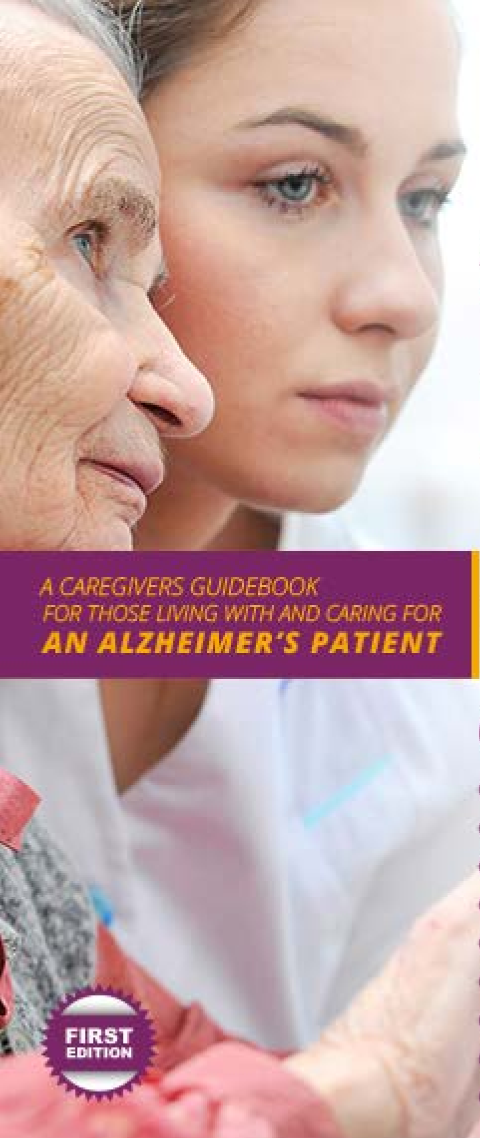

Alzheimer's
Research Association

A National Non-Profit Dedicated to Alzheimer's Caregivers

A Caregivers Guide To Alzheimer's Patients

A CAREGIVERS GUIDEBOOK
FOR THOSE LIVING WITH AND CARING FOR
AN ALZHEIMER'S PATIENT

Chapters

1. *Understanding Alzheimer's and Its different Stages*
2. *Home and Personal Safety*
3. *Home Safety by Behavior*
4. *Coping Strategies by Symptom*
5. *Providing Everyday care for People*
6. *Adapting Activities for People*
7. *Caring For the Caregiver*
8. *Quick Tips for Caregivers by Category*
9. *Caregiver Tool Kit*

FIRST
EDITION

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A CAREGIVERS GUIDEBOOK
FOR THOSE LIVING WITH AND CARING FOR
AN ALZHEIMER'S PATIENT

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Research Association

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Research Association

Learn more about
How we can
to help you
Today

A Caregiver's Guide for Alzheimer's Patients

Welcome to the Alzheimer's Research Association (ARA)

Dedicated to helping the Caregivers of Dementia and Alzheimer's patients

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Caregiver Tool Kit

Provided by A Place for Mom

aPlace for Mom

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Introduction

This Guidebook serves as a quick, essential resource for the most common challenges you are likely to face as a Caregiver.

It can be a complement to the more in-depth exploration of symptoms, behavioral problems, and approaches found in our online class, **"For Caregiver of Alzheimer's Patients, A Comprehensive Course."**

This Guidebook is organized as an immediate, easy-to-use reference when problems arise. Click on any topic in the table of contents for the section of the book that applies.

Our Story

After my own experiences caring for a family member with Alzheimer's – the challenges and successes, the quests for information, the lessons learned the hard way, the grief, love and loss – I was committed to sharing the best information I could find on caring for a person with Alzheimer's disease through the filter of all I have learned.

Much of the information in this guide draws from the excellent publications of the National Institutes for Health Institute on Aging. Their resources fill a critical need. My goal is to frame that information and advice from the perspective of a person who has been in your shoes.

Why this guide?

This guide is for people who care for family members or others with Alzheimer's disease at home. Sometimes, taking care of the person with AD makes you feel good because you are providing love and comfort. Other times, it can be overwhelming. Each day brings new challenges.

It is important that, as a caregiver, you know about the different stages of Alzheimer's disease. Over time, the AD patient will slowly decline in his or her abilities to do different things, and you will need to be able to recognize when your patient passes from one stage to another. Things will change in the way you deliver your care and how well the patient responds to you.

Your role, and your relationship

Merriam-Webster defines “caregiver” as “a person who gives help and protection to someone (such as a child, an old person, or someone who is sick).”

While "help and protection" may be a good starting point, we all know that being a caregiver is a little more complicated than that. When caring for a person with Alzheimer's disease, you may not even realize how much you have taken on because changes can happen slowly over a long period of time.

First, know that you are not alone, and there is a lot of help out there for you. There are many organizations ready, willing, and able to give you as much help as they can. Use it.

Utilize every source of assistance you can in your caregiving routine; you will need it. We have included a list of organizations in the back of this book that you can contact for assistance, and we have included a chapter on some technology advancements that will also help you.

We have prepared this book to serve as a resource you can return to again and again as your situation changes. We hope you will see us as an ally in the days ahead.

Chapter 1

Understanding Alzheimer's and its different Stages

Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills and, eventually, even the ability to carry out the simplest tasks of daily living

In most people with Alzheimer's, symptoms first appear after age sixty. Alzheimer's disease is the most common cause of dementia among older people. Although treatment can help manage symptoms in some people, currently, there is no cure for this devastating disease.

Discovery: Plaques and tangles

In 1906, Dr. Alois Alzheimer examined the brain tissue of a woman who had died of an unusual mental illness. The patient's symptoms had included memory loss, language problems, and unpredictable behavior.

Overview: A Disease's progression

While we still don’t know how the Alzheimer’s disease process begins, it seems likely that damage to the brain starts a decade or more before symptoms become evident.

During the preclinical stage of Alzheimer’s disease, people are free of symptoms, but toxic changes are taking place in the brain. Abnormal deposits of proteins form amyloid plaques and tangles throughout the brain, and once-healthy neurons begin to work less efficiently. Over time, these neurons lose the ability to function and communicate with each other, and eventually, they die.

Before long, the damage spreads to a nearby structure in the brain called the hippocampus, which is essential in forming memories. As more neurons die, affected brain regions begin to shrink. By the final stage of Alzheimer’s, damage is widespread, and brain tissue has shrunk significantly.

Alzheimer’s disease typically develops slowly and gradually gets worse over the course of several years. It eventually affects most areas of the brain, including those important in memory, thinking, judgment, language, problem-solving abilities, personality, and movement. People with Alzheimer’s **typically live an average of eight years after diagnosis**, but many may survive anywhere from three to twenty years.

Chapter 1

> It seems likely that damage to the brain starts a decade or more before symptoms become evident.

The Seven Stages of Alzheimer’s Disease

For years, Alzheimer’s Disease has been recognized as having three stages:

1. Mild – Sometimes known as the early or early onset stage
2. Moderate – Middle stage
3. Severe – Late stage

Recently, leaders in the field — including the Alzheimer’s Association, whom we recognize as the authority on everything Alzheimer's — have recognized seven stages of the disease, based on a system developed by Barry Reisberg, MD, Department of Psychiatry, at the New York University Langone Medical Center.

The "Seven Stages" framework outlines key symptoms that characterize the stages, ranging from unimpaired function to very severe cognitive decline.

Not everyone living with Alzheimer’s or a related dementia will experience the same symptoms or decline at the same rate. While that uncertainty is difficult on both patients and caregivers, our hope is that the stages described here can help guide your expectations.

Within this framework, we have noted which stages correspond to the widely used concepts of mild, moderate, moderately severe, and severe Alzheimer's disease. We have also noted which stages fall within the more general divisions of early-stage, middle-stage, and late-stage categories.

Stage 1

Symptoms: No impairment (normal function)

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Stage 2

Symptoms: Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease).

Individuals may feel as if they have memory lapses such as:

- Forgetting familiar words or names
- Misplacing keys, eyeglasses, or other everyday objects

These problems are not evident during a medical examination or apparent to friends, family, or coworkers.

Stage 3

Symptoms: Mild cognitive decline Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms.

Friends, family, or coworkers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include the following:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings noticeable to family, friends, or coworkers
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

Stage 4

Symptoms: Moderate cognitive decline (Mild or early-stage Alzheimer's)

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic; for example, to count backward from 75 by 7s
- Decreased capacity to perform complex tasks, such as planning dinner for guests, paying bills, and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

Stage 5

Symptoms: Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated;
- become confused about where they are or about the date, day of the week, or season;
- have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s;

- need help choosing proper clothing for the season or the occasion;
- usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children; and
- usually require no assistance with eating or using the toilet.

Stage 6

Symptoms: Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease)

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with their daily routine and activities. At this stage, individuals may:

- lose most awareness of recent experiences and events as well as of their surroundings;
- recollect their personal history imperfectly, although they generally recall their own name;
- occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces;
- need help getting dressed properly; without supervision, they may make such errors as putting pajamas over daytime clothes

or shoes on the wrong feet;

- experience disruption of their normal sleep/waking cycle;
- need help with handling details of toileting (flushing toilet, wiping, and disposing of tissue properly);
- have increasing episodes of urinary or fecal incontinence;
- experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding; and tissue shredding; and
- tend to wander and become lost.

Stage 7

Symptoms: Very severe cognitive decline (Severe or late-stage Alzheimer's disease)

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered.

Individuals need help with eating and toileting and there is general incontinence of urine.

Individuals lose the ability to walk without assistance and then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

Just as people have their own distinct personalities, not everyone will react the same to the varied symptoms of Alzheimer's disease.

Even if you think you know about these different stages, how they work, and what they do to your patient, every AD patient is different; not everyone responds the same to all the different stages.

What these cases share in common is a need for resources, information and caregiver support that will increase as the disease progresses.

Chapter One Review:

☑ In most people with Alzheimer's, symptoms first appear after age sixty.

☑ Just as every individual has a different personality, every person diagnosed with Alzheimer's will respond differently to different stages of the disease.

☑ It is important that caregivers have a framework for understanding the stages of Alzheimer's, to guide expectations and to plan for the time when they will need more support.

Chapter 2
Home and Personal Safety

This chapter is for those who provide in-home care for people with Alzheimer's disease or related disorders. Our goal is to improve home safety by identifying potential dangers in the home and offering possible solutions to help prevent accidents.

A safe home can be a less stressful home for the person with Alzheimer's disease, the caregiver, and family members.

As a caregiver, you face the ongoing challenge of adapting to each change in the person's behavior and functioning. The following general principles may be helpful.

Think prevention.

It is difficult to predict what a person with Alzheimer's might do. The fact that an incident has not yet occurred does not rule it out in the future. Assessing home using the checklist that follows will help you take some control of potentially hazardous situations.

Adapt the environment.

It is more effective to change the environment than to change most behaviors. While some Alzheimer's behaviors can be managed with medications prescribed by a doctor, many cannot. You can make changes to the environment to decrease the hazards and minimize stressors.

A safer environment means more freedom.

By minimizing danger, you can maximize independence. A safe environment can be a less restrictive environment in which the person with Alzheimer's disease can enjoy increased security and mobility.

Is It Safe to Leave the Person with Alzheimer's Disease Alone?

This issue needs careful evaluation and is certainly a safety concern. The following points may help you decide. Refer back to this list often as the disease progresses.

Does the person with Alzheimer's:

- Become confused or unpredictable under stress?
- Recognize a dangerous situation, such as a fire?
- Know how to use the telephone in an emergency?
- Stay content within the home?
- Wander and become disoriented?
- Show signs of agitation, depression, or withdrawal when left alone for any period of time?
- Attempt to pursue former interests or hobbies that might

warrant supervision, such as cooking, appliance repair, or woodworking?

You may want to seek input and advice from a health care professional to assist you in these assessments.

Caregiver self-care:

Your home is a personal and precious environment. Some of the changes you make may impact your surroundings positively, and some may affect you in ways that are inconvenient or undesirable. Consider setting aside a special space for yourself, an off-limits area.

Prevention begins with a safety check of every room in your home. Use the following room-by-room checklist to identify potential hazards and record changes you need to make.

You can buy products or gadgets necessary for home safety at stores carrying hardware, electronics, medical supplies, and children's items. Keep in mind that it may not be necessary to make all of the suggested changes.

You don't have to make these changes alone. Consider enlisting the help of a friend, professional, or community service organization such as the Alzheimer's Research Association.

Home Safety Checklist: Throughout the Home

Display emergency numbers and your home address near all telephones.

Set your phone to go to voicemail or an answering system when you cannot answer calls. A person with Alzheimer's disease often may be unable to take messages or could become a victim of telephone exploitation. Turn ringers to low to avoid distraction and confusion.

Store portable and cell phones and their chargers in a safe place so they will not be easily lost.

Install smoke alarms and carbon monoxide detectors in or near the kitchen and all sleeping areas. Check their functioning and batteries frequently.

Avoid the use of flammable and volatile compounds near gas appliances. Do not store these materials in an area where a gas pilot light is used.

Install secure locks on all outside doors and windows.

Hide a spare house key outside in case the person with Alzheimer's locks you out of the house.

Avoid the use of extension cords if possible by placing lamps and appliances close to electrical outlets. Tack extension cords to the baseboards of a room to avoid tripping.

Cover unused electrical outlets with childproof plugs.

Place red tape around floor vents, radiators, and other heating devices to deter the person with Alzheimer's from standing on or touching them when hot.

Check all rooms for adequate lighting.

Place light switches at the top and the bottom of stairs.

Stairways should have at least one handrail that extends beyond the first and last steps. If possible, stairways should be carpeted or have safety grip strips. Install a gate across stairs if balance problems are an issue.

Keep all prescription and over-the-counter medications locked. Each bottle of prescription medicine should be clearly labeled with the person's name, name of the drug, drug strength, dosage frequency, and expiration date. Request child-resistant caps if needed.

Keep all alcohol in a locked cabinet or out of reach of the person with Alzheimer's. Drinking alcohol can increase confusion.

Always monitor smoking if you permit it in the home. Remove matches, lighters, ashtrays, cigarettes, and other means of smoking from view to reduce fire hazards. With reminders out of sight, the person may forget the desire to smoke.

Avoid clutter, which can create confusion and danger. Throw out or recycle newspapers and magazines regularly. Keep all areas where people walk free of furniture.

Keep plastic bags out of reach. A person with Alzheimer's disease may choke or suffocate.

Remove all guns and other weapons from the home or lock them up. Install safety locks on guns or remove ammunition and firing pins.

Lock all power tools and machinery in the garage, workroom, or basement.

Remove all poisonous plants from the home. Check with local nurseries or contact the poison control center (1-800-222-1222) for a list.

Make sure all computer equipment and accessories, including electrical cords, are kept out of the way. If valuable documents or materials are stored on a home computer, protect the files with passwords and back up the files.

Password protect access to the Internet, and restrict the amount of online time without supervision. Consider monitoring computer use by the person with Alzheimer's, and install software that screens for objectionable or offensive material on the Internet.

Keep fish tanks out of reach. The combination of glass, water, electrical pumps, and potentially poisonous aquatic life could be harmful to a curious person with Alzheimer's disease.

Remove scatter rugs and throw rugs.

Use textured strips or nonskid wax on hardwood and tile floors to prevent slipping.

Home Safety Checklist: Outside Approaches to the House

Keep steps sturdy and textured to prevent falls in wet or icy weather.

Mark the edges of steps with bright or reflective tape.

Consider installing a ramp with handrails as an alternative to steps.

Eliminate uneven surfaces or walkways, hoses, and other objects that may cause a person to trip.

Restrict access to a swimming pool by covering it and fencing it with a locked gate. Closely supervise when in use.

In the patio area, remove the fuel source and fire starters from grills when not in use, and supervise their use when the person with Alzheimer's is present.

Place a small bench or table by the entry door to hold parcels while unlocking the door.

Make sure outside lighting is adequate. Sensors that turn on lights automatically as you approach the house may be useful. They also may be used in other parts of the home.

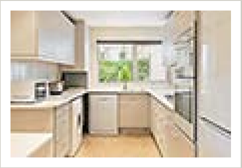
Prune bushes and foliage well away from walkways and doorways.

Consider a NO SOLICITING sign for the front gate or door.

Home Safety Checklist: Room by Room

Kitchen

Install childproof door latches on storage cabinets and drawers designated for breakable or dangerous items. Lock away all household cleaning products, matches, knives, scissors, blades, small appliances, and anything valuable.



If prescription or nonprescription drugs are kept in the kitchen, store them in a locked cabinet.

Remove scatter rugs and foam pads from the floor.

Install safety knobs and an automatic shut-off switch on the stove.

Do not use or store flammable liquids in the kitchen. Lock them in the garage or in an outside storage unit.

Keep a night-light in the kitchen.

Remove or secure the family "junk drawer." A person with Alzheimer’s may eat small items such as matches, hardware, erasers, and plastics.

Remove artificial fruits and vegetables or food-shaped kitchen magnets, which might appear to be edible.

Insert a drain trap in the kitchen sink to catch anything that may otherwise become lost or clog the plumbing.

Consider disconnecting the garbage disposal. People with Alzheimer’s may place objects or their own hands in the disposal.

Bedroom

Anticipate the reasons a person with Alzheimer’s disease might get out of bed, such as hunger, thirst, going to the bathroom, restlessness, and pain. Try to meet these needs by offering food and fluids and scheduling ample toileting.

Use a night-light.

Use a monitoring device (such as those used for infants) to alert you to any sounds that indicate a fall or other need for help. This is also an effective device for bathrooms.

Remove scatter rugs and throw rugs.

Remove portable space heaters. If you use portable fans, be sure that objects cannot be placed in the blades.

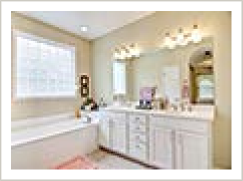
Be cautious when using electric mattress pads, electric blankets, electric sheets, and heating pads, all of which can cause burns and fires. Keep controls out of reach.

If the person with Alzheimer's disease is at risk of falling out of bed, place mats next to the bed, as long as they do not create a greater risk of accident.

Use transfer or mobility aids.

If you are considering using a hospital-type bed with rails and/or wheels, read the Food and Drug Administration's up-to-date safety information at www.fdagov/cdrh/beds

Bathroom



Do not leave a severely impaired person with Alzheimer's alone in the bathroom.

Remove the lock from the bathroom door to prevent the person with Alzheimer's from being locked inside.

Place nonskid adhesive strips, decals, or mats in the tub and shower. If the bathroom is uncarpeted, consider placing these strips next to the tub, toilet, and sink.

Use washable wall-to-wall bathroom carpeting to prevent slipping on wet tile floors.

Use a raised toilet seat with handrails, or install grab bars beside the toilet.

Install grab bars in the tub/shower. A grab bar in contrasting color to the wall is easier to see.

Use a foam rubber faucet cover (often used for small children) in the tub to prevent serious injury if the person with Alzheimer's disease should fall.

Use a plastic shower stool and a handheld shower head to make bathing easier.

In the shower, tub, and sink, use a single faucet that mixes hot and cold water to avoid burns.

Set the water heater at 120 degrees Fahrenheit to avoid scalding tap water.

Insert drain traps in sinks to catch small items that may be lost or flushed down the drain.

Store medications (prescription and nonprescription) in a locked cabinet. Check medication dates and throw away outdated medications.

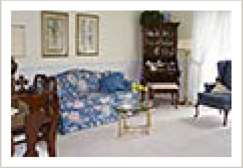
Remove cleaning products from under the sink, or lock them away.

Use a night-light.

Remove small electrical appliances from the bathroom. Cover electrical outlets.

If a man with Alzheimer's disease uses an electric razor, have him use a mirror outside the bathroom to avoid water contact.

Living Room



Clear electrical cords from all areas where people walk.

Remove scatter rugs and throw rugs. Repair or replace torn carpet.

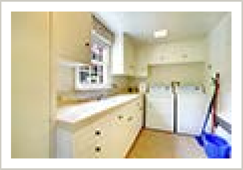
Place decals at eye level on sliding glass doors, picture windows, and furniture with large glass panels to identify the glass pane.

Do not leave the person with Alzheimer's disease alone with an open fire in the fireplace. Consider alternative heating sources.

Keep matches and cigarette lighters out of reach.

Keep the remote controls for the television, DVD player, and stereo system out of sight.

Laundry Room



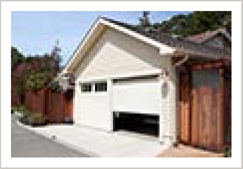
Keep the door to the laundry room locked, if possible.

Lock all laundry products in a cabinet.

Remove large knobs from the washer and dryer if the person with Alzheimer's tampers with machinery.

Close and latch the doors and lids to the washer and dryer to prevent objects from being placed in the machines.

Garage/Shed/Basement



Lock access to all garages, sheds, and basements, if possible.

Inside a garage or shed, keep all potentially dangerous items, such as tools, tackle, machines, and sporting equipment, either locked away in cabinets or in appropriate boxes or cases.

Secure and lock all motor vehicles and keep them out of sight, if possible. Consider covering vehicles, including bicycles that are not frequently used. This may reduce the possibility that the person with Alzheimer's will think about leaving.

Keep all toxic materials, such as paint, fertilizers, gasoline, or cleaning supplies, out of view. Either put them in a high, dry place, or lock them in a cabinet.

If the person with Alzheimer’s is permitted in a garage, shed, or basement, preferably with supervision, make sure the area is well lit and that stairs have a handrail and are safe to walk up and down. Keep walkways clear of debris and clutter, and place overhanging items out of reach.

Chapter Two Review:

☑ Thinking preventatively, adapting the environment, and a safer environment means more freedom are the hallmarks of home and personal safety.

☑ Environmental safety impacts every aspect of the home, inside and out, and extends to each new environment the person with Alzheimer's encounters.

☑ Frequent reassessment of the person's condition, surroundings and changing vulnerabilities is essential to his or her home and personal safety.

Chapter 3

Home Safety by Behavior

Some patients with Alzheimer's disease will experience significant behavior and sensory problems. Those sensory problems can contribute to safety issues as the disease progresses. The following safety recommendations may help reduce risks.

Wandering

- **Remove clutter** and clear pathways from room to room to prevent falls and allow the person with Alzheimer's to move about more freely.
- **Make sure floors provide good traction** for walking or pacing. Use nonskid floor wax or leave floors unpolished. Secure all rug edges and eliminate throw rugs or install nonskid strips. Ensure that the person with Alzheimer's wears only nonskid shoes or sneakers.
- **Place locks high or low on exit doors** so they are out of direct sight. Consider installing double locks that require a key. Keep a key for yourself, and hide one near the door for emergency exit purposes.
- **Use loosely fitting doorknob covers** so that the cover turns instead of the actual knob. Note that locked doors and doorknob covers should be used only when a caregiver is present to prevent entrapment in case of fire or other emergency...

- **Install window safety devices**, found in hardware stores, to limit how far windows can be opened.
- If possible, **secure the yard with fencing and a locked gate**. Use door alarms such as loose bells above the door or devices that ring when the doorknob is touched or the door is opened.
- **Divert attention away from the door** by placing small scenic posters on the door; placing removable gates, curtains, or brightly colored streamers across the door; or wallpapering the door to match adjoining walls.
- Place **STOP, DO NOT ENTER**, or **CLOSED signs on doors** in strategic areas.
- **Keep signs of departure out of sight**, for example shoes, keys, suitcases, coats and hats.
- **Order a medical identification bracelet** inscribed with the words "memory loss" and an emergency phone number. Place the bracelet on the person's dominant hand to limit the possibility of removal, or solder the bracelet closed.
- **Label garments** to aid in identification.
- **Keep an article of the person's worn, unwashed** clothing in a plastic bag in case of an emergency search situation that requires tracking dogs.
- **Notify neighbors** of the person's potential to wander or become lost. Instruct them to contact you or the police immediately if the individual is seen alone and on the move.
- **Give local police, neighbors, and relatives a recent** photo of the person with Alzheimer's, along with the person's name and

- pertinent information, as a precaution should he or she become lost. Keep extra photos on hand.
- Consider making an up-to-date **home video of the person** with Alzheimer's disease to use on social media for identification purposes.
- **Never leave a person with a history of wandering unattended.**

Rummaging/Hiding Things

- **Lock up dangerous or toxic products** including cleaning agents, or place them out of the person's reach.
- **Remove all old or spoiled** food from the refrigerator and cupboards. A person with Alzheimer's may rummage for snacks but may lack the judgment or taste to rule out spoiled foods.
- **Simplify the environment by removing clutter** or valuable items that could be misplaced, lost, or hidden by the person with Alzheimer's disease. These include important papers, checkbooks, charge cards, and jewelry.
- If your yard has a fence with a locked gate, **place the mailbox outside the gate**. People with Alzheimer's often hide, lose, or throw away mail. If this is a serious problem, consider obtaining a post office box.
- **Create a special place where the person can rummage**

freely or sort (for example, a chest of drawers, a bag of selected objects, or a basket of clothing to fold or unfold). Often, safety problems occur when the person with Alzheimer's becomes bored and looks for activity or busywork.

- **Provide the person a safe box**, treasure chest, or cupboard to sort and store special objects.
- **Close access to unused rooms** to limit opportunities for rummaging and hiding things.
- **Search the house periodically to discover hiding places**. Once found, these hiding places can be discreetly and frequently checked.
- **Keep all trash cans covered or out of sight**. The person with Alzheimer's disease may not remember the purpose of the container or may rummage through it.
- **Check trash containers** before emptying them in case something has been hidden there or accidentally thrown away.

Hallucinations, Illusions, and Delusions

Complex changes in the brain can cause some people with Alzheimer's disease to experience visions and sounds that have no basis in reality.

Hallucinations involve hearing, seeing, smelling, or feeling things that are not really there. For example, a person with Alzheimer's may see children playing in the living room when no children are there.

Illusions differ from hallucinations because the person with Alzheimer's is misinterpreting something that actually does exist. Shadows on the wall may look like people, for example.

Delusions are false beliefs that the person thinks are real. For example, some patients think that someone may be stealing from them.

It is important to seek medical evaluation if a person with Alzheimer's has ongoing disturbing hallucinations, illusions, or delusions. An illness or medicine may cause or exacerbate hallucinations or delusions. Often, symptoms can be treated with medication or behavior management techniques.

You may try asking the person with Alzheimer's if he or she can point to a specific area that is producing confusion. The following environmental adaptations may also be helpful:

- **Paint walls a light color** to reflect more light. Use solid colors, which, to an impaired person, are less confusing than a patterned wall. Large, bold prints (for example, florals in wallpaper or drapes) may cause confusing illusions.
- **Make sure there is adequate lighting** and keep extra bulbs handy in a secured place. Dimly lit areas may produce confusing shadows or difficulty with interpreting everyday objects.

- **Reduce glare by using soft light** or frosted bulbs, partially closing blinds or curtains, and maintaining adequate globes or shades on light fixtures.
- **Remove or cover mirrors** if they cause the person with Alzheimer's disease to become confused or frightened.
- **Maintain a consistent environment** to minimize the potential for visual confusion. Keep furniture in the same place.
- **Avoid violent or disturbing television programs**. The person with Alzheimer's may believe a story is real.

> ### When you are faced with aggression
>
> Aggressive behavior from a person with Alzheimer's disease is heartbreaking — and can be very dangerous for both of you. Never confront aggression. Withdraw and make sure you have access to an exit, then get help immediately.

Holidays, Gatherings and Special Occasions

Whether it's a wedding, birthday or important family holiday, large groups of people, combined with a disruption in routine, can cause a person with Alzheimer's disease increased confusion and anxiety.

Remember, too, that you have more responsibilities yourself than in previous years. There are steps you can take to make a situation easier on all involved.

- Consider having a more intimate gathering with only a few people in your home. Invite guests to visit in small groups rather than all at once.
- Prepare the person with Alzheimer’s for large gathering ahead of time. Be sure to have a space available where he or she can rest, be alone, or spend some time with a smaller number of people, if needed.
- Consider simplifying your holidays around the home. For example, replace an elaborate cooked meal with a potluck dinner.
- Choose a few select decorations to celebrate holidays. Make sure holiday decorations do not significantly alter the environment or clutter up hallways or walkways.
- Take particular care with decorations like Christmas trees, lights, or menorahs that can fall or catch fire. Anything flammable should be monitored at all times. Take care that lights or breakable items are fixed firmly and out of the way. Candles, even unlit, pose a particular hazard and temptation.

Impairment of the senses

Alzheimer’s disease can change a person’s ability to interpret what he or she can see, hear, taste, feel, or smell. The person with Alzheimer's should be evaluated periodically by a physician for any such changes that may be correctable with glasses, dentures, hearing aids, or other devices. To try and avoid some of the safety concerns caused by these changes, consider the following steps.

Vision

> ### Seeing differently
>
> People with Alzheimer's may experience changes in vision or lose their ability to understand what they see. Their sense of perception and depth may be altered.

- Create color contrast between floors and walls to help the person see depth. Solid-colored floor coverings are less confusing.
- Mark the edges of steps with brightly colored strips of tape to outline changes in height.
- Use dishes and placemats in contrasting colors for easier identification.
- Place brightly colored signs or simple pictures on doors to important rooms (the bathroom, for example) for easier identification.

- Be aware that a small pet that blends in with the environment, gets underfoot or lies in walkways may be a tripping hazard.

Smell

From personal hygiene to fire safety, a lost sense of smell has a wide impact.

- Install smoke detectors and check them frequently.
- Keep refrigerators clear of spoiled foods.
- Have someone stay on top of proper trash and food disposal since the person with Alzheimer's may not notice strong odors.
- A person with Alzheimer's may not be aware of his or her own body odor, or may use excessive perfume or cologne as sense of smell declines.

Touch

At greater risk

People with Alzheimer's may be at risk of injury if they're no longer able to accurately sense heat, cold, or discomfort.

- Set water heaters at 120 degrees Fahrenheit to avoid scalding tap water. Most hot water heaters are set at 150 degrees, which can cause burns.

- Label or color-code water faucet handles with red for hot and blue for cold.
- Place signs on oven, coffee maker, toaster, crockpot, iron, and other appliances that read **DO NOT TOUCH** or **STOP! VERY HOT**. The person with Alzheimer's should not use appliances without supervision. Unplug appliances when not in use.
- Remove furniture or other objects that have sharp corners, or pad the corners to reduce potential for injury.

Taste

People with Alzheimer's disease may lose taste sensitivity. As their judgment declines, they may place dangerous or inappropriate things in their mouths.

- Keep condiments such as salt, sugar, and spices hidden if you see the person with Alzheimer's using excessive amounts.
- Remove or lock up toiletries like toothpaste, perfume, lotions, shampoos, rubbing alcohol, and soap, which may look and smell like food to the person with Alzheimer's. Consider a childproof latch, if necessary.
- Keep the toll-free poison control number (1-800-222-1222) by the telephone. Keep a bottle of ipecac (vomit-inducing agent) available, but use it only with instructions from poison control or 911.
- Keep pet litter boxes out of reach of the person with

Alzheimer's disease. Do not store pet food in the refrigerator.

- Learn the Heimlich maneuver and first aid in case of choking. Check with your local Red Cross chapter for more information and instruction.
- If possible, keep a spare set of dentures. If the person keeps removing dentures, check for correct fit.

Hearing

Even a person with Alzheimer's disease who retains normal hearing can lose the ability to interpret what they hear accurately. This loss may result in confusion or overstimulation.

- Avoid excessive noise in the home such as having the stereo and the TV on at the same time.
- Be sensitive to the amount of noise outside the home, and close windows or doors if necessary.
- Avoid large gatherings of people if the person with Alzheimer's shows signs of agitation or distress in crowds.
- If the person wears a hearing aid, check the batteries and functioning often.

Chapter 3

Challenge: Addressing the Unsafe Driver

Driving is a complex activity that demands quick reactions, alert senses, and split-second decision making. For a person with Alzheimer's disease, driving becomes increasingly difficult. Memory loss, impaired judgment, disorientation, impaired visual and spatial perception, slow reaction time, certain medications, diminished attention span, and inability to recognize cues like stop signs and traffic lights can make driving particularly hazardous.

People with Alzheimer's who continue to drive are a danger to themselves, their passengers, and the community at large. Unfortunately, people with Alzheimer's often cannot recognize when they should no longer drive. It is extremely important to have the person's driving abilities carefully evaluated.

Explaining to the person with Alzheimer's disease that he or she can no longer drive can be extremely difficult. Loss of driving privileges may represent a tremendous loss of independence, freedom, and identity. It is a significant concern for the person with Alzheimer's and the caregiver. The issue of not driving may produce anger, denial, and grief in the person with Alzheimer's as well as guilt and anxiety in the caregiver. Family and concerned professionals need to be both sensitive and firm. Above all, they should be persistent and consistent.

> ### Enlisting the physician's help
>
> The doctor of a person with Alzheimer's disease can advise the person with Alzheimer's to reduce his or her driving, go for a driving evaluation or test, or stop driving altogether. An increasing number of states have laws requiring physicians to report Alzheimer's and related disorders to the Department of Motor Vehicles, which is then responsible for retesting the at-risk driver.

When an impaired person continues to insist on driving, a number of different approaches may be necessary.

- Work as a team with family, friends, and professionals, and use a single, simple explanation such as: "You have a memory problem, and it is no longer safe to drive," "You cannot drive because you are on medication," or "The doctor has prescribed that you no longer drive."
- Ask the doctor to write on a prescription pad **DO NOT DRIVE**. Request that the doctor write to the Department of Motor Vehicles or Department of Public Safety saying the person

should no longer drive. Show the letter to the person with Alzheimer's disease as evidence.

- Offer to drive, or ask a friend or family member to drive.
- Walk when possible, and make these outings special events.
- Use public transportation or any special transportation provided by community organizations. Ask about senior discounts or transportation coupons. The person with Alzheimer's should not take public transportation unsupervised.
- Park the person's car at a friend's home.
- Hide the car keys.
- Exchange car keys with a set of unusable keys. Some people with Alzheimer's are in the habit of carrying keys.
- Have a mechanic install a "kill switch" or alarm system that disengages the fuel line to prevent the car from starting.

When it's time to stop driving...

Does the person with Alzheimer's

- Get lost while driving in a familiar location?
- Fail to observe traffic signals?
- Drive at an inappropriate speed?
- Become angry, frustrated, or confused while driving?
- Make slow or poor decisions?
- Never leave a person with Alzheimer's alone in a parked car.

Natural Disaster Safety

Natural disasters seldom give warning, and they call upon goo judgment and the ability to follow through with crisis plans. People with Alzheimer's disease are at a serious disadvantage. Their impairments in memory and reasoning severely limit their ability to act appropriately in crises.

- Get to know the neighbors, and identify specific individuals who would be willing to help in a crisis. Formulate a plan of action with them should the person with Alzheimer's be unattended during a crisis.
- Give neighbors a list of emergency phone numbers of caregivers, family members, and primary medical resources.
- Educate neighbors beforehand about the person's specific disabilities, including inability to follow complex instructions, memory loss, impaired judgment, and probable disorientation and confusion. Give examples of some of the simple one-step instructions that the person may be able to follow.
- Realize that the person with Alzheimer's disease cannot be expected to hold any responsibility in a crisis plan and that someone will need to take primary responsibility for supervising the individual.
- Always have at least an extra week's supply of any medical or personal hygiene items critical to the person's welfare, such as medications, incontinence undergarments, hearing aid batteries and an extra pair of eyeglasses.

- Ensure that the person with Alzheimer’s wears an identification bracelet inscribed “memory loss” should he or she become lost or disoriented.

Chapter Three Review:

☑ People with Alzheimer’s disease will vary in range and severity of symptoms.

☑ A thorough review of safety issues by behavior must be conducted at regular intervals and will help you identify risks that are otherwise easily missed.

☑ The sensory implications of Alzheimer's disease bring unique challenges for patients and caregivers.

Chapter 4

Coping Strategies by Symptom

As an illness of the brain, Alzheimer's disease brings different categories of challenges for caregivers that are especially difficult for those closest to the person with Alzheimer's. These include changes in:

- Communication skills
- Personality and behavior
- Intimacy and sexuality

This chapter covers specific coping strategies for each of these areas.

Challenge: Changes in Communication Skills

Communication is hard for people with AD because they have trouble remembering things. They may struggle to find words or forget what they want to say. A better understanding of these challenges, and being able to anticipate them, can help you cope.

Communication problems caused by Alzheimer's disease include:

- Trouble finding the right word when speaking
- Problems understanding what words mean
- Problems paying attention during long conversations
- Loss of train of thought when talking
- Trouble remembering the steps in common activities, such as cooking a meal, paying bills, getting dressed, or doing laundry

- Problems blocking out background noises from the radio, TV, telephone calls, or conversations in the room
- Experiencing frustration if communication isn't working
- Sensitivity to touch and to the tone and loudness of voices

Alzheimer's disease can also cause language confusion. For example, the person might forget or no longer understand English if it was learned as a second language.

How to Cope: Changes in Communication Skills to connect with a person who has Alzheimer's Disease:

- Make eye contact to get his or her attention, and call the person by name.
- Be aware of your tone and how loud your voice is, how you look at the person, and your "body language."
- Encourage a two-way conversation for as long as possible to help build confidence in the person with Alzheimer's disease.
- Use other methods besides speaking to help the person, such as a gentle touch to guide him or her.

Above all, be patient with angry outbursts, and try to take a time-out for yourself as needed.

When Words Fail: Nonverbal ways to engage

A gentle presence, simply being with the person, can go a long way ….

- Show a warm, loving, matter-of-fact manner
- Hold the person's hand while you talk
- Be open to the person's concerns, even if he or she is hard to understand
- Let him or her make some decisions and stay involved

To speak effectively with a person who has Alzheimer's Disease:

- Offer simple, step-by-step instructions
- Repeat instructions and allow more time for a response; try not to interrupt
- Don't talk about the person as if he or she isn't there
- Don't talk to the person using "baby talk" or a "baby voice"

Here are some examples of what you can say:

- "Let's try it this way," instead of pointing out mistakes
- "Please do this," instead of "Don't do that"
- "Thanks for helping," even if the results aren't perfect

You can also:

- Ask questions that require a yes or no answer. For example, you could say, “Are you tired?” instead of “How do you feel?”

- Limit the number of choices. For example, you could say, “Would you like a hamburger or chicken for dinner?” instead of “What would you like for dinner?”
- Use different words if he or she doesn’t understand what you say the first time. For example, if you ask the person whether he or she is hungry and you don’t get a response, you could say, “Dinner is ready now. Let’s eat.”
- Try not to say, “Don’t you remember?” or “I told you.”

Helping the Person Who is Aware of these Changes

As AD diagnosed at earlier and earlier stages, many people are aware of how the disease is affecting their memory. Here are tips on how to help someone who knows that he or she has memory problems:

- Take time to listen. The person may want to talk about the changes he or she is noticing.
- Be as sensitive as you can. Try not to correct the person every time he or she forgets something or says something odd.
- Help the person find words to express thoughts and feelings.
- Be careful not to put words in the person’s mouth or “fill in the blanks” too quickly.

As people lose the ability to talk clearly, they may rely on other ways to communicate their thoughts and feelings. For example, their facial expressions may show sadness, anger, or frustration.

Grasping at their undergarments may tell you they need to use the bathroom.

Helping her Find the Words

Mrs. D cried after forgetting to attend her garden club meeting. She finally said, “I wish they stopped.” Her daughter said, “You wish your friends had stopped by for you?” Mrs. D nodded and repeated some of the words. Then Mrs. D said, “I want to go.” Her daughter said, “You want to go to the garden club meeting?” Again, Mrs. D nodded and repeated the words.

Challenge: Changes in Personality and Behavior

Here are some personality changes common among those with Alzheimer's disease.

- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren’t there
- Wandering away from home
- Pacing a lot of the time

- Showing unusual sexual behavior
- Hitting you or other people
- Misunderstanding what he or she sees or hears

Also, you may notice that the person stops caring about how he or she looks, stops bathing, and wants to wear the same clothes every day.

Other Factors that May Affect How People with Alzheimer's Disease Behave

In addition to changes in the brain, the following aspects may affect how people with AD behave and feel:

- Problems in their surroundings such as being in an unfamiliar space or being exposed to too much background noise, or being confused by the presence of mirrors or unfamiliar signs.
- Depression, confusion, or situational anxiety caused by changes in routine or anticipating such changes.
- Health-related problems caused by:
    - Illness or pain
    - New medications
    - Lack of sleep
    - Infections, constipation, hunger, or thirst
    - Poor eyesight or hearing
    - Alcohol abuse
    - Too much caffeine

How to Cope: Personality and Behavior Changes

Keeping things simple – from how you speak to the person, to maintaining a predictable routine, are key. Other strategies that may help:

- Reassure the person that he or she is safe and you are there to help
- Focus on his or her feelings rather than on words. For example, say, "You seem worried."
- Don't argue or try to reason with the person
- Try not to show your anger or frustration. Step back. Take deep breaths, and count to 10. If it is safe to do so, leave the room for a few minutes.
- Use humor when you can
- Give people who pace a lot a safe place to walk. Provide comfortable, sturdy shoes. Give them light snacks and make sure they have enough to drink.
- Use distractions. Try using music, singing, or dancing to distract the person. One caregiver found that giving her husband chewing gum stopped his cursing.
- Ask the person for help. For instance, say, "Let's set the table" or "I really need help folding the clothes."

Other ideas:

- Talk to the doctor about any serious behavior or emotional problems such as hitting, biting, depression, or hallucinations.

How to Cope: Sleep Problems

Evenings are hard for many people with AD. Some may become restless or irritable around dinnertime. This restlessness is called "sundowning." It may even be hard to get the person to go to bed and stay there.

Here are some tips that may help:

- Help the person get exercise each day, limit naps, and make sure the person gets enough rest at night. Being overly tired can increase late-afternoon and nighttime restlessness.
- Plan activities that use more energy early in the day. For example, try bathing in the morning or having the largest family meal in the middle of the day.
- Set a quiet, peaceful mood in the evening to help the person relax. Keep the lights low, try to reduce the noise levels, and play soothing music if he or she enjoys it.
- Try to have the person go to bed at the same time each night. A bedtime routine, such as reading out loud, also may help.
- Limit caffeine
- Use nightlights in the bedroom, hall, and bathroom

How to Cope: Hallucinations and Delusions

As the disease progresses, the person with AD may have hallucinations. During a hallucination, a person sees, hears, smells, tastes, or feels something that isn't there. Delusions are false beliefs that the person thinks are real. For example, the person may think his or her spouse is in love with someone else.

Here are some things you can do:

- Tell the doctor or AD specialist about the delusions or hallucinations.
- Discuss with the doctor any illnesses the person has and medicines he or she is taking. Sometimes an illness or medicine may cause hallucinations or delusions.
- Try not to argue about what the person with AD sees or hears. Comfort the person if he or she is afraid.
- Distract the person. Sometimes moving to another room or going outside for a walk helps.
- Turn off the TV when violent or upsetting programs are on. Someone with AD may think these events are really going on in the room.
- Make sure the person is safe and can't reach anything that could be used to hurt anyone or him- or herself.

How to Cope: Paranoia

Paranoia is a type of delusion in which a person may believe without a good reason that others are mean, lying, unfair, or "out to get him or her." He or she may become suspicious, fearful, or jealous of people.

In a person with AD, paranoia is often linked to memory loss. It can become worse as memory loss gets worse. For example, the person may become paranoid if he or she forgets any of the following:

- Where he or she put something. The person may believe that someone is taking his or her things.
- That you are the person's caregiver. Someone with AD might not trust you if he or she thinks you are a stranger.
- People to whom he or she has been introduced. The person may believe that strangers will be harmful.
- Directions you just gave. The person may think you are trying to trick him or her.

Paranoia may be the person's way of expressing loss. The person may blame or accuse others because no other explanation seems to make sense.

Here are some tips for dealing with paranoia:

- Try not to react if the person blames you for something.
- Don't argue with him or her.
- Let the person know that he or she is safe.
- Use gentle touching or hugging to show the person you care.
- Explain to others that the person is acting this way because he or she has AD.
- Search for missing things to distract the person, and then talk about what you found. For example, talk about a photograph or keepsake.
- Have extra sets of keys or eyeglasses in case they are lost.

How to Cope: Agitation and Aggression

Agitation means that a person is restless and worried. He or she doesn't seem to be able to settle down. Agitated people may pace a lot, not be able to sleep, or act aggressively toward others. They may verbally lash out or try to hit or hurt someone. When this happens, try to find the cause. There is usually a reason.

For example, the person may have pain, depression, or stress. The person may be exhausted from too little rest or sleep, may be constipated or may have soiled his or her underwear or diaper.

Other causes of agitation and aggression:

- Sudden change in a well-known place, routine, or person's behavior
- A feeling of loss—for example, the person with AD may miss driving or caring for children
- Too much noise or confusion or too many people around
- Being pushed by others to do something—for example, to bathe or remember events or people—when AD has made the activity very hard or impossible
- Feeling lonely and not having enough contact with other people
- Interaction of medicines

Agitation and Aggression: How to cope

- Look for the early signs of agitation or aggression so that you can deal with the cause before the problem behaviors start.
- Doing nothing can make things worse. Try to find the causes of the behavior. If you deal with the causes, the behavior may stop.
- Slow down and try to relax if you think your own worries may be affecting the person with AD. Try to find a way to take a break from caregiving.
- Allow the person to keep as much control in his or her life as possible.
- Try to distract the person with a favorite snack, object, or activity.

- Reassure him or her. Speak calmly. Listen to the person's concerns and frustrations. Try to show that you understand if the person is angry or fearful.
- Keep well-loved objects and photographs around the house to make the person feel more secure.
- Reduce noise, clutter, or the number of people in the room.
- Try gentle touching, soothing music, reading, or walks.
- Build quiet times into the day, along with activities.
- Limit the amount of caffeine, sugar, and "junk food" the person drinks and eats.

Ask the doctor

Schedule regular physical exams to confirm there are no other medical issues causing the behavior, such as pain, depression, or the effects of certain medicines. Also, have the person's vision and hearing checked each year. Ask the doctor or AD specialist if medicine may be needed to prevent or reduce agitation or aggression.

How to Cope: Wandering

As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

- Make sure the person carries some kind of ID or wears a medical bracelet
- Let neighbors and the local police know that the person with AD tends to wander.
- Keep a recent photograph or video recording of the person to help police or use on social media if the person becomes lost.
- Keep doors locked. Consider a keyed deadbolt, or add another lock placed up high or down low on the door. If the person can open a lock, you may need to get a new latch or lock.
- Install an "announcing system" that chimes when the door opens.

Consider using GPS technology; there are a whole host of new devices that can locate a wandering person with AD.

How to Cope: Rummaging and Hiding Things

Someone with AD may start rummaging or searching through cabinets, drawers, closets, the refrigerator, and other places where things are stored. He or she also may hide items around the house.

In some cases, there might be a logical reason for this behavior. For instance, the person may be looking for something specific, although he or she may not be able to tell you what it is. He or she may be hungry or bored. Try to understand what is causing the behavior so you can fit your response to the cause.

Here are some other steps to take:

- Lock up dangerous or toxic products, or place them out of the person's sight and reach.
- Remove spoiled food from the refrigerator and cabinets.
- Remove valuable items that could be misplaced or hidden by the person such as important papers, checkbooks, charge cards, jewelry, and keys.
- People with AD often hide, lose, or throw away mail. If this is a serious problem, consider getting a post office box. If you have a yard with a fence and a locked gate, place your mailbox outside the gate.
- Keep the person with AD from going into unused rooms. This limits his or her rummaging through and hiding things.
- Search the house to learn where the person often hides things. Once you find these places, check them often, out of sight of the person.
- Keep all trash cans covered or out of sight. People with AD may not remember the purpose of the container or may rummage through it.
- Check trash containers before you empty them to ensure that something has not been hidden there or thrown away by accident.

You can also create a special place where the person with AD can rummage freely or sort things.This could be a chest of drawers, a bag of objects, or a basket of clothing to fold or unfold.

Give him or her a personal box, chest, or cupboard to store special objects. You may have to remind the person where to find his or her personal storage place.

Challenge: Changes in Intimacy and Sexuality

Intimacy is the special bond we share with a person we love and respect. It includes the way we talk and act toward one another. This bond can exist between spouses or partners, family members, and friends. AD often changes the intimacy between people.

Sexuality is one type of intimacy. It is an important way that spouses or partners express their feelings physically for one another. AD can cause changes in intimacy and sexuality in both the person with AD and the caregiver. The person with AD may be stressed by the changes in his or her memory and behaviors. Fear, worry, depression, anger, and low self-esteem are common.

The person may become dependent and cling to you. He or she may not remember your life together and feelings toward one another. Sometimes the person may even fall in love with someone else.

You, the caregiver, may pull away from the person in both an emotional and physical sense. You may be upset by the demands of caregiving.

You also may feel frustrated by the person's constant forgetfulness, repeated questions, and other bothersome behaviors.

Most caregivers learn how to cope with these challenges, but it takes time. Some learn to live with the illness and find new meaning in their relationships with people who have AD.

How to Cope: Changes in Intimacy

Remember that most people with AD need to feel that someone loves and cares about them. They also need to spend time with other people as well as with you.

Your efforts to take care of these needs can help the person with AD to feel happy and safe. It's important to reassure the person that:

- you love him or her
- you will keep him or her safe, and
- others also care about him or her.

When intimacy changes, the following tips may help you cope with your own needs:

- Talk with a doctor, social worker, or clergy member about these changes. It may feel awkward to talk about such personal issues, but it can help.
- Talk about your concerns in a support group.
- Think more about the positive parts of the relationship.

- Get more information. Some books, articles, and DVDs/videos can help you understand how AD affects intimacy.

Hypersexuality

Sometimes, people with AD are overly interested in sex. This is called "hypersexuality." The person may masturbate a lot and try to seduce others. These behaviors are symptoms of the disease, and they do not always mean that the person wants to have sex.

To cope with hypersexuality, try giving the person more attention and reassurance. You might gently touch, hug, or use other kinds of affection to meet his or her emotional needs.

Some people with this problem need medicine to control their behaviors. Talk to the doctor about what steps to take.

Changes in Sexuality

The well spouse/partner or the person with AD may lose interest in having sex. This change can make you feel lonely or frustrated. Here are some possible reasons for changes in sexual interest.

The well spouse/partner may feel:

- It's not okay to have sex with someone who has AD
- The person with AD seems like a stranger
- The person with AD seems to forget that the spouse/partner is there or how to make love.

A person with AD may have:

- Side effects from medications that affect his or her sexual interest; or
- Memory loss, changes in the brain, or depression that affect his or her interest in sex.

Some caregivers find that snuggling or holding hands reduces their need for a sexual relationship. Try other nonsexual forms of touching, such as giving a massage, hugging, and dancing.

Finally, consider other ways to meet your sexual needs. Some caregivers report that they masturbate to meet their needs.

Chapter Four Review:

☑ People with Alzheimer’s disease may undergo changes and challenges related to communication, personality and behavior.

☑ There are steps you can take to address these issues and maintain a positive connection to the person with Alzheimer's disease.

☑ Understanding and anticipating these changes, asking for help, and taking care of yourself are all important for a caregiver to cope.

Chapter 5

Activity and Exercise

Being active and getting exercise helps people with AD feel better. Exercise helps keep their muscles, joints, and heart in good shape. It also helps people stay at a healthy weight and have regular toilet and sleep habits. You can exercise together to make it more fun. You want someone with AD to do as much as possible for him or herself. At the same time, you also need to make sure that the person is safe when active.

Here are some tips for helping the person with AD to stay active:

- Take a walk together each day. Exercise is good for caregivers, too.
- Make sure the person with AD has an ID bracelet with your phone number if he or she walks alone.
- Check your local TV guide to see if there is a program to help older adults exercise.
- Add music to the exercises if it helps the person with AD. Dance to the music if possible.
- Watch exercise videos/DVDs made for older people. Try exercising together.
- Make sure he or she wears comfortable clothes and shoes that fit well and are made for exercise.
- Make sure the person drinks water or juice after exercise.

- For more information on exercise and physical activity, visit www.nia.nih.gov/Go4Life or call 1-800-222-2225.

Some people with AD may not be able to get around well. This is another problem that becomes more challenging to deal with as the disease gets worse.

Some possible reasons for this include the following:

- Trouble with endurance
- Poor coordination
- Sore feet or muscles
- Illness
- Depression or general lack of interest

Even if people have trouble walking, they may be able to:

- do simple tasks around the home, such as sweeping and dusting;
- use a stationary bike;
- use soft rubber exercise balls or balloons for stretching or throwing back and forth; or
- use stretching bands, which you can buy in sporting goods stores. Be sure to follow the instructions.

Healthy Eating

Eating healthy foods helps us stay well. It's even more important for people with AD. Here are some tips for healthy eating.

When the person with AD lives with you:

- Buy healthy foods such as vegetables, fruits, and whole-grain products. Be sure to buy foods that the person likes and can eat.
- Buy food that is easy to prepare, such as premade salads and single food portions.
- Have someone else make meals, if possible.
- Use a service such as meals-on-wheels, which will bring meals right to your home. For more information, check your local phone book, or contact the Meals On Wheels Association at 1-888-998-6325 (www.mowaa.org).

When a person with early-stage AD lives alone:

- Follow the steps above.
- Buy foods that the person doesn't need to cook.
- Call to remind him or her to eat. In the early stage of AD, the person's eating habits usually don't change. When changes do occur, living alone may not be safe anymore.

Look for these signs to see if living alone is no longer safe for the person with AD:

- The person forgets to eat.
- Food has burned because it was left on the stove.
- The oven isn't turned off.

Personal Care

At some point, people with AD will need help bathing, combing their hair, brushing their teeth, and getting dressed. Because these are private activities, people may not want help. They may feel embarrassed about being naked in front of caregivers. They also may feel angry about not being able to care for themselves. Below are suggestions that may help with everyday care.

Bathing Safety

Helping someone with AD take a bath or shower can be one of the hardest things you do. Planning can help make the person's bath time better for both of you. The person with AD may be afraid. If so, follow the person's lifelong bathing habits, such as doing the bath or shower in the morning or before going to bed.

Here are other tips for bathing.

- Never leave a confused or frail person alone in the tub or shower.
- Always check the water temperature before he or she gets in the tub or shower.
- Use plastic containers for shampoo or soap to prevent them from breaking.
- Use a hand-held showerhead.

- Use a rubber bath mat and put safety bars in the tub.
- Use a sturdy shower chair in the tub or shower. This will support a person who is unsteady, and it could prevent falls. You can get shower chairs at drug stores and medical supply stores.

Before a bath or shower:

- Get the soap, washcloth, towels, and shampoo ready.
- Make sure the bathroom is warm and well lighted. Play soft music if it helps to relax the person.
- Be matter-of-fact about bathing- Say, “It’s time for a bath now.” Don’t argue about the need for a bath or shower.
- Be gentle and respectful. Tell the person what you are going to do, step-by-step.
- Make sure the water temperature in the bath or shower is comfortable.
- Don’t use bath oil. It can make the tub slippery and may cause urinary tract infections.

During a bath or shower:

- Allow the person with AD to do as much as possible. This protects his or her dignity and helps the person feel more in control.
- Put a towel over the person’s shoulders or lap. This helps him or her feel less exposed. Then use a sponge or washcloth to clean under the towel.

- Distract the person by talking about something else if he or she becomes upset.
- Give him or her a washcloth to hold. This makes it less likely that the person will try to hit you.

After a bath or shower:

- Prevent rashes or infections by patting the person's skin with a towel. Make sure the person is completely dry. Be sure to dry between folds of skin.
- If the person has trouble with incontinence, use a protective ointment, such as Vaseline®, around the rectum, vagina, or penis.
- If the person with AD has trouble getting in and out of the bathtub, do a sponge bath instead.

Other bathing tips:

- Give the person a full bath two or three times a week. For most people, a sponge bath to clean the face, hands, feet, underarms, and genital or "private" area is all you need to do every day.
- Washing the person's hair in the sink may be easier than doing it in the shower or bathtub. You can buy a hose attachment for the sink.
- Get professional help with bathing if it becomes too hard for you to do on your own.

Grooming: Tips and Strategies

For the most part, when people feel good about how they look, they feel better. Helping people with AD brush their teeth, shave, or put on makeup often means they can feel more like themselves. Here are some grooming tips.

Mouth Care

Good mouth care helps prevent dental problems such as cavities and gum disease.

- Show the person how to brush his or her teeth. Go step-by-step. For example, pick up the toothpaste, take the top off, put the toothpaste on the toothbrush, and then brush. Remember to let the person do as much as possible.
- Brush your teeth at the same time.
- Help the person clean his or her dentures. Make sure he or she uses the denture cleaning material the right way.
- Ask the person to rinse his or her mouth with water after each meal and use mouthwash once a day.
- Try a long-handled, angled, or electric toothbrush if you need to brush the person's teeth.
- Take the person to see a dentist. Some dentists specialize in treating people with AD. Be sure to follow the dentist's advice

about how often to make an appointment.

Other Grooming Tips:

- Encourage a woman to wear makeup if she has always used it. If needed, help her put on powder and lipstick. (Don't use eye makeup; putting it on can pose hazards.)
- Encourage a man to shave, and help him as needed. Use an electric razor for safety.
- Take the person to the barber or beauty shop. Some barbers or hairstylists may come to your home.
- Keep the person's nails clean and trimmed.

Dressing Help

People with AD often need more time to dress. It can be hard for them to choose their clothes. They might wear the wrong clothing for the season. They also might wear colors that don't go together or forget to put on a piece of clothing. Allow the person to dress on his or her own for as long as possible.

Other tips include the following:

- Lay out clothes in the order the person should put them on, such as underwear first, then pants, then a shirt, and then a sweater.

- Hand the person one thing at a time or give step-by-step dressing instructions.
- Put away some clothes in another room to reduce the number of choices. Keep only one or two outfits in the closet or dresser.
- Keep the closet locked if needed. This prevents some of the problems people may have while getting dressed.
- If the person wants to wear the same clothing every day, buy three or four sets of the same clothes.
- Buy loose-fitting, comfortable clothing. Avoid girdles, control-top pantyhose, knee-high nylons, garters, high heels, tight socks, and bras for women. Sports bras are comfortable and provide good support. Short cotton socks and loose cotton underwear are best. Sweat pants and shorts with elastic waistbands are helpful.
- Use Velcro® tape or large zipper pulls for clothing, instead of shoelaces, buttons, or buckles. Try slip-on shoes that won’t slide off or shoes with Velcro® straps.

The physical care of a person with Alzheimer's becomes increasingly demanding over time. It is important to plan for the future before things become too difficult. Consider who can help you prepare for the possibility of increased professional care.

Chapter Five Review:

☑ Activity, exercise and healthy eating are critical elements of a care program for a person with Alzheimer’s disease, and are equally important for caregivers.

☑ There are a range of strategies and safety tips that can help and guide caregivers providing day-to-day care.

☑ The day-to-day care of a person with Alzheimer's disease will become increasingly difficult, so exploring options for additional help in advance is important.

Chapter 6

Doing things we enjoy gives us pleasure and adds meaning to our lives. People with AD need to be active and do things they enjoy. However, don't expect too much. It's not easy for them to plan their days and do different tasks.

They may have trouble deciding what to do each day. This could make them fearful and worried or quiet and withdrawn. They may also have trouble starting tasks. He or she might need help organizing the day or doing an activity.

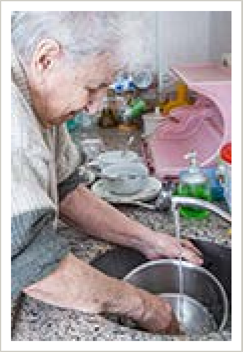
Daily Activities

Plan activities that the person with AD enjoys. He or she can be a part of the activity or just an observer. Also, you don't always have to be the "activities director." For ideas and guidance, consult with an adult day care service and ask how they might be able help you.

Here are things you can do to help the person enjoy an activity:

- Match the activity with what the person with AD can do.
- Choose activities that can be fun for everyone.
- Help the person get started.
- Decide if he or she can do the activity alone or needs help.
- Watch to see if the person gets frustrated.
- Make sure he or she feels successful and has fun.
- Let him or her simply watch if that is more enjoyable.

Household Chores



Doing household chores can boost the person's self-esteem. When the person helps you, don't forget to say, "Thank you."

The person could:

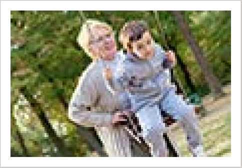
- Wash dishes, set the table, or prepare food
- Sweep the floor
- Polish shoes
- Sort mail and clip coupons
- Sort socks and fold laundry
- Sort recycling materials or other things.

Cooking and Baking

Cooking and baking can bring the person with AD a lot of joy. He or she might help do the following:

- Decide on what is needed to prepare the dish.
- Make the dish.
- Measure, mix, and pour.
- Tell someone else how to prepare a recipe.
- Taste the food.
- Watch others prepare food.

Activities with Children



Being around children can give the person with AD someone to talk with, bring back happy memories, and remind the person how much he or she can still love others and be loved.

Here are some things the person might enjoy doing with children:

- Play a simple board game.
- Read stories or books.
- Visit family members who have small children.
- Walk in the park or around schoolyards.
- Go to sports or school events that involve young people.
- Talk about fond memories from childhood.

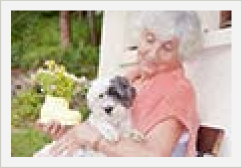
Music and Dancing

Music can bring back happy memories and feelings. Some people feel the rhythm and may want to dance. Others enjoy listening to or talking about their favorite music. Even if the person with AD has trouble finding the right words to speak, he or she still may be able to sing songs from the past.

Consider the following musical activities:

- Play CDs, tapes, or records.
- Talk about the music and the singer.
- Ask what he or she was doing when the song was popular.
- Talk about the music and past events.
- Sing or dance to well-known songs.
- Play musical games such as “Name That Tune.”
- Attend a concert or musical program.

Pets and Alzheimer’s disease



Many people with AD enjoy pets, such as dogs, cats, or birds. Pets may help “bring them to life.” Pets can also help people feel more loved and less worried. The person may be able to help with walking, feeding, or grooming the pet, or may find joy in simply sitting with and holding an animal.

Gardening

Gardening is a way to be part of nature. It may also help people remember past days and fun times. Gardening can help the person focus on what he or she still can do.

Here are some suggested gardening activities:

- Take care of indoor or outdoor plants.
- Plant flowers and vegetables.
- Water the plants when needed.
- Talk about how much the plants are growing.

Going and Eating Out

Early in the disease, people with AD may still enjoy the same kinds of outings they enjoyed in the past. Keep going on these outings as long as you are comfortable doing them.

Plan outings for the time of day when the person is at his or her best. Keep outings from becoming too long. You want to note how tired the person with AD gets after a certain amount of time (1/2 hour, 1 hour, 2 hours, etc.).

The person might enjoy outings to one of the following:

- Favorite restaurant
- Zoo, park, or shopping mall

- Swimming pool (during a slow time of day at the pool)
- Museum, theater, or art exhibits for short trips

Remember that you can use a business-size card to tell others about the person's disease. Sharing the information with store clerks or restaurant staff can make outings more comfortable for everyone.

Eating Out

Going out to eat can be a welcome change, but it can also have some challenges. Planning can help. You need to think about the layout of the restaurant, the menu, the noise level, waiting times, and the helpfulness of staff. Below are some tips for eating out with the person who has AD.

Before choosing a restaurant, ask yourself the following:

- Does the person with AD know the restaurant well?
- Is it quiet or noisy most of the time?
- Are tables easy to get to? Do you need to wait before you can be seated?
- Is the service quick enough to keep the person from getting restless?
- Does the restroom meet the person's needs?
- Are foods the person with AD likes on the menu?
- Is the staff understanding and helpful?

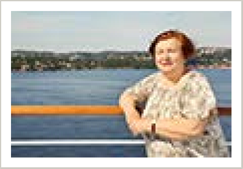
Before going to the restaurant, consider the following:

- Is your patient having a good day? Is your patient feeling well? Make sure they have had the needed rest and they want to go.
- When is the best time to go? Going out earlier in the day may be best, so the person is not too tired. The service may be quicker, and there may be fewer people. If you decide to go later, try to get the person to take a nap first.
- What should you take with you? You may need to take utensils, a towel, wipes, or toilet items that the person already uses. If so, make sure this is OK with the restaurant.

At the restaurant

- Tell the server about any special needs, such as extra spoons, bowls, or napkins.
- Ask for a table near the washroom and in a quiet area.
- Seat the person with his or her back to the busy areas.
- Help the person choose his or her meal, if needed. Suggest food you know the person likes. Read parts of the menu or show the person a picture of the food. Limit the number of choices.
- Ask the waiter or waitress to fill glasses half full or leave the drinks for you to serve.
- Order some finger food or snacks to hold the attention of the person with AD.
- Go with the person to the restroom. Go into the stall if the person needs help.

Traveling



Taking the person with AD on a trip is a challenge. Traveling can make the person more worried and confused. Planning can make travel easier for everyone. Below are some tips that you may find helpful.

Before you leave on the trip

- Talk with your doctor about medicines to calm someone who gets upset while traveling.
- Find someone to help you at the airport or train station.
- Keep important documents with you in a safe place. These include insurance cards, passports, doctor's name and phone number, list of medicines, and a copy of medical records.
- Pack items the person enjoys looking at or holding for comfort.
- Travel with another family member or friend.
- Take an extra set of clothing in a carry-on bag.

After you arrive

- Allow lots of time for each thing you want to do. Do not plan too many activities.
- Plan rest periods.
- Follow a routine like the one you use at home. For example, try to have the person eat, rest, and go to bed at the same time he or she does at home.

- Keep a well-lighted path to the toilet, and leave the bathroom light on all night.
- Be prepared to cut your visit short.

People with memory problems may wander around a place they don't know well. In case someone with AD gets lost:

- Make sure they wear or have something with them that tells who they are, such as an ID bracelet.
- Carry a recent photo of the person with you on the trip.

Spiritual Activities

Like you, the person with AD may have spiritual needs. If so, you can help the person stay a part of his or her faith community. This can help the person feel connected to others and remember pleasant times.

Here are some tips for helping a person with AD who has spiritual needs:

- Involve the person in spiritual activities that he or she has known well. These might include worship, religious or other readings, sacred music, prayer, and holiday rituals.
- Tell people in your faith community that the person has AD. Encourage them to talk with the person and show him or her that they still care.

- Play religious or other music that is important to the person. It may bring back old memories. Even if the person with AD has a problem finding the right words to speak, he or she still may be able to sing songs or hymns from the past.

Holidays

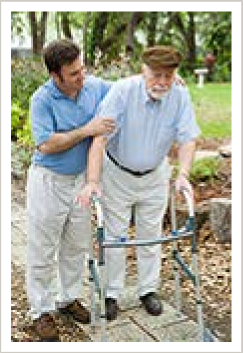
Many caregivers have mixed feelings about holidays. They may have happy memories of the past, but they may also worry about the extra demands that holidays make on their time and energy.

Here are some suggestions to help you find a balance between doing many holiday-related things and resting:

- Celebrate holidays that are important to you. Include the person with AD as much as possible.
- Understand that things will be different. Be realistic about what you can do.
- Ask friends and family to visit. Limit the number of visitors at any one time. Plan visits when the person usually is at his or her best.
- Avoid crowds, changes in routine, and strange places that may make the person with AD feel confused or nervous.
- Do your best to enjoy yourself. Find time for the holiday activities you like to do. Ask a friend or family member to spend time with the person while you're out.

- Make sure there is a space where the person can rest when he or she goes to larger gatherings such as weddings or family reunions.

Visitors



Visitors are important to people with AD. They may not always remember who visitors are, but they often enjoy the company.

Here are ideas to share with a person planning to visit someone with AD:

- Time the visit when the person with AD is at his or her best.
- Consider bringing along some kind of activity, such as a well-known book or photo album to look at. This can help if the person is bored or confused and needs to be distracted. But be prepared to skip the activity if it is not needed.
- Be calm and quiet. Don't use a loud voice or talk to the person as if he or she were a child.
- Respect the person's personal space, and don't get too close.
- Make eye contact and call the person by name to get his or her attention.
- Remind the person who you are if he or she doesn't seem to know you.

- Don’t argue if the person is confused. Respond to the feelings that they express. Try to distract the person by talking about something different.
- Remember not to take it personally if the person doesn’t recognize you, is unkind, or gets angry. He or she is acting out of confusion.

Chapter Six Review:

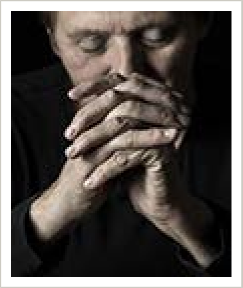
☑ From household chores to holiday visitors, there are ways to modify day-to-day activities that can help a person with Alzheimer's disease feel useful, and even joyful.

☑ Some beloved activities, such as cooking and baking, may also come with safety risks and will require supervision.

☑ Finding new ways to enjoy shared interests can be an important means of bonding between a caregiver and person with AD.

Chapter 7

Getting Help with Caregiving



Caring for someone with Alzheimer's could be the toughest job you ever have. It's important to stay physically and emotionally healthy when you are providing care. It is not selfish to worry about your own health—taking care of yourself means you will be there for the person who needs you.

Some caregivers require help when the person is still in the early stages of AD. Others need support when the person is in the later stages of AD. It is important to look ahead and plan for help before your need becomes critical.

Alzheimer's caregivers frequently report experiencing high levels of stress. It can be overwhelming to take care of a loved one with Alzheimer's or other dementia, but too much stress can be harmful to both of you.

Respite Care: A Chance to Re-Charge

Respite care offers the opportunity for the primary caregiver to have breaks for varying periods of time while another skilled individual takes over the caregiving. It may be for a full weekend or just a few hours so that you can do things you need to do, such as

grocery shopping, going to an appointment, running errands, having your nails done, or going out to lunch with a friend.

Caregiving is no easy task, respite care services can be critical for you to recharge your batteries, clear your head, and forget about your duties as a caregiver for a while.

Ten Symptoms of Caregiver Stress

- **Denial** about the disease and its effect on the person who has been diagnosed: “I know Mom is going to get better.”
- **Anger** at the person with Alzheimer’s, anger that no cure exists, or anger that people don’t understand what’s happening: “If he asks me that one more time, I’ll scream!”
- **Social withdrawal** from friends and activities that once brought pleasure: “I don't care about getting together with the neighbors anymore.”
- **Anxiety** about the future: "What happens when he or she needs more care than you can provide?"
- **Depression** that begins to break your spirit and affects your ability to cope: “I don’t care anymore.”
- **Exhaustion** that makes it nearly impossible to complete

necessary daily tasks: “I’m too tired for this.”

- **Sleeplessness** caused by an unending list of concerns.
- **Irritability** that leads to moodiness and triggers negative responses and actions: “Leave me alone!”
- **Lack of concentration** that makes it difficult to perform familiar tasks: “I was so busy, I forgot we had an appointment.”
- **Health problems** that begin to take a mental and physical toll: “I can’t remember the last time I felt good.”

If you experience any of these signs of stress on a regular basis, make time to talk to your doctor.

Caregiver Coping Strategies

Know the Range of Resources Available to You
Adult day programs, in-home assistance, visiting nurses, and meal delivery are just some of the services that can help you manage daily tasks.

Get comfortable asking for help.
Trying to do everything by yourself will leave you exhausted. Seek the support of family, friends, as well as caregivers going through similar experiences. Tell others exactly what they can do to help.

Use relaxation techniques.
There are several simple relaxation techniques that can help relieve

stress. Try more than one to find which works best for you. Techniques include the following:

- Visualization (mentally picturing a place or situation that is peaceful and calm)
- Meditation (which can be as simple as dedicating fifteen minutes a day to letting go of all stressful thoughts)
- Breathing exercises (slowing your breathing and focusing on taking deep breaths)
- Progressive muscle relaxation (tightening and then relaxing each muscle group, starting at one end of your body and working your way to the other end)

Get your body moving.

Physical activity—in any form—can help reduce stress and improve overall well-being. Even ten minutes of exercise a day can help. Take a walk. Do an activity you love, such as gardening or dancing.

Make time for yourself.

As a caregiver, it's hard to find time for yourself, but staying connected to friends, family, and activities that you love is important for your well-being. Even if it's only thirty minutes a week, carve out a pocket of time just for yourself.

Become an educated caregiver.

As the disease progresses, new caregiving skills may be necessary.

Take care of yourself.

Visit your doctor regularly. Watch your diet, exercise, and get plenty of rest. Making sure that you stay healthy will help you be a better caregiver.

Tips to Help You Cope

Alzheimer's caregivers frequently report high levels of stress. Manage your level of stress. Consider how stress affects your body (e.g., stomachaches, high blood pressure) and your emotions (e.g., overeating, irritability). Find ways to relax.

- Be realistic. The care you give does make a difference, but many behaviors can't be controlled. Grieve the losses, focus on positive times as they arise, and enjoy good memories.
- Give yourself credit, not guilt. It's normal to lose patience or feel like your care may fall short sometimes. You're doing the best you can. Seek out support and encouragement.
- Take a break. It's normal to need a break from caregiving duties. No one can do it alone. Look into respite care to allow time to take care of yourself.
- Accept changes. Eventually your loved one will need more intensive kinds of care. Research care options now so you are ready for the changes as they occur.

Mutual Movement: Exercise as Part of Caregiving

There also are many ways you can be active with the person with dementia. Here are a few ideas:

- Take a walk together to enjoy the fresh air
- Go to the mall and take a stroll indoors
- Do seated exercises at home
- Dance together to favorite music
- Garden or do other routine activities that you both enjoy

Caregiver Depression

Many caregivers experience depression. If you are experiencing symptoms, know that you are not alone and that help is available. Depression is a serious condition, but it is one that is treatable.

Symptoms of Depression

Caregiving is hard and can lead to feelings of stress, guilt, anger, sadness, isolation, and depression. Depression affects different people in different ways and at different times. For example, someone may experience depression right after a family member has been diagnosed with Alzheimer's. Other caregivers may experience it as Alzheimer's progresses and the cognitive abilities of the person with Alzheimer's diminish.

Signs and symptoms of depression include the following:

- Becoming easily agitated or frustrated
- Feelings of worthlessness or guilt
- Feelings of hopelessness
- Thoughts of death, dying, or suicide
- Disturbed sleep
- Fatigue or loss of energy
- Loss of interest or pleasure in usual activities
- Difficulty thinking or concentrating
- Changes in appetite and weight
- Physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and pain

Source: American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders

See Your Doctor

If you are concerned that you might be depressed, see your doctor as soon as possible. Certain medications and some medical conditions can cause the same symptoms as depression. A doctor can rule out these possibilities by doing a medical exam and lab tests.

If depression is left untreated, it can lead to emotional and physical problems. It can also affect the quality of care you're able to provide the person with Alzheimer's or dementia.

Treatment

Depression can be effectively treated. And the earlier treatment begins, the earlier you'll feel better. Treatment commonly involves a combination of medication, therapy, and support.

Medication

Feeling better takes time. If your doctor has prescribed an antidepressant, talk with him or her about how long it will take to feel the full benefit. In some cases, it may take six to eight weeks. Never stop taking an antidepressant without consulting your doctor first. Abruptly stopping antidepressants can cause unwanted side effects.

Counseling

Your doctor may refer you to a mental health professional, such as a counselor, psychologist, psychiatrist, or social worker. Counseling can be very effective in the treatment of depression and can help you deal with the problems you are facing. It's important to be comfortable with the professional you seek treatment with, so consider interviewing several to find a good fit. Your primary care physician, insurance provider, or community mental health clinic may be able to provide referrals.

Coping

In addition to seeking help from a professional, you can take steps to help yourself.

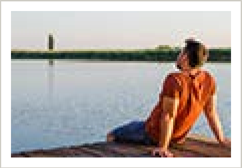
- **Let family and friends help you.** Take others up on offers to help and ask for help when you need it.
- **Seek out caregiver support.** Consider respite services, a local caregiver support group. Building a support network can keep you from feeling isolated.
- **Try keeping a journal.** Expressing your emotions (both negative and positive) in a journal may boost your mood.
    - **Learn ways to relax and manage stress.** Try meditation or yoga to help reduce caregiver stress.
    - **Take time for yourself.** Participate in activities that you enjoy.

Nourishment: Eating Well.

Heart-healthy eating patterns, such as the Mediterranean diet, are good for overall health and may help protect the brain. A Mediterranean diet includes relatively little red meat and emphasizes whole grains, fruits, vegetables, fish, nuts, olive oil, and other healthy fats. Try new recipes and involve the person with dementia.

Finding Time for Self Care

No doubt, you know that exercise is an important part of staying healthy—it can help relieve stress, prevent disease, and make you feel good. But finding the time to exercise is another story.



Take friends and family members up on their offers to help. You can get in a good workout in a short amount of time, even a thirty minute break.

Start small.

Although it is recommended that you get thirty minutes of physical activity at least five days a week, even ten minutes a day can help. Fit in what you can, and work toward a goal.

Exercise at home.

When the person with dementia naps, pull out a yoga mat and stretch, set up a stationary bike, or try exercise tapes.

Find something you love.

If you enjoy the activity, it will be easier to make it a habit.

Chapter Seven Review:

☑ Support for the caregiver is just as important as support for the person with Alzheimer.

☑ Signs of caregiver stress range from sleeplessness and anxiety to anger and health problems.

☑ Knowing how to identify caregiver stress and prevent its consequences is crucial for all involved.

Chapter 8

Quick Tips for Caregivers by Category

The Diagnosis

Finding out that a loved one has Alzheimer's disease can be stressful, frightening, and overwhelming. As you begin to take stock of the situation, here are some tips that may help.

Ask the doctor any questions you have about Alzheimer's disease. Find out what treatments might work best to alleviate symptoms or address behavior problems.

Contact organizations such as the Alzheimer's Research Association, the Alzheimer's Association, and the Alzheimer's Disease Education and Referral (ADEAR) Center for more information about the disease, treatment options, and caregiving resources. Some community groups may offer classes to teach caregiving, problem-solving, and management skills.

Find a support group where you can share your feelings and concerns. Members of support groups often have helpful ideas or know of useful resources based on their own experiences. Online support groups make it possible for caregivers to receive support without having to leave home. The Alzheimer's Association and other organizations sponsor support groups.

Study your day to see if you can develop a routine that makes things go more smoothly. If there are times of day when the person with Alzheimer's is less confused or more cooperative, plan your routine to make the most of those moments. Keep in mind that the way the person functions may change from day to day, so try to be flexible and adapt your routine as needed.

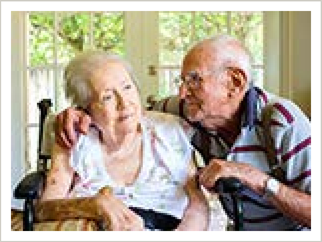
Consider using adult day care or respite services to ease the day-to-day demands of caregiving. These services allow you to have a break while knowing that the person with Alzheimer's is being well cared for

Begin to plan for the future. This may include getting financial and legal documents in order, investigating long-term care options, and determining what services are covered by health insurance and Medicare.

Communication

Trying to communicate with a person who has Alzheimer's disease can be a challenge. Both understanding and being understood may be difficult.

Choose simple words and short sentences and use a gentle, calm tone of voice.



Avoid talking to the person with Alzheimer's like a baby or talking about the person as if he or she weren't there.

Minimize distractions and noise—such as the television or radio—to help the person focus on what you are saying.

Make eye contact and call the person by name, making sure you have his or her attention before speaking.

Allow enough time for a response. Be careful not to interrupt.

If the person with Alzheimer's is struggling to find a word or communicate a thought, gently try to provide the word he or she is looking for.

Try to frame questions and instructions in a positive way.

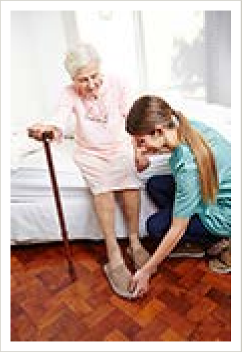
Be open to the person's concerns, even if he or she is hard to understand.

Dressing

For someone who has Alzheimer's, getting dressed presents a series of challenges: choosing what to wear, getting some clothes off and other clothes on, and struggling with buttons and zippers. Minimizing the challenges may make a difference.

Try to have the person get dressed at the same time each day so he or she will come to expect it as part of the daily routine.

Encourage the person to dress himself or herself to whatever



degree possible. Plan to allow extra time so there is no pressure or rush.

Allow the person to choose from a limited selection of outfits. If he or she has a favorite outfit, consider buying several identical sets.

Store some clothes in another room to reduce the number of choices. Keep only one or two outfits in the closet or dresser.

Arrange the clothes in the order they are to be put on to help the person move through the process.

Hand the person one item at a time or give clear, step-by-step instructions if the person needs prompting.

Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro®enclosures minimize struggles with buttons and zippers.

Eating

Eating can be a challenge. Some people with Alzheimer's disease want to eat all the time, while others have to be encouraged to maintain a good diet.

View mealtimes as opportunities for social interaction and success for the person with Alzheimer's. Try to be patient and avoid rushing,

and be sensitive to confusion and anxiety.

Aim for a quiet, calm, reassuring mealtime atmosphere by limiting noise and other distractions.

Maintain familiar mealtime routines, but adapt to the person's changing needs.

Give the person food choices, but limit the number of choices. Try to offer appealing foods that have familiar flavors, varied textures, and different colors.

Serve small portions or several small meals throughout the day. Make healthy snacks, finger foods, and shakes available. In the earlier stages of dementia, be aware of the possibility of overeating.

Choose dishes and eating tools that promote independence. If the person has trouble using utensils, use a bowl instead of a plate, or offer utensils with large or built-up handles.

Use straws or cups with lids to make drinking easier. Encourage the person to drink plenty of fluids throughout the day to avoid dehydration.

As the disease progresses, be aware of the increased risk of choking because of chewing and swallowing problems.

Maintain routine dental checkups and daily oral health care to keep the mouth and teeth healthy.

Chapter 8

Bathing

While some people with Alzheimer's disease don't mind bathing, for others it is a frightening, confusing experience. Advance planning can help make bath time better for both of you.

Plan the bath or shower for the time of day when the person is most calm and agreeable. Be consistent. Try to develop a routine.

Respect the fact that bathing is scary and uncomfortable for some people with Alzheimer's. Be gentle and respectful. Be patient and calm.

Tell the person what you are going to do, step by step, and allow him or her to do as much as possible.

Prepare in advance. Make sure you have everything you need ready and in the bathroom before beginning. Draw the bath ahead of time.

Be sensitive to the temperature. Warm up the room before hand if necessary and keep extra towels and a robe nearby. Test the water temperature before beginning the bath or shower.

Minimize safety risks by using a handheld showerhead, shower bench, grab bars, and nonskid bath mats. Never leave the person alone in the bath or shower.

Try a sponge bath. Bathing may not be necessary every day. A sponge bath can be effective between showers or baths.

Activities

What to do all day? Finding activities that the person with Alzheimer's disease can do and is interested in can be a challenge. Building on current skills generally works better than trying to teach something new.

Don't expect too much. Simple activities often are best, especially when they use current abilities.

Help the person get started on an activity. Break the activity down into small steps and praise the person for each step he or she completes.

Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.

Incorporate activities the person seems to enjoy into your daily routine and try to do them at a similar time each day.

Try to include the person with Alzheimer's in the entire activity process. For instance, at mealtimes, encourage the person to help prepare the food, set the table, pull out the chairs, or put away the dishes. This can help maintain functional skills, enhance feelings of personal control, and make good use of time.

Chapter 8

Exercise

Incorporating exercise into the daily routine has benefits for both the person with Alzheimer's disease and the caregiver. Not only can it improve health, but it also can provide a meaningful activity for both of you to share.

Think about what kind of physical activities you both enjoy, perhaps walking, swimming, tennis, dancing, or gardening. Determine the time of day and place where this type of activity would work best.

Be realistic in your expectations. Build slowly, perhaps just starting with a short walk around the yard, for example, before progressing to a walk around the block.

Be aware of any discomfort or signs of overexertion. Talk to the person's doctor if this happens.

Allow as much independence as possible, even if it means a less-than-perfect garden or a scoreless tennis match.

See what kinds of exercise programs are available in your area. Senior centers may have group programs for people who enjoy exercising with others. Local malls often have walking clubs and provide a place to exercise when the weather is bad.

Encourage physical activities. Spend time outside when the weather permits. Exercise often helps everyone sleep better.

Incontinence

As the disease progresses, many people with Alzheimer's begin to experience incontinence, or the inability to control their bladder and/or bowels. Incontinence can be upsetting to the person and difficult for the caregiver. Sometimes incontinence is due to physical illness, so be sure to discuss it with the person's doctor.

Have a routine for taking the person to the bathroom and stick to it as closely as possible. For example, take the person to the bathroom every 3 hours or so during the day. Don't wait for the person to ask.

Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes. Respond quickly.

Be understanding when accidents occur. Stay calm and reassure the person if he or she is upset. Try to keep track of when accidents happen to help plan ways to avoid them.

To help prevent nighttime accidents, limit certain types of fluids—such as those with caffeine—in the evening.

If you are going to be out with the person, plan ahead. Know where restrooms are located, and have the person wear simple, easy-to-remove clothing. Take an extra set of clothing along in case of an accident.

Sleep Problems

For the exhausted caregiver, sleep can't come too soon. For many people with Alzheimer's disease, however, the approach of nighttime may be a difficult time. Many people with Alzheimer's become restless, agitated, and irritable around dinnertime, often referred to as "sundowning" syndrome. Getting the person to go to bed and stay there may require some advance planning.

Encourage exercise during the day and limit daytime napping, but make sure that the person gets adequate rest during the day because fatigue can increase the likelihood of late afternoon restlessness.

Try to schedule physically demanding activities earlier in the day. For example, bathing could be done in the morning, or the largest family meal could be served at midday.

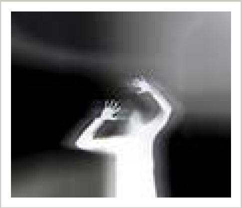
Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, even play soothing music if the person seems to enjoy it.

Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.

Limit caffeine.

Use night-lights in the bedroom, hall, and bathroom if the darkness is frightening or disorienting.

Hallucinations and Delusions



As the disease progresses, a person with Alzheimer’s disease may experience hallucinations and/or delusions. Hallucinations are when the person sees, hears, smells, tastes, or feels something that is not there. Delusions are false beliefs that the person thinks are real.

Sometimes hallucinations and delusions are signs of physical illness. Keep track of what the person is experiencing and discuss it with the doctor.

Avoid arguing with the person about what he or she sees or hears. Try to respond to the feelings he or she is expressing. Comfort the person if he or she is afraid.

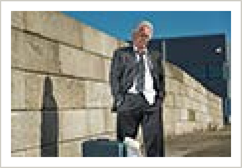
Try to distract the person to another topic or activity. Sometimes moving to another room or going outside for a walk may help.

Turn off the television set when violent or disturbing programs are on. The person with Alzheimer’s may not be able to distinguish television programming from reality.

Make sure the person is safe and does not have access to anything he or she could use to harm anyone.

Discuss with the doctor any illness the person has had or medicines he or she is taking. Sometimes an illness or medicine may cause hallucinations or delusions.

Wandering



Keeping the person safe is one of the most important aspects of caregiving. Some people with Alzheimer's disease have a tendency to wander away from their home or their caregiver. Knowing how to limit wandering can protect a person from getting lost.

Make sure that the person carries some kind of identification or wears a medical bracelet.

Notify neighbors and local authorities in advance that the person has a tendency to wander.

Keep a recent photograph or videotape of the person with Alzheimer's to assist police if the person becomes lost.

Keep doors locked. Consider a keyed deadbolt or an additional lock up high or down low on the door. If the person can open a lock because it is familiar, a new latch or lock may help.

Install an "announcing system" that chimes when the door opens.

Home Safety

Caregivers of people with Alzheimer's disease often have to look at their homes through new eyes to identify and correct safety risks. Creating a safe environment can prevent many stressful and dangerous situations.

Install secure locks on all outside windows and doors, especially if the person is prone to wandering. Remove the locks on bathroom doors to prevent the person from accidentally locking himself or herself in.

Use childproof latches on kitchen cabinets and anyplace where cleaning supplies or other chemicals are kept.

Label medications and keep them locked up. Also make sure knives, lighters and matches, and guns are secured and out of reach.

Keep the house free from clutter. Remove scatter rugs and anything else that might contribute to a fall.

Make sure lighting is good both inside and outside the home.

Be alert to and address kitchen-safety issues, such as the person forgetting to turn off the stove after cooking. Consider installing an automatic shut-off switch on the stove to prevent burns or fire.

Be sure to secure or put away anything that could cause danger, both inside and outside the house.

Driving

Making the decision that a person with Alzheimer's is no longer safe to drive is difficult, and it needs to be communicated carefully and sensitively. Even though the person may be upset by the loss of independence, safety must be the priority.

Look for clues that safe driving is no longer possible, including getting lost in familiar places, driving too fast or too slow, disregarding traffic signs, or getting angry or confused.

Be sensitive to the person's feelings about losing the ability to drive, but be firm in your request that he or she no longer do so. Be consistent—don't allow the person to drive on "good days" but forbid it on "bad days."

Ask the doctor to help. The person may view the doctor as an authority and be willing to stop driving. The doctor also can contact the Department of Motor Vehicles and request that the person be reevaluated.

If necessary, take the car keys. If just having keys is important to the person, substitute a different set of keys.

If all else fails, disable the car or move it to a location where the person cannot see it or gain access to it.

Ask family or friends to drive the person or find out about services that help people with disabilities get around their community.

Visiting the Doctor

It is important that the person with Alzheimer's disease receive regular medical care. Advance planning can help the trip to the doctor's office go more smoothly.

Try to schedule the appointment for the person's best time of day. Also, ask the office staff what time of day the office is least crowded.

Let the office staff know in advance that this person may be confused because of Alzheimer's disease. Ask them for help to make the visit go smoothly.

Don't tell the person about the appointment until the day of the visit or even shortly before it is time to go. Be positive and matter-of-fact.

Bring along something for the person to eat and drink and any materials or activities that he or she enjoys.

Have a friend or another family member go with you on the trip, so that one of you can be with the person while the other speaks with the doctor.

Take a brief summary listing the person's medical history, primary care doctor, and current medications.

Coping with Holidays

Holidays are bittersweet for many Alzheimer's disease caregivers. The happy memories of the past contrast with the difficulties of the present, and extra demands on time and energy can seem overwhelming. Finding a balance between rest and activity can help.

Keep or adapt family traditions that are important to you. Include the person with Alzheimer's as much as possible.

Recognize that things will be different, and be realistic about what you can do.

Encourage friends and family to visit. Limit the number of visitors at one time, and try to schedule visits during the time of day when the person is at his or her best.

Avoid crowds, changes in routine, and strange places that may cause confusion or agitation.

Do your best to enjoy yourself. Try to find time for the holiday things you like to do.

Ask a friend or family member to spend time with the person while you are out.

At larger gatherings such as weddings or family reunions, try to have a space available where the person can rest, be alone, or spend some time with a smaller number of people, if needed.

Making Visits Easier

Here are some ideas to share with someone who is planning to visit a person with the disease:

Plan the visit for the time of day when the person with Alzheimer's is at his or her best.

Consider bringing along an activity, such as something familiar to read or photo albums to look at, but be prepared to skip it if necessary.

Be calm and quiet. Avoid using a loud tone of voice or talking to the person as if he or she were a child.

Respect the person's personal space and don't get too close.

Try to establish eye contact and call the person by name to get his or her attention.

Remind the person who you are if he or she doesn't seem to recognize you.

Don't argue if the person is confused. Respond to the feelings you hear being communicated, and distract the person to a different topic if necessary.

Remember not to take it personally if the person doesn't recognize you, is unkind, or responds angrily. He or she is reacting out of confusion.

Connection and Community

Visitors are important to people with Alzheimer's. They may not always remember who the visitors are, but human connection has value to everyone affected by an Alzheimer's diagnosis, including you, the caregiver.

Chapter Eight Review:

☑ From initial diagnosis through the most advanced stages of the disease, there are important, practical tips that can make all the difference in managing the care of a patient with Alzheimer's disease.

☑ Keeping these tips and strategies accessible and reviewing them periodically is important for anyone caring for a person with AD.

☑ The tips and strategies outlined here can help you set guidelines for others who interact with the person with AD.

Chapter 9

There may come a time when the person with Alzheimer's disease requires more care than can be provided at home, and you need to consider a residential facility that can provide more specialized care.

There are a range of facilities that specialize in Alzheimer’s and dementia care, and provide highly specialized, quality care.

> It is important to prepare early, taking into consideration the desires of the person with Alzheimer's disease, the necessary current and future levels of care, as well as location, and budget constraints.

This is where Health, Legal, and Financial planning comes in, and it is important to do it as early as possible.

Your Senior Housing Resource – A Place for Mom

Research, Legal, and Financial planning for senior housing can be overwhelming. Fortunately, our long-term partner A Place for Mom has developed a practical **“Caregiver Tool Kit”** that walks you through all these difficult steps.

Chapter 9

A Place for Mom helps seniors find suitable housing with the assistance of Specialized Senior Care Advisors. Their comprehensive tool kit covers everything you need to know about Senior Housing, and features a printable checklist of the questions to ask when considering any Senior Housing option.

Click here for the free Caregiver Tool Kit from our partners at A Place for Mom.

Chapter Nine Review:

- ☑ For many patients with Alzheimer's disease, there comes a time when full-time, professional care is necessary.
- ☑ Considering and researching options in advance can help you identify the best possible arrangement.
- ☑ Our partners at A Place For Mom offer expert, reliable guidance for those looking into assisted living and nursing home programs.

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