows, not knowing where to turn for help, and not having much (or any) experience as a primary caretaker. Men’s Health Network has lovingly, caringly, and helpfully provided this crucial aid which we hope you will find helpful during your time of need.

Jehan El-Bayoumi, MD, FACP

Founding Director, Rodham Institute

Associate Professor of Medicine, The George Washington University School of Medicine and Health Sciences

This toolkit was developed to **educate, empower, and provide support** for males who are caring for a loved one with Alzheimer’s disease. Whether you are a husband, brother, friend, son, or partner of someone who has Alzheimer’s, we want to ensure you are prepared and have the knowledge, support, and resources needed to take care of your loved one to the best of your ability.

Men’s Health Network is dedicated to building healthy families, one man at a time. This toolkit provides an explanation of Alzheimer’s disease, the common behaviors presented by someone diagnosed with Alzheimer’s, options for treatment, and tips/strategies on communication and caregiving. There are available resources and advice on how to take care of yourself throughout the caregiving process, because if you aren’t caring for yourself, it will make caring for your loved one more difficult. Remember, you are not alone!

The Staff at Men’s Health Network

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INTRODUCTION

How do you get used to giving a bath to the person who used to bathe you? What do you do when your parent or a loving spouse of 30 years doesn't remember your name?

If you're reading this, you've probably learned that a loved one has been diagnosed with Alzheimer's disease and you've stepped up to the plate to be the caregiver. And you're certainly not alone.

Although women have traditionally been the primary caregivers in their family, more and more men are rolling up their sleeves and taking charge of caring for their loved ones. **(Not many years ago, fewer than 25% of all caregivers in the United States were men, but that number has nearly doubled,**

to 45%¹). When it comes to Alzheimer's, the men's role becomes especially important, since two thirds of those diagnosed with the disease are women.

ALZHEIMER'S IS THE 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES.

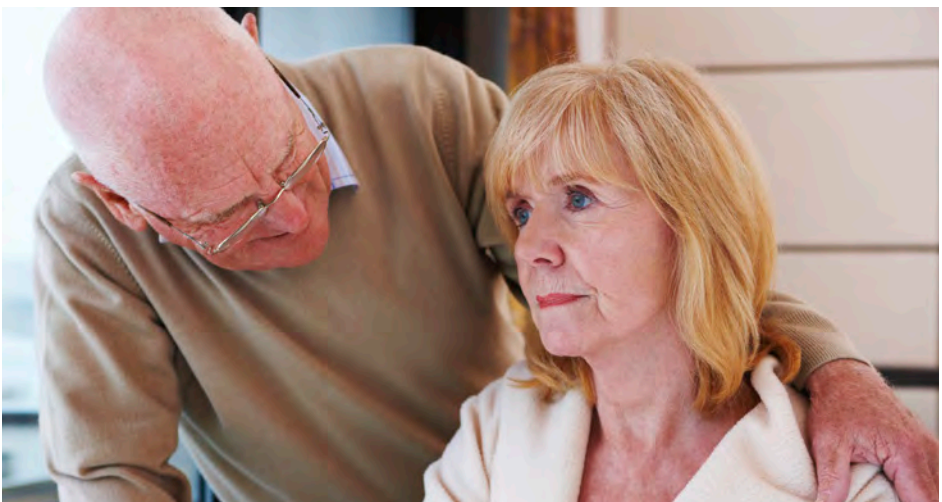
MEN REPRESENT APPROXIMATELY 45% OF ALL CAREGIVERS IN THE UNITED STATES.

AN ESTIMATED 1 IN 9 AMERICANS AGES 65 AND OVER HAVE ALZHEIMER'S.

Today, more than five 5 million Americans have Alzheimer's disease; by 2050, that number is expected to grow to 16 million.

Despite these astounding statistics—and men's increasing involvement as caregivers—there are very few resources or programs that focus on supporting men in what for many will be a completely unfamiliar role.

Men's Health Network has developed this toolkit specifically for men, because as men, we may handle caregiving situations differently than a women. We hope you'll find this resource helpful in the months and years ahead.



1. Pew Research Center's Internet & American Life Project—Pew Research Center's Internet & American Life Project, August 9–September 13, 2010 Survey. N=3001 adults for the full sample. N=860 caregivers. N=2141 noncaregivers. Margin of error is +/- 3.2 percentage points when comparing the two groups. Retrieved from www.pewinternet.org/files/old-media/Files/Reports/2012/PIP_Family_Caregivers_Online.pdf



WE'RE MEN. WE DO THINGS DIFFERENTLY.

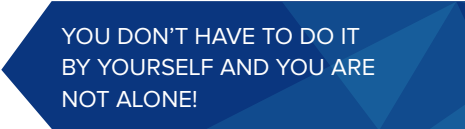
WE'RE MEN. WE DO THINGS DIFFERENTLY.

Let's face it. Men and women are different. We think differently, we behave differently, and our approach to caregiving may also be different.

EXACTLY HOW ARE WE DIFFERENT?

- **Processing News.** Many men take a “block and tackle” approach to bad news. We identify a problem and immediately begin thinking about how to solve it.
- **Handling Stress.** Men often feel that we can cope with stress by staying focused on the job at hand, finishing it, and moving on to the next one.
- **Asking for Help.** Unfortunately, there's some truth in the old stereotype: It's often very hard to ask for help or to accept help when it's offered. Some guys prefer to go it alone.
- **Housework.** If the women in your life have handled basic household tasks like cooking, cleaning, or shopping for groceries, you may be a little nervous about having to take on so many new responsibilities.
- **Talking About Feelings.** Another stereotype with a grain of truth: Some men find it difficult to talk about their feelings—especially when a loved one is ill. They know they have to be strong for their loved one and they feel that talking about their own emotions is a sign of weakness. It's not.
- **Taking Care of Yourself.** There's not a lot of room in the traditional provider-protector role for men to take care of their own needs. So, all too often, we simply ignore them. Don't do that.

All of these male ways of dealing with what life throws at us can be very useful in the right circumstances. But caring for someone with Alzheimer's will be a challenge unlike anything you've ever faced. You may be confused, angry, or afraid of being unprepared. You may be worried about how the disease will affect the dynamics in your family. You will want to provide the best care and make your loved one feel as comfortable as possible. But you might also be anxious about how you're going pay your bills and still have time for cooking, cleaning, doing laundry, and shopping, not to mention bathing, dressing, feeding your loved one, and providing emotional support.



YOU DON'T HAVE TO DO IT
BY YOURSELF AND YOU ARE
NOT ALONE!

Some days will be more demanding and overwhelming than others. As your friend or loved one's behavior changes from day to day and the symptoms get worse, you need to understand two very important things: First, resources and support are available—that's what this book is all about. Second, **you don't have to do this by yourself; you are not alone!** So when (not *if*) you're feeling overwhelmed, admit it to yourself and allow friends, family, or other caregivers to support *you*. **You can't take care of someone else if you can't take care of yourself.**



ALZHEIMER'S DISEASE: WHAT IS IT?

ALZHEIMER'S DISEASE: WHAT IS IT?

Ok, so you've learned that your wife, sister, brother, mother, father, friend, partner, or other loved one has Alzheimer's. At this point, you probably have a lot of questions: What, exactly, is Alzheimer's? What caused your loved one to get it? What changes should you expect in the years to come? You'll find the answers to these and many more questions as you go through this toolkit.

DEFINITION OF ALZHEIMER'S²

- Alzheimer's is a type of *dementia*, a term that's used to describe brain disorders where gradual decline in memory or other thinking skills interferes with daily life.
- The disease starts forming in the brain 5–10 years before symptoms appear.
- Abnormal clumps (*amyloid plaques*) and tangled fibers (*tau tangles*) start spreading in the brain.
- The connections between nerve cells (neurons) stop working.
- The brain tissue shrinks over time.

ALZHEIMER'S IS NOT A
NORMAL PART OF AGING.

Although genetics and age play a large role in causing Alzheimer's, it is not a normal part of aging.¹

THE SEVEN STAGES AND SYMPTOMS

Some experts classify Alzheimer's into three broad stages: mild, moderate, and severe. Others, however, prefer the 7-stage model developed by Barry Reisberg, M.D., Clinical Director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center. Each stage lasts for a varying amount of time and is marked by different symptoms. Behaviors that are common across most of the seven stages include depression, anger, wandering, anxiety, and sleeplessness.



1. Pew Research Center's Internet & American Life Project—Pew Research Center's Internet & American Life Project, August 9–September 13, 2010 Survey. N=3001 adults for the full sample. N=860 caregivers. N=2141 noncaregivers. Margin of error is +/- 3.2 percentage points when comparing the two groups. Retrieved from www.pewinternet.org/files/old-media/Files/Reports/2012/PIP_Family_Caregivers_Online.pdf

2. National Institute of Health, National Institute on Aging, Alzheimer's Disease Education and Referral Center. (2011). Alzheimer's Disease Fact Sheet (NIH Publication No. 11-6423). Silver Spring, MD. Retrieved from www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet

SIGNS AND SYMPTOMS OF ALZHEIMER'S³

Stage 1: Normal	No difficulties with memory, judgment, communication, or conducting daily activities. People remember their name, where they live, and what time of day it is.	
Stage 2: Normal Aged Forgetfulness	Your loved one may have some “senior moments”—occasional difficulties remembering things. Friends and family aren’t usually aware of these cognitive problems.	
Stage 3: Mild Cognitive Impairment	Small changes in memory, behavior, communication, personality, or mood. For many, symptoms never get any worse. But for most, symptoms become more severe within two to four years.	<ul style="list-style-type: none"> • Trouble remembering names (people and things) • Problems organizing/planning events • Taking longer than usual to finish tasks • Repeating questions and stories • Difficulty remembering something recently read • Problems functioning at work • Misplacing important items
Stage 4: Mild Alzheimer’s	Symptoms become more obvious now. Treatments are available that may make the disease advance more slowly. May last about two years.	<ul style="list-style-type: none"> • Difficulty remembering recent events/personal details • Difficulty managing finances and paying bills • Withdrawing from social interaction • Depression and moodiness • Confusion about where commonly used household items typically go • Lack of emotional responsiveness
Stage 5: Moderate Alzheimer’s	Memory worsens and everyday activities become difficult. Your loved one needs 24/7 monitoring and cannot live alone. She or he should definitely not be cooking anymore and will need help with everyday tasks (cleaning, dressing, feeding, bathing, and so on). May last about 1 ½ years.	<ul style="list-style-type: none"> • Severe memory loss; remembering some things but not others • Difficulty remembering the date/season/country • Wandering around (may get lost) • Difficulty bathing or cleaning oneself • Wearing the same clothes everyday • Sleeping more than usual

3. National Alliance for Caregiving, MetLife Mature Market Institute. (2013). Alzheimer’s Disease: Caregiving Challenges—Retrieved from www.metlife.com/assets/caommi/publications/Guides/mmi-alzheimers-challenge.pdf

SIGNS AND SYMPTOMS OF ALZHEIMER'S³

<p>Stage 6: Moderately Severe Alzheimer's</p>	<p>Can't recognize people or do basic, everyday activities. Family, friends, and loved ones typically find this stage to be the most painful.</p> <p>May last about 2 ½ years.</p>	<ul style="list-style-type: none"> • Continued severe memory loss • Inability to identify friends/family • Confusing one person for another • Fidgeting/pacing • Behaving in a paranoid or suspicious way • Inability to dress one's self, or dresses inappropriately • Inability to bathe one's self or adjust water temperature • Inability to answer questions about themselves • Wandering • Restlessness, agitation, and frustration when the sun goes down into evening (called sundowning) • Inability to use the toilet; may have accidents and require adult diapers • Fear of being alone • Following people around the house • Threatening/violent verbal outbursts • Stuttering and/or inability to speak clearly • Sees, hears, feels, tastes, and believes things are there even if they're not
<p>Stage 7: Severe Alzheimer's</p>	<p>This is the final, most severe stage. Your loved one can't move, can't communicate, and depends on a caretaker for everything. She or he has little muscle control and spends all day in bed. Body functions slowly shut down.</p>	<ul style="list-style-type: none"> • Losing the ability to talk • Decrease in vocabulary—forgetting words • Inability to walk, smile, sit, swallow, and hold head up • Mouth sucking reflex • Inability to move joints, or it could be too painful to move • Gets sick easily. May develop pneumonia or ulcerated infections

3. National Alliance for Caregiving, MetLife Mature Market Institute. (2013). Alzheimer's Disease: Caregiving Challenges— Retrieved from www.metlife.com/assets/caommi/publications/Guides/mmi-alzheimers-challenge.pdf



TREATMENT OPTIONS

There is currently no cure for Alzheimer's disease, but scientists are hard at work trying to discover one. In the meantime, there are many treatment options that may slow down the disease's progress. Some don't require any medication or drugs. Others do. Your loved one's healthcare provider will most likely start with non-drug approaches.

NON-DRUG TREATMENTS

Managing your loved one's behavior and/or finding ways to provide comfort and a sense of security can be very effective. You'll find more information on managing behaviors in the **Caregiving Tips & Understanding Behaviors: Tips on Everyday Things** section.

MEDICATIONS

The Food and Drug Administration (FDA) has approved treatments that may improve your loved one's quality of life. These treatments help maintain memory, learning, awareness, information processing, thinking, and speaking skills. They may also control some of the common behavioral symptoms, such as depression, agitation, hallucinations, and delusions.

It's important to understand that these drug treatments **do not stop** the changes that are caused by Alzheimer's, or prevent brain cells from dying. But they may temporarily slow the symptoms,⁴ which, in turn, may help your loved one perform everyday life functions for a longer period of time.

DRUG TREATMENT MAY
TEMPORARILY SLOW THE
SYMPTOMS OF ALZHEIMER'S.



4. National Institute of Health, National Institute on Aging, Alzheimer's Disease Education and Referral Center. (2011). Alzheimer's Disease Fact Sheet (NIH Publication No. 11-6423). Silver Spring, MD. Retrieved from www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet

ALZHEIMER'S DRUGS FALL INTO TWO BROAD CATEGORIES:⁵

- 1. Cholinesterase inhibitors**, which help prevent the breakdown of a brain chemical (acetylcholine) that is important for memory and thinking. These drugs are donepezil, galantamine, and rivastigmine.
- 2. N-methyl-D-aspartate (NMDA) receptor antagonists**, which block the activity of a different brain chemical (glutamate) by binding to NMDA receptors on brain cells. When the body overproduces glutamate, brain cells may die. If it doesn't produce enough glutamate, cognitive problems can develop. Memantine is an NMDA receptor.

Drug	Stage
galantamine	mild to moderate
memantine	moderate to severe
memantine + donepezil	moderate to severe
donepezil	all stages
rivastigmine	all stages

These drugs vary in their method of administration. Some are taken orally (through the mouth), others transdermally (through the skin). The drugs are available in various forms, including tablets, oral disintegrating tablets, oral solutions, capsules (regular and extended release), and patches.

Everyone's Alzheimer's is a little different, so be sure to consult with your loved one's healthcare provider to come up with a treatment plan that's best for her or his individual circumstances. During visits with the provider, make sure you understand the medication that's being prescribed, the dosage, safety precautions and possible side effects, and whether any other medicines your loved one may be taking might interact with the Alzheimer's medication. This is extremely important. If you aren't 100% clear on these details, keep asking questions until you are.

Remember, these drugs won't cure Alzheimer's. They're only able to *temporarily* keep existing symptoms from getting worse and may be able to delay the onset of new ones. The two drug classes discussed above are designed to treat the specific symptoms of Alzheimer's. There are also several other medications that can be used to treat some of the behavior problems that may develop. These include antidepressants, anticonvulsants, sleep aids, anti-anxiety drugs, and antipsychotics.

NEW THERAPIES

Researchers are hard at work developing new treatments. Ask your healthcare provider if new treatments are available.

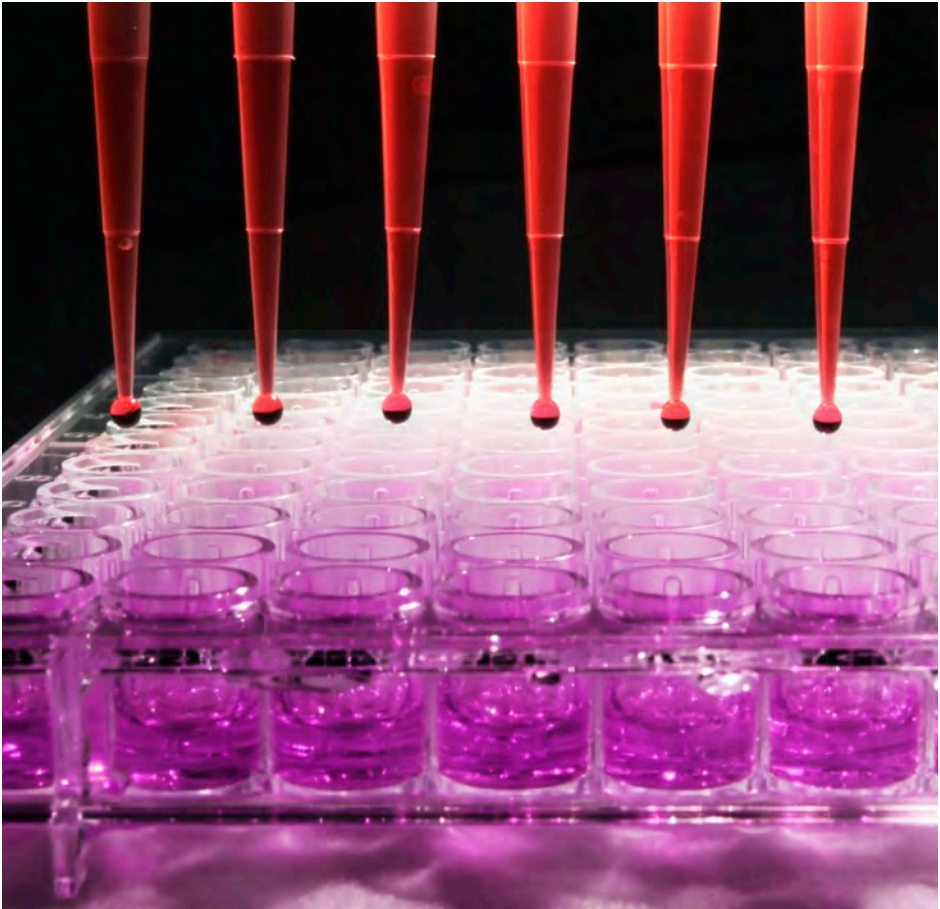
5. National Institute of Health, National Institute on Aging, Alzheimer's Disease Education and Referral Center. (2008). Alzheimer's Disease Medications Fact Sheet (NIH Publication No. 08-3431). Silver Spring, MD. Retrieved from www.nia.nih.gov/sites/default/files/ad_meds_fact_sheet-2014_update-final_2-12-14.pdf

PARTICIPATING IN CLINICAL RESEARCH

Clinical trials and clinical studies test potential treatments with volunteer participants. They help researchers understand what's happening in the brain and may result in the development of newer, safer, and more-effective drugs to prevent or treat Alzheimer's. Talk with your doctor about the advantages and disadvantages of participating in a clinical trial and to learn which one may be right for your loved one. Participating in clinical research may improve the quality and length of your loved one's life, and it may help other patients and caregivers as well.

For more information on clinical trials, visit the resources below.

- **National Institute on Aging:**
www.nia.nih.gov/alzheimers
- **National Institutes of Health:**
www.clinicaltrials.gov
- **Alzheimer's Association:**
www.alz.org/trialmatch
- **Alzheimer's Foundation of America:**
www.alzfdn.org/ClinicalTrials/findatrial.html
- **The Center For Information & Study on Clinical Research Participation (CISCRP):**
www.searchclinicaltrials.org or 1-888-CISCRP3
- **ResearchMatch:**
www.ResearchMatch.org





CAREGIVING TIPS

Creating a Plan

As we've discussed, caring for someone with Alzheimer's isn't going to be easy. One thing that can make life a lot more enjoyable for you and your loved one is to put together a plan of action. And the sooner you get started, the better.

If your loved one is in the early stages of Alzheimer's, he or she may be able to participate in the planning. For example, your loved one may still be independent and care for herself. However, you both know that she'll eventually need 24-hour care. It's important to start thinking about—and arranging for—this care long before you actually need it.

KNOW YOUR STRENGTHS: YOU DON'T HAVE TO BE AN EXPERT ON EVERYTHING.

The decision to become a caregiver is very commendable. But it's easy to fall into the trap of trying to do too much. As men, we often feel that we need to know everything and do everything well. That can make us reluctant to share the caregiving with anyone else. But here's one of the most important pieces of information we can give you: **It's ok to not be an expert.** Know your strengths and focus on them. For everything else, think about bringing in people who have the expertise you don't. This isn't to say that you can't learn new skills—of course you can. But there's no reason to spend 10 hours trying to figure something out when there's an expert out there who could solve the problem in 10 minutes.

YOU'LL HAVE TO MAKE
HARD CHOICES AND SET
REALISTIC EXPECTATIONS.

This is especially true as the disease progresses. Eventually, you, your family, and even outside caregivers will reach a point when you'll no longer be able to respond to your loved one's symptoms and behaviors or medical needs. When this happens, understand that relocating your loved one to a facility specializing in caring for those with Alzheimer's or other related diseases, doesn't mean that you've failed. **You'll have done the best job you could with the resources that were available to you. No one could possibly ask for more.**



LEGAL AND FINANCIAL PLANNING⁶

Once you've made your overall plan for how to care for your loved one, you'll need to start thinking about the many behind-the-scenes legal and financial issues that are sure to come up. Start discussing these issues with your family and your loved one's medical team now. The decisions you make could have a major impact on the type of care he or she receives from today forward. The following documents are essential:

- **Durable Power of Attorney (for finances and healthcare).** This document gives you or anyone else your loved one designates the power to make legal, financial, and healthcare decisions if your loved one is no longer able to do so.
- **Advance Directives, including:**
 - a. **Living will.** This document lays out your loved one's wishes for end-of-life health care.
 - b. **Do-not-resuscitate (DNR) form.** This document tells your loved one's healthcare team that they should not perform CPR (cardiopulmonary resuscitation) in an attempt to revive your loved one if he or she stops breathing or his or her heart stops beating.
- **Will.** This document sets out how your loved one would like her property and assets to be distributed after her death.
- **Living Trust.** This document gives someone appointed by your loved one the power to distribute your loved one's property and money upon her death.

KEEPING YOUR HOME SAFE

If you and your loved one are still living in your home, do a thorough walkthrough to identify any and all potential safety risks, to determine what you'll have to do to make your home safer and more comfortable.

- Keep your home bright and well-lit.
- Lock all doors and windows to prevent your loved one from wandering outside.
- Remove locks on bathroom doors, closets, or any other place where your loved one could possibly get locked in.
- Safely lock up toxic cleaning supplies, matches, knives, lighters, gardening chemicals, and so on.
- Label all medications clearly and keep them locked in a drawer.
- Remove any items that could cause your loved one to trip or fall or that might be dangerous in some other way (for example, unpadded or loose rugs and carpets, loose wires, and dangling window shade cords).
- Know where your loved one is in the house at all times.
- If your loved one is still cooking, it's up to you to make sure the oven, microwave and stove are turned off when she's done.
- Lock up ladders and consider installing safety guards around stairs and swimming pools.
- If you have weapons in the house, make sure they are secured in a locked case.

DAY-TO-DAY LIVING⁷

Sometimes the things we take for granted—the easy stuff we do every day without even thinking about it—are the hardest to plan for. Remember to **be patient**, **use humor** when possible, and **don't take it personally** if your loved one becomes angry, suspicious, or frustrated, or says or does something that hurts your feelings. That sort of behavior is almost never deliberate.

6. National Institute of Health, NIH Senior Health. (2012). Legal and Financial Issues. Alzheimer's Caregiving. Retrieved from www.nihseniorhealth.gov/alzheimerscare/legalandfinancial/01.html

7. National Institute of Health, National Institute on Aging. (2010). Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease (NIH Publication No 01-4013). Gaithersburg, MD. Retrieved from www.nia.nih.gov/sites/default/files/alzheimers_caregiver_guide.pdf

COMMUNICATING

As Alzheimer's progresses, you may find it difficult to understand what your loved one is trying to tell you. Here are some tips that will help:

- Keep communication short, simple, and clear.
- Always use your loved one's name.
- Use short sentences and simple words.
- Speak slowly and calmly.
- Make eye contact.
- Offer the words if he or she can't find the right ones.
- Give him or her plenty of time to respond to your questions. Repeat yourself if needed.
- Minimize background noise when you're trying to talk to him or her.
- Speak in a positive way.
- Lower your pitch (speak in a deeper voice) if he or she has hearing loss.
- Use old photos, videos, books, or other items to help him or her recognize faces and names.
- Don't move furniture, except as needed for safety. Keep surroundings familiar.

KEEP COMMUNICATION
SHORT, SIMPLE, AND CLEAR.

When Talking With Your Loved One...

Never *argue*, instead *agree*.

Never *command* or *demand*, instead *ask* or *show*.

Never say "*I told you so*," instead *repeat*.

Never *lecture*, instead *reassure*.

Never *reason*, instead *divert*.

Never say "*remember?*" Instead *reminisce*.

Never *shame*, instead *distract*.

Never say "*you can't*." Instead say "*do what you can*."

Never *force*, instead *reinforce*.

Gwyther, Lisa P., Ballard, Edna (2002). *Working With Family Caregivers of People with Memory Disorders: A North Carolina Information & Assistance Toolkit*. Chapel Hill, NC. Duke University, Center for the Study of Aging and Human Development. Retrieved from www.dukefamilysupport.org.

BATHING

Bathing can be an awkward and embarrassing task for both you and your loved one at first—especially if you're caring for your mother, sister, aunt, or a female friend. Here's how to make this necessary task a little less uncomfortable.

- Prepare everything you'll need for the bath ahead of time.
- Use a non-skid bath mat and foam cover for the faucet to prevent falling injuries. Also make sure your bathing area is equipped with a hand-held shower head and a bench.
- Try to make bathing part of a regular routine; schedule it at a time when your loved one is the most calm and agreeable.
- Understand that bath time can be scary for your loved one and could make him or her feel uneasy.
- Hold a bath towel over the body while you gently clean your loved one.

- Speak to your loved one before and during the bath process, letting him or her know what you're doing every step of the way.
- Be sensitive to the temperature of the water and the room.
- Don't leave your loved one alone in the bath or shower, even for a few minutes.

DRESSING

Helping your loved one get dressed probably won't be as stressful for either of you as bathing. But there still can be feelings of embarrassment, discomfort, and frustration. Here's how to keep those feelings to a minimum:

- Offer a limited number of choices and don't feel that everything has to match perfectly.
- Choose clothing that is easy to get on and off (Velcro instead of shoe laces, snaps instead of buttons, and so on).

EATING

Chances are, you're going to be doing a lot more meal preparation than you used to, so keep the following in mind:

- Cook familiar foods.
- Include a variety of fruits, vegetables, and other nutritious foods.
- Avoid sugary and processed foods as much as possible. Also limit packaged, boxed, or canned foods and simple carbohydrates (such as candy, soda, white bread, and white pasta).
- Serve plenty of liquid with each meal.
- Keep healthy snacks around.
- Establish a daily mealtime routine and keep the atmosphere quiet and calm.
- Be patient and try not to rush your meals.
- Serve small portions of food throughout the day.
- Be aware of the risk of choking due to problems with swallowing.
- You may consider cutting food into bite-size portions before serving a meal.



GIVING MEDICATION

When giving medication to your loved one—whether it’s for Alzheimer’s or some other health condition—you’ll want to be very careful to ensure that he or she takes the right drugs at the right time and in the right dosage. To help you do that:

- Create a medication routine and put it in your calendar. You may also want to schedule reminder alarms on your phone.
- Use a pill box organizer.
- When you’re not actually giving the medication, make sure all drugs are safely locked away to prevent accidental overdoses.
- Don’t force it. If your loved one refuses, stop and try again later. If this happens frequently, let his or her healthcare provider know and ask for advice on what to do.

ACTIVITIES AND EXERCISING

Exercise is very important and, if prescribed by your loved one’s healthcare provider, it should be a part of your daily routine. Focus on simple activities and offer reassurance and praise before, during, and after exercise sessions. In addition:

- Keep your expectations realistic.
- Watch out for signs of frustration or overwork.
- Break each activity down into small steps or take short, slow walks together.
- Build on existing skills.
- Be careful to avoid trips and falls.

SLEEPING

Your loved one may become irritated and restless after dinnertime, so it’s important to allow him or her to wind down slowly. To the extent possible, help your loved one get 7–8 hours of sleep every night (that should be relatively easy, as Alzheimer’s patients tend to sleep more than other adults the same age).

- Keep lights dim.
- Eliminate loud noises.
- Keep the same bedtime every night.
- Use night-lights in the bedroom, hall, and bathroom.

USING THE TOILET/INCONTINENCE

Your loved one may not be able to find the bathroom, use the bathroom, or position himself or herself on the toilet. He or she may even have accidents or urinate or defecate in inappropriate places like trash cans. To limit these problems, try to:

- Label bathrooms with signs in large, easy-to-read letters so they’re easy to find.
- Monitor your loved one for signs he or she needs to use the toilet, such as pacing back and forth, seeming agitated, or fidgeting with clothing.
- Take your loved one to the bathroom around the same time every day and every three hours or so during the day. Don’t wait to be asked.
- Stay calm if your loved one has an accident. Try to understand what the problem was so you can keep it from happening again.
- Limit fluids in the evening, especially right before bed, to minimize nighttime accidents.
- Whenever you go out, be sure your loved one wears easy-to-remove clothing. And bring along a change of clothes. You might consider having adult diapers with you, just in case.

WANDERING

Keeping your loved one from wandering is one of the more difficult caregiving challenges. Alzheimer's patients who wander risk getting lost or injured. Here's what to do:

- Let your neighbors know that your loved one has a tendency to wander.
- Keep the house doors locked and install deadbolt locks too high on the doors for your loved one to reach.
- Install a system that chimes when doors or windows are opened.
- Enroll your loved one in a monitoring program that can tell you where your loved one is if she or he has wandered off. Monitoring programs are explained later in this publication.
- Make sure your loved one carries identification and wears an I.D. bracelet. You may also label all clothes with your phone number in case he or she wanders and gets lost.
- Put **STOP** or **DO NOT ENTER** signs on doors that lead to the outdoors, stairs, or other areas that might be dangerous.

HALLUCINATIONS AND DELUSIONS

Hallucinations are the perception of sights, sounds, smells, tastes, or feelings that aren't truly there. Delusions are false beliefs that a person thinks are real. Here are some tips for dealing with these difficult symptoms:

- Comfort and distract your loved one.
- Make sure she's safe and can't use anything to hurt herself or anyone else.
- Go on a walk.
- Don't argue. Instead, respond to feelings in a positive way.



ENROLL YOUR LOVED ONE IN A MONITORING PROGRAM

Thanks to some truly amazing pieces of technology, there are a number of potentially life-saving location and surveillance devices available that can help you keep track of your loved one in the event that she wanders out of the house and gets lost. There are real-time GPS (global positioning system) tracking devices that let you track your loved one on your smart phone or computer, alarm systems, web-based in-home video

MAKE SURE THEY HAVE IDENTIFICATION WITH THEM AT ALL TIMES.

monitoring services, and emergency response programs. There are also lower-tech items such as ID bracelets and necklaces that make it easy for police and emergency response teams to quickly identify your loved one. Here are just a few of your options:

MediAlert® and Alzheimer's Association Safe Return

This is a 24-hour nationwide emergency response service. For less than \$100, you enroll in the program and purchase a bracelet or pendant device engraved with your loved one's personal information. If he or she wanders off, you'll call the emergency response number (1-800-625-3780) and law enforcement and other agencies will begin a search. Anyone who finds your loved one will be able to call the emergency response number.

The Alzheimer's Association's **Comfort Zone** and **Comfort Zone Check-In** services are for families who wish to monitor their loved ones using web-based location services. You can put a small tracking device in your loved one's purse or pocket or join a program that will track your loved one's cell phone. For more information on the above services, visit:

www.alz.org/care/dementia-medic-alert-safe-return.asp

Project Lifesaver

The primary mission of Project Lifesaver is to save lives and reduce potential injury for adults and children who wander due to Alzheimer's, autism, Down syndrome, dementia, and other cognitive conditions or disorders. People enrolled in the program wear a small transmitter around the ankle or wrist. If your loved one goes missing, you notify Project Lifesaver and they'll dispatch emergency personnel to track the signal. For more information on the Project Lifesaver program, please visit:

www.projectlifesaver.org

How to Initiate a "Silver Alert"

If you haven't enrolled in any of the above programs and your loved one wanders, you need to know how to alert authorities and what to expect once the process starts.

Every state has its own Silver Alert program, but they all have a common goal of helping to locate people whose disappearance could pose a threat to their health and safety. As with Amber Alerts for missing or kidnapped children, Silver Alerts notify law enforcement and the public (through broadcast media and highway signs) of a missing senior citizen. To find the name of, and eligibility requirements for, the Silver Alert program in your state, visit: www.alzfdn.org/EducationandCare/silver_alert.html



DON'T FORGET TO TAKE CARE OF YOURSELF

DON'T FORGET TO TAKE CARE OF YOURSELF

Caring for a loved one with Alzheimer's is a noble and selfless task. But let's be honest: it can also be both physically and mentally exhausting. The constant pressure and responsibility can leave you feeling disheartened, frustrated, stressed, and just plain burned out. So as much as you want to be there for your loved one and provide the best possible care, you can't take care of someone else if you can't take care of yourself.

Over time, stress can cause high blood pressure, depression, a weakened immune system, and other health problems that could prevent you from caring for your loved one. Without a doubt, the best things you can do for yourself are to **eat healthy, nutritious foods, exercise, and get 7–8 hours of sleep every night**. You'll still need breaks, but doing those three things will help you keep up the energy to provide your loved one with the best care possible.

TAKE ACTION!

Besides taking good physical care of yourself, you can avoid caregiver burnout by educating yourself, sharing your experiences, and getting support (which involves finding out about the resources and help that are available to you).

1. Get Educated

This toolkit provides valuable information on Alzheimer's and tips for the male caregiver. But there's always more to learn. Fortunately, many answers are just a mouse-click away. So if you have any questions, you'll probably find answers on the Internet. But be very careful. It's just as easy to find inaccurate and even dangerous information online as it is to find accurate and helpful information. So before taking action based on something you found online, check it out with your loved one's healthcare provider.

GET EDUCATED, SHARE EXPERIENCES, GET SUPPORT, AND TAKE BREAKS

2. Sharing Your Experiences and Creating a Network

Caregiving can be a lonely job. Joining a support group isn't just about talking about your feelings and emotions—we understand that that may not be right for you. But at least consider the possibility. Research shows that joining a support group may actually improve your life in a number of ways.

Being in a support group can reduce your stress by exposing you to other people's practical tips and the lessons they've learned. Whether you participate or not, it's very reassuring to know that there are a lot of other men out there—men just like you—who are going through or have gone through the same challenges. Hearing their stories may make you feel less alone.

There are a growing number of in-person caregiver support groups. Some are co-ed, but some are for **men only**. If you're interested in in-person groups, your loved one's healthcare provider may have a list of some in your area. If meeting face-to-face isn't for you, you'll find a variety of web-based, online groups and forums where men can talk anonymously to other caregivers and get—and give—pointers on how to handle specific challenging situations.

Other sources of support include family, friends, in-home nursing—and residential care facilities, and day care centers.

3. Know What Help is Available: Take a Class

You're already pressed for time, so the prospect of taking a class on caregiving might sound crazy. But learning new skills and finding new (and more efficient) ways of doing what you're already doing can make you feel a lot more confident. Trainings may include finding better ways to interact with your loved one, enhancing mealtimes, encouraging independence, understanding Alzheimer's behaviors, or getting a handle on the legal and financial planning processes.

4. Give Yourself a Break

Admitting to yourself that you could use a break—and then either taking one or asking for help—in no way means you're giving up or that you're too weak to handle things. A less-stressed “you” is a better-equipped caregiver. Here are a few suggestions:

- Use respite care (also called “short break” care) while you take a break, hold a job, or find a way to relax. Respite care comes in many forms: a professional caretaker who helps with day-to-day duties for a short while, or placing your loved one in an adult day care center each day, or a placing him or her in a very short term residential facility. The Alzheimer's Association can explain respite care options, www.alz.org or 1-800-272-3900.
- Ask friends or family to relieve you so you can step out of the house to run errands or take a nap.
- Go for a walk, meet up with a friend, watch a game, see a movie, play your favorite sport, work on your car, prune your roses, or do anything that you enjoy.

GIVE YOURSELF A BREAK!

You'll find many excellent resources that offer Alzheimer's education, in-person and online support groups, caregiving training classes and workshops, health fairs, respite services, and more, in the **Caregiver Resources and Tools** section of this toolkit.



10 Signs of Caregiver Stress

Irritability	Anger
Sleeplessness	Exhaustion
Depression	Denial
Anxiety	Can't concentrate
Social withdrawal	Health problems

ARE YOU STRESSED OUT?

Because we're so conditioned to put everyone else's needs before our own, men often don't realize how much stress we're under. Here's a quick quiz that we're betting you'll find eye opening. Have you thought or said any of these sentences below lately?

1. I just want to be left alone.
2. I'm too tired for this!
3. I'm afraid to go to sleep because he may wander outside and hurt himself.
4. I forgot to go to an appointment today because I was so busy.
5. I don't remember the last time I felt good.
6. I don't care about anything anymore.
7. If she asks me that question one more time, I'll scream!
8. I don't want to spend time with my friends anymore.
9. I know he'll get better with time.
10. What do I do when she needs more care that I'm able to provide?

If you answered "Yes" to more than one of these, chances are, you're experiencing symptoms of stress. Take the hint and start focusing on yourself for a while.⁸



8. Alzheimer's Association. (2012). *Take Care of Yourself 10 Ways to Be a Healthier Caregiver* [Brochure]. N.p.: Author. Retrieved from www.alz.org/national/documents/brochure_caregiverstress.pdf



YOU AND THE HEALTHCARE PROVIDER

When taking care of your loved one, it's important to learn everything you can about Alzheimer's and to ask your loved one's healthcare provider as many questions as it takes for you feel confident and prepared to deal with anything that might come up. Don't be shy about this. If you don't ask the questions, no one else—especially not your loved one—will.


PREPARE FOR THE VISIT TO THE HEALTHCARE PROVIDER

To make the most out of your loved one's visit to the healthcare provider, try to communicate areas of concern or questions to the healthcare provider **before** the appointment. Make a list or keep a diary/journal to take with you to the healthcare provider and use them to talk about specific experiences or problems. You can do this on the phone, by email, or by making a separate office visit while someone else cares for your loved one. This will help the healthcare provider prepare for the visit and give you the information and support you need.



WHAT TO ASK

As we've mentioned, it's important that you understand as much as possible about your loved one's diagnosis and what you'll have to do to be an effective caregiver. Below you'll find some of the questions you may want to ask. Because every situation is different, your questions won't always be the same as everyone else's. Asking—and getting answers to—all your questions can be completely overwhelming. So if possible, don't feel that you have to do it in one visit. If you need two or three, that's okay. Try whatever will work best for the time you have and your caregiving situation.



PREPARE FOR THE
VISIT TO THE DOCTOR
BEFORE THE VISIT.

Here are some questions you may want to ask:

- What's the actual diagnosis?
- Is it certain that this is Alzheimer's?
- What tests are needed and why?
- What medications are available?
- What's the best treatment option and why?
- What non-drug therapies are available for us?
- What are the possible side effects of medications and how common are they?
- What signs and symptoms should I expect in the upcoming stages?
- How will this diagnosis affect my loved one's overall health?
- Are there any foods that should be avoided during the recommended treatment?
- Will we need to see other doctors or specialists?
- How can I best prepare for each visit to the doctor's office?
- Do you have any tools that I can use to monitor my loved one's daily activities and symptoms?
- Who should we talk to about Alzheimer's care?
- What do I do in an emergency?
- Are there any life-threatening situations I should be aware of where I need to act quickly?
- Are there any clinical trials my loved one can be a part of?
- Are there any caregiver training classes or support groups near where I live?
- Do you have any brochures or other educational materials I can take home?
- Do you recommend any specific websites for support resources?
- If I can't reach you in an emergency, whom can I contact?
- How do I talk to my kids and other family members about this?
- How can I include family into the caregiving process?

For more questions to ask your loved one's doctor, please visit: www.alzfdn.org

HIPAA PRIVACY RULES

Make sure you talk to your healthcare provider about the federal Health Insurance Portability and Accountability Act (HIPAA). HIPAA ensures that a patient's health information is confidential, protected, and cannot be communicated by the healthcare provider to anyone (spouse or caregiver included) without a Durable Power of Attorney for Health Care in place.





FREQUENTLY ASKED QUESTIONS

FREQUENTLY ASKED QUESTIONS

Below are answers to some of the most common questions male caregivers ask.

1. Is there a cure for Alzheimer's disease?

No. However, there may be in the not-too-distant future. Researchers are conducting many clinical trials and working hard to develop new treatments and possibly even vaccines for Alzheimer's. Participation in clinical trials has the potential to help others with Alzheimer's by determining whether a drug is effective. Please talk with your healthcare provider about the best clinical trial option for your loved one.

2. I've noticed that my mother is getting more confused. How can I help her?

There are many things you can do to help:

- Be supportive and patient.
- Help her keep up her normal, everyday routine with minimal changes.
- Avoid situations where she has to make decisions.
- At the start of the day, remind her of the date, time, place, etc., and go over the names of those she'll be interacting.
- Put large labels on drawers and shelves to indicate what should go there.
- Simplify your words if she's having trouble understanding you.
- Have her take her medication (or give it to her) at the same time every day.
- Prepare nutritious food and encourage her to exercise if she's able.



3. I'm thinking about taking a trip with my father, who has Alzheimer's disease. Is there anything special I should do?

It's important to plan ahead. Start by considering which stage of the disease your father is in. Read about the behaviors that are common to that stage, and think about how those behaviors might change when your father is out of his familiar, everyday environment. Here are a few other ideas to consider:

- Plan simple activities (reading magazines, playing cards, listening to music, etc.).
- Plan for regular stops at rest areas.
- Don't try to calm down your father while you're driving. Stop at the first available place if he gets restless.
- When driving, be sure the car doors are locked and seat belts are properly buckled.
- Avoid crowded places if you think it will agitate your father.
- Make sure he's carrying or wearing identification, including his address and your cell phone number.
- Let the airlines know that you're flying with someone who's memory-impaired.

4. I'm having trouble getting my loved one to eat. What can I do?

- Give small, frequent meals and nutritious, high-protein and high-calorie snacks.
- Consider serving finger foods that are easy to handle and chew.
- Prepare your loved one's favorite foods.
- Prepare food options of varying colors, temperatures, and flavors. Add colorful garnishes like bright bell peppers or parsley.
- Don't force your loved one to eat. Gently encourage her or him, and calmly ask why she or he doesn't want to eat.
- Be aware of possible swallowing problems in some patients. Preparing food in small bite sizes is best.
- If the problem persists, talk to your loved one's healthcare provider. Sometimes, poor appetite can be caused by depression or another condition.
- Make mealtime pleasurable by playing background music or using colorful placemats.
- Make sure your loved one doesn't eat alone.

5. Do the symptoms of Alzheimer's disease vary by the time of day?

They often do. In the early evening, when the sun starts to set, your loved one may start to exhibit "sundowning" behavior: becoming anxious, agitated, disoriented, confused, or having difficulty sleeping. Hallucinations may occur or worsen. Sundowning may last for a few hours or all night. Sundowning is sometimes caused by being exhausted after a long day. Other times, it's a side effect of medication. Here are some tips to help your love one cope with these behaviors.

- Control what your loved one eats and limit caffeine consumption and sweets to the morning time.
- Help your loved one relax by offering herbal tea (decaf) or warm milk.
- Keep the house well lit and close the curtains so your loved one can't see the sun going down.
- Have your loved one do the most difficult tasks early in the day.
- Encourage walking or other physical activity. This may help your loved one sleep better at night.
- If needed, distract your loved one with favorite things such as music or a TV show.






HEALTHY AGING AND BRAIN HEALTH

HEALTHY AGING AND BRAIN HEALTH

Our brain is responsible for “cognition,” a term that includes memory, decision making, processing speed, wisdom, and learning. As we age, these functions may change and even decline. It’s a process called “cognitive aging.”⁹ But while cognitive aging is normal, it doesn’t necessarily develop into Alzheimer’s or dementia.

WHAT IS HEALTHY AGING?

One way to reduce the impact that cognitive aging can have—as well as to possibly slow the advance of Alzheimer’s symptoms—is to make “healthy aging” a regular part of your life. Healthy aging is really nothing more than maintaining an active, healthy lifestyle. Besides being good for your brain, healthy aging will help improve your overall health. Here’s what you and your loved one need to do:¹⁰



BE ACTIVE, MEDITATE,
GET ENOUGH SLEEP,
DO PUZZLES

- Visit the doctor regularly.
- Be active. Exercise at least 30 minutes every day.
- Eat healthy foods (fruits, vegetables, whole grains, and those rich in Vitamin C, E, and folic acid).
- Get enough sleep.
- Limit alcohol consumption.
- Find ways to reduce stress (meditation, yoga, etc.).
- Take part in mentally stimulating activities (puzzles, games, cards, books, etc.).
- Have a social network of family and friends. Besides keeping you emotionally healthy, this may prevent mental health issues, such as depression.
- Manage medications that can have cognitive health effects.

GET SCREENED¹¹

If you suspect that someone you love might be suffering from Alzheimer’s, you may want to explore some of the available, non-invasive screening tests. The Alzheimer’s Foundation of America (contact info is in the Caregiver Resources and Tools section) has a National Memory Screening Program that uses a number of those tests. Keep in mind that these tests are not intended to (nor are they able to) diagnose Alzheimer’s or any other illness. If the results of the screen are troubling, schedule an appointment with your loved one’s healthcare provider right away. He or she may be able to administer additional tests and make a diagnosis in the office.

9. Institute of Medicine of the National Academies. Cognitive Aging. An Action Guide for Individuals and Families. (2015). Washington, DC. Retrieved from www.iom.edu/~/media/Files/Report%20Files/2015/Cognitive_aging/Action%20Guide%20for%20Individuals%20and%20Families_V3.pdf

10. Alzheimer’s Foundation of America. (2015). Brain Health, Lifestyle Choices. Retrieved from www.alzfdn.org/BrainHealth/successfulaging.html

11. Alzheimer’s Foundation of America. (2014). National Memory Screening Program. Retrieved from www.nationalmemoryscreening.org/index.php



CAREGIVER RESOURCES AND TOOLS

In this toolkit we've covered the basics of caring for someone with Alzheimer's. The organizations listed below will give you access to even more valuable information about support groups, research, publications, trainings, community events, education programs, respite care, state programs, social workers, and other services. The list below isn't comprehensive, but it'll get you pointed in the right direction.

ALZHEIMER'S SUPPORT

47% OF MALE CAREGIVERS
REPORT SEEKING ADDITIONAL
CAREGIVING RESOURCES.

■ **Alzheimers.gov**

www.alzheimers.gov

Managed by the U.S. Department of Health and Human Services,

Alzheimers.gov provides free information about Alzheimer's disease and related dementias from agencies and organizations with expertise in these areas.

1-877-696-6775

■ **Alzheimer's Association**

www.alz.org

A national non-profit that offers education and local care options. The hotline provides support to people with memory loss, healthcare professionals, caregivers, and the public.

1-800-272-3900 (helpline 24/7)

1-866-403-3073 (TDD)

■ **Alzheimer's Foundation of America (AFA)**

www.alzfdn.org

A national non-profit that unites more than 2,300 member organizations from coast-to-coast that are dedicated to meeting the educational, social, emotional, and practical needs of individuals with Alzheimer's disease and related illnesses, and their caregivers and families. The AFA's services include educational workshops and conferences, health education materials, dementia training, and a toll-free help line.

1-866-232-8484

■ **National Institute on Aging—Alzheimer's Disease Education and Referral (ADER) Center**

www.nia.nih.gov/alzheimers

ADER provides health education and publications for diagnosis, treatment, patient care, caregivers, long-term care, training, and Alzheimer's research. The staff answers the toll-free number and refers you to local or national resources based upon your need. The website also offers free publications in English and Spanish, a database of Alzheimer's clinical trials, an Alzheimer's disease library, and much more.

1-800-438-4380

CAREGIVING AND CAREGIVER SUPPORT

■ **Aging Life Care Association (ALCA)**

www.aginglifecare.org

Specialists offer professional services and advice on caregiving for older adults. The organization also has a searchable database that can help you locate a local geriatric care manager near you.

1-520-881-8008

■ **American Association of Retired Persons (AARP)**

www.aarp.org/home-family/caregiving

A non-profit, membership-based organization for people 50 and older. They have a Caregiving Resource Center.

1-888-687-2277

■ **BrightFocus Foundation**

www.brightfocus.org/alzheimers

A good source of fact sheets, newsletters, and other publications on Alzheimer's Disease.

1-855-345-6237

■ **Caregiver Action Network (CAN)**

www.caregiveraction.org

Serves a broad group of caregivers who provide education, peer support, resources, and care for loved ones of various age groups with different diseases or illnesses.

1-202-454-3970

■ **Falls Prevention Center of Excellence**

www.stopfalls.org

Offers information on preventing falls and making your home safe.

■ **Family Caregiver Alliance (FCA)**

www.caregiver.org

Provides information, support, and a forum for caregivers who care for those with various brain health conditions, such as Alzheimer's, stroke, traumatic brain injuries, and other cognitive disorders.

1-800-445-8106

■ **National Adult Day Services Association (NADSA)**

www.nadsa.org

Offers adult day services in local communities.

1-877-745-1440

■ **National Alliance for Caregiving**

www.caregiving.org

A non-profit coalition of organizations that are focused on advancing family caregiving efforts through research, policy analysis, program development, and increasing awareness of issues associated with family caregiving.

1-301-718-8444

■ **National Center for Assisted Living (NCAL)**

www.ncal.org

Represents assisted living communities and offers information on assisted living.

1-202-842-4444

SUPPORT GROUPS AND DISCUSSION FORUMS

- **Alzheimer’s Association**

www.alz.org/apps/care

Choose “Get Support” and then search for support groups by zip code or by state.

- **Alzheimers.net**

www.alzheimers.net

Offers a forum and blog for Alzheimer’s caregivers only.

1-888-704-7779

- **Caring.com**

www.caring.com/alzheimers-support

Online resource that provides comprehensive information and support groups for caregivers providing care to those suffering from various health conditions.

- **Family Caregiver Alliance (FCA)**

www.caregiver.org/support-groups

Provides a forum for the voice of the caregiver through various ways, including online and in-person support groups.

- **Homewatch Caregivers**

Homewatch Caregivers are independently-owned franchised businesses that offer caregiver services to the public.

www.homewatchcaregivers.com

- **Male Caregiver Community**

www.malecaregivercommunity.com

This is an online, male-only support group forum.

SOCIAL WORKER SUPPORT PROGRAMS

Social workers can be an excellent source of information, resources, and support. However, not all of them specialize in caring for patients with Alzheimer’s. The best way to find local licensed social workers with the right training and expertise is to contact the local chapter of a national organization, such as the ones listed above. If your loved one is a military veteran, you may also want to check with the U.S. Department of Veterans Affairs. On each organization’s website, you’ll find information about its social worker support programs and other caregiver programs.

- **Alzheimer’s Foundation of America**

Look for the “Connect With Social Workers” section.

www.alzfdn.org

1-866-232-8484

HOSPICE CARE AND HOUSING

- **Assisted Living Federation of America (ALFA)**

www.alfa.org

- **LeadingAge**

www.leadingage.org

- **National Association for Home Care and Hospice**

www.nahc.org

1-202-547-7424

- **National Hospice and Palliative Care Organization (NHPCO)**

www.nhpco.org

1-703-837-1500

1-800-658-8898 (helpline)

RESPIRE CARE

- **Agency on Aging, Eldercare Locator**

www.eldercare.gov

A federally funded service that helps caregivers find community caregiving resources such as respite care, nursing homes, local social workers, or adult day care.
1-800-677-1116

- **The ARCH National Respite Network and Resource Center**

www.archrespite.org

This national organization's missions are to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums. They offer a free guide, *The ABCs of Respite: A Consumer Guide for Family Caregivers*, and their National Respite Locator helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs and also provide technical assistance to respite providers.

1-919-490-5577

- **National Adult Day Services Association, Inc.**

www.nadsa.org

1-877-745-1440

info@nadsa.org

- **National Respite Locator**

www.archrespite.org/respitelocator

MONITORING SERVICES

- **Alzheimer's Association Comfort Zone**

A web-based location management service. Families can remotely monitor a person with Alzheimer's by receiving automated alerts throughout the day and night when a person has traveled beyond a present zone.

- **MedicAlert and Alzheimer's Association Safe Return**

A 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia who wander or have a medical emergency. It provides 24 hour nationwide assistance, no matter when or where the person is reported missing.



BENEFITS AND FINANCIAL RESOURCES

- **BenefitsCheckUp®**

www.benefitscheckup.org

A free service that matches seniors with the right local, state, and federal assistance programs.

- **Department of Veterans Affairs—Veterans Benefits Administration**

www.va.gov

Provides information about the benefits available to veterans, those who are active duty service members/military, and their caregivers and family members.

1-800-827-1000

- **Disability.gov**

www.disability.gov

Provides resources and information about available government programs on benefits, civil rights, community life, education, employment, housing, health, technology and transportation.

1-800-FED-INFO (1-800-333-4636)

- **Medicaid**

www.medicaid.gov

Offers health-insurance and other benefits given by the state for those with low incomes and certain disabilities (including assisted living).

- **Medicare**

www.medicare.gov

Provides federal health insurance for people aged 65 and older.

1-800-633-4227

- **Social Security Administration**

www.ssa.gov

Offers information on Social Security, or retirement, disability, and survivors' benefits, online and through over 1,400 offices around the United States.

1-800-772-1213

- **State Health Insurance Assistance Program (SHIP)**

www.shiptacenter.org

A national program that helps those with Medicare, and their families, find counseling services and other assistance in their state.

LEGAL RESOURCES

- **American Bar Association (ABA)—Commission on Law and Aging**

www.abanet.org/aging

Helps find legal assistance and lawyers in your area, and provides information on aging-specific legal issues.

1-800-285-2221

- **National Academy of Elder Law Attorneys (NAELA)**

www.naela.org

Offers a database of attorneys who specialize in legal issues for seniors and those with special needs.

1-703-942-5711

- **Financial Planning Association (FPA)**

www.fpanet.org

The principal professional organization for Certified Financial Planner™ professionals, educators, and financial services providers. The website offers resources designed to help individuals understand the importance of financial planning.

FOR GENERAL CAREGIVING READING...

■ National Alliance for Caregiving

www.caregiving.org

Offers a free and very helpful booklet, *Care for the Family Caregiver*, that focuses on the voice of the caregiver and provides family caregiver stories. Also offers helpful tips and training resources, and advice on how to take care of one's health while providing care.

TAKING CARE OF YOURSELF...

MHN offers various free resources to men and their families.

■ Your Head: An Owner's Manual

We've all heard the expression, "It's all in your head." Your mental health affects everything: your mood, your physical health, your behavior, how you sleep, your appetite, your relationships, your social life, your performance at work or school, and more.

This book was written to provide men of all ages, and those who love them, with important and realistic perspectives about mental health along with commonsense, and practical approaches that can make a difference in their lives. A variety of experts (psychiatrists, physicians, psychologists, public health experts, counselors, and social workers) have come together to provide insights and reflections on the emotional needs of men while explaining how men can ask for help with dignity, when needed. This book highlights common signs and symptoms of trouble to help men and those who love them recognize the need for intervention and suggestions for dealing with everyday problems when intervention may not be needed. *Your Head: An Owner's Manual* is found at www.YourHead.org

■ Blueprint for Men's Health

This book discusses the main health issues that men face today. Each chapter focuses on a single condition or group of related conditions, and explains risk factors and symptoms, gives practical, easy-to-implement prevention strategies, and offers advice on working with a medical provider.

To make the information in this book as helpful as possible, every chapter was carefully checked by a professional with expertise in that particular field. While no book should be used as a substitute for professional advice about medical or lifestyle issues, *Blueprint for Men's Health* is a resource and a guide that may help you protect your health and get the most out of life. The *Blueprint for Men's Health* series of publications is found at www.BlueprintForMensHealth.com

■ Men's Health Online Resource Center

MHN provides a wide and comprehensive array of resources about men's health for men, women, and families. You can visit the Men's Health Online Resource Center at www.MensHealthResourceCenter.com

■ Men's Health Library

This searchable library contains hundreds of helpful studies, reports, brochures, and flyers.

www.MensHealthLibrary.com







APPENDIX: COMPARISON OF DEMENTIA TYPES

SUPPLEMENT: COMPARISON OF DEMENTIA TYPES

TYPE OF DEMENTIA	SYMPTOMS	WHAT HAPPENS IN THE BRAIN?
Alzheimer’s Disease Most common type (60–80% of all cases)	First symptom: memory loss. Mood changes, confusion about the day or year, losing things, trouble remembering names; problems with speaking, eating, and/or walking.	Plaques (made of proteins called <i>beta-amyloid</i>) and tangles (twisted fibers of a protein called <i>tau</i>) in the brain cause brain cells and nerve cells to die.
Vascular Dementia Second most common type (10% of all cases)	First symptoms: memory loss, poor judgment, and trouble planning, making decisions, and organizing. Confusion, trouble concentrating, vision problems, and possible hallucinations.	A stroke, advanced heart disease, or aging causes blood vessels in the brain to narrow or get blocked. The brain does not get enough oxygen and the nerve cells in the brain break down.
Dementia with Lewy bodies (DLB)	Similar to Alzheimer’s and vascular dementia (confusion, memory loss, poor judgment). Also, trouble paying attention, daytime sleepiness, staring, stiff muscles, shaking or body tremors, sleep disturbances, hallucinations, or dreams involving walking, talking, or kicking.	Proteins, called Lewy bodies, collect in the cortex of the brain where they interfere with or stop chemical messages from getting sent back and forth within the brain. This gets in the way or stops chemical messages from getting sent back and forth in the brain.
Traumatic Brain Injury (TBI)	Mild to severe unconsciousness, concussions, and memory loss.	Caused by an object penetrating the skull or a violent bump, jolt, or blow to the head/body. Can result in temporary impaired brain function, physical damage (like bruising or bleeding) to the brain, or death.
Mixed Dementia (Combination of two or more types of dementia)	Symptoms vary depending on the part of the brain involved.	Depends on which two or more types of dementia are present. Most commonly Alzheimer’s with vascular dementia, Alzheimer’s with DLB, Alzheimer’s with vascular dementia, and dementia with Lewy bodies.
Parkinson’s Disease Dementia (50–80% of those with Parkinson’s Disease get it)	Similar to dementia with Lewy bodies. Tremors, slow movement, stiff muscles, soft or slurred speech, or problems with posture, walking, or balance.	Nerve cells in the brain break down and die. Causes are unknown but research points to genetics and environmental factors (pesticides, herbicides, etc.).
Fronto-temporal lobar Dementia	Changes in personality, behavior, and difficulty with putting words together to speak, lack of inhibitions in personal and social situations, shakiness, and problems with balance. Symptoms generally develop at a younger age (about age 60). People with this type of dementia have a shorter lifespan than those with Alzheimer’s.	Cells in the front and side areas of the brain (that control planning, judgment, emotions, speech, and types of movement) are damaged.

TYPE OF DEMENTIA	SYMPTOMS	WHAT HAPPENS IN THE BRAIN?
Huntingdon's Disease	Memory loss, problems thinking, reasoning, planning and organizing, concentrating, poor judgment, abnormal involuntary movements, irritability, depression, and other mood changes.	A defective gene on chromosome 4 causes a specific brain protein to be abnormal, worsening symptoms.
Creutzfeldt-Jakob disease (CJD) (very rare, sometimes called "mad cow" disease)	Severe problems with memory and concentration, confusion, poor judgment, depression, mood swings, sleep problems, or twitching. Thinking and social skills may seem unaffected. Rapidly fatal disorder.	Specific proteins in the brain (called prions) cause normal proteins in the brain to turn into abnormal shapes. About 5% to 10% of CJD cases are hereditary.
Normal Pressure Hydrocephalus	Trouble walking, thinking, concentrating; personality and behavior changes, and inability to control urination.	Fluid build-up causes increasing pressure in the brain. Those with a medical history of brain hemorrhage/ meningitis are at higher risk.
Wernicke-Korsakoff Syndrome	Problems with remembering short-term and long-term memories, learning new information, and may make up information they can't remember. Thinking and social skills are not affected.	Causes may include a severe shortage of vitamin B-1 or long-term, heavy alcohol drinking.

Sources:

The Alzheimer's Association: <http://www.alz.org/dementia/types-of-dementia.asp>

National Institute on Aging: <http://www.nia.nih.gov/alzheimers/topics/other-dementias>

<http://www.nia.nih.gov/alzheimers/publication/dementias/other-conditions-cause-dementia#cyj>



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