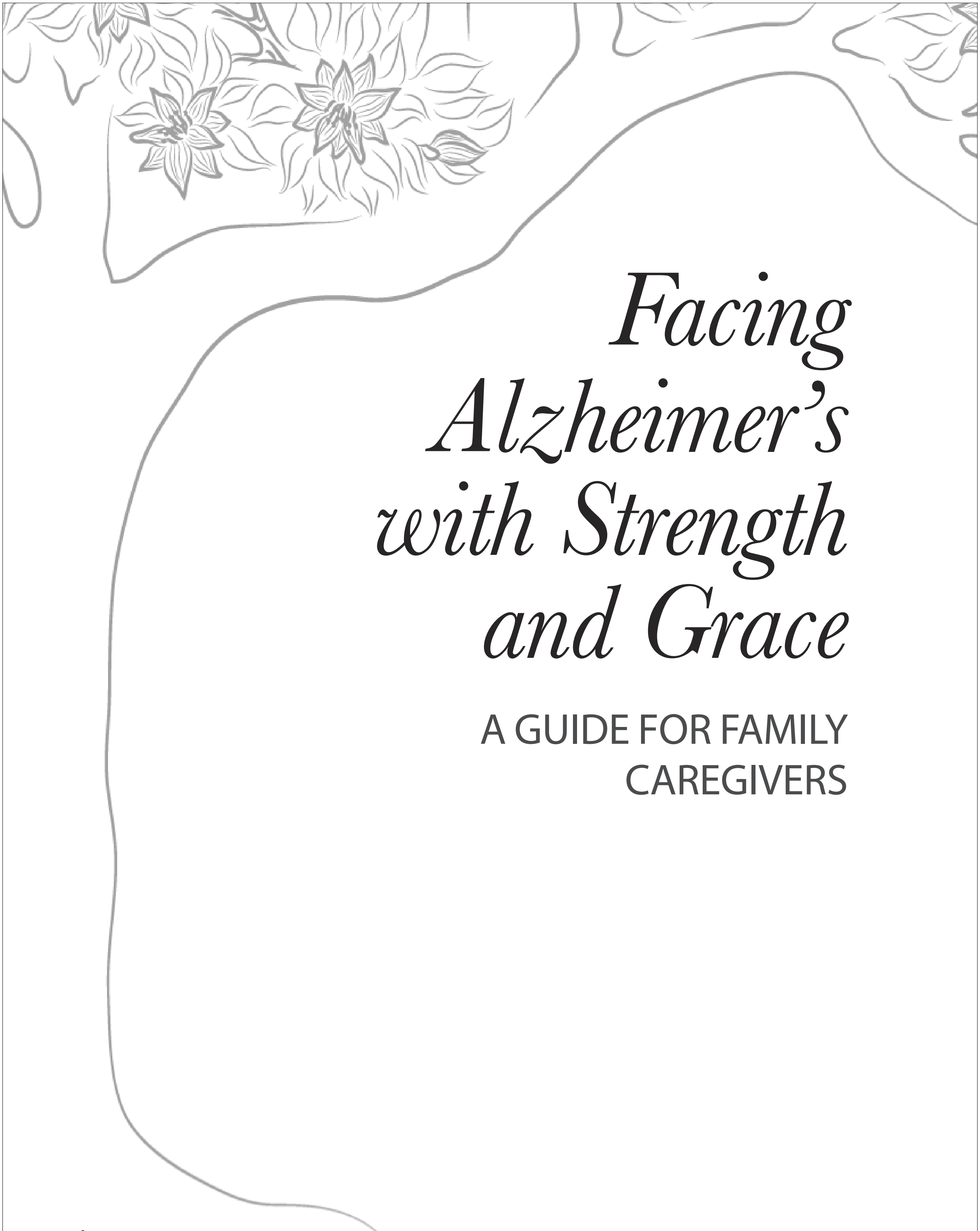

Facing Alzheimer's with Strength and Grace

A GUIDE FOR FAMILY CAREGIVERS

Agingcare.com®
Connecting Caregivers

Introduction

Alzheimer's has entered your life and everything is changing.

Your loved one has been diagnosed, but you still don't know what to expect. Will your mom maintain her sweet demeanor, or will she turn into a rage-fueled menace, prone to hallucinations and outbursts? How long will it be before your husband of 50 years no longer remembers who you are—and how will you ever be strong enough to handle that?

A disease unlike any other, Alzheimer's will forever alter you, your loved one and your entire family. Facing these changes may seem impossible, but the maxim of "knowledge is power" is never more applicable than when discussing the issues of Alzheimer's caregiving.

This guide will equip you with the information necessary to face the mental, physical, emotional, medical and financial challenges of caring for a loved one with Alzheimer's disease with strength and grace. Within these pages you will discover how to approach caregiving for what it is: a journey, during which you and your family will experience the full spectrum of emotions; love, pain, joy, sorrow and—most importantly—hope.

LIVING IN THEIR WORLD

Throughout this eBook, you will encounter special sections labeled, "Living in Their World." These segments feature insights and tips from real-life dementia caregivers and patients who are currently bloggers on AgingCare.com, including:

- **David Hilfiker:** An author and former physician, Dr. David Hilfiker was diagnosed in 2012 with a progressive mild cognitive impairment. His doctor thought it was Alzheimer's but additional testing proved the diagnosis wrong. Now David must learn how to come to terms with the reality of worsening cognitive issues that appear to have no cause.

- **Rick Phelps:** Rick Phelps became an advocate for dementia awareness after being diagnosed with Early Onset Alzheimer's Disease in June of 2010, at the age of 57.

- **Michele DeSocio:** Growing up in a close family, Michele DeSocio learned about the power of love at a very young age and still maintains that she is happiest when with her loved ones. In 1999, she became caregiver to her mom, Jean DelCampo.

- **Marlis Powers:** Marlis describes herself as a "Gramma who loves technology and has a lot to say." She blogs about the issues facing the elderly and her experiences caring for her husband, Charlie, who suffers from dementia.

About AgingCare.com

AgingCare.com arose out of the idea that caregiver-to-caregiver collaboration is the single most potent source of empowerment for people who are taking care of elderly loved ones. We aim to nurture these compassionate men and women by connecting them with each other, as well as an ever-growing collection of online resources, both instructive and inspirational.

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CHAPTER ONE:

Life as an Alzheimer's Caregiver

Life as a caregiver for someone with Alzheimer's disease (or another form of dementia) is defined by change. A loved one's emotional and cognitive states will fluctuate by the day, hour—even by the minute. Relationships with friends, other family members and the outside world will shift as well.

This first chapter will outline the few constants of Alzheimer's caregiving, and prepare you to more effectively cope with the unanswered questions and social stigma you might face while caring for your loved one.

Articles in this chapter include:

- What to Expect as Alzheimer's Progresses
- Standing Tall Against the Stigma of Dementia
- Alzheimer's Caregivers Face Unanswered Questions

What to Expect as Alzheimer's Progresses

The first question many people have after a family member has been diagnosed with Alzheimer's disease is: "What can I expect?"

It's a query without a concrete answer, since cognitive impairment progresses differently in different people. Your mother may maintain her sweet, nurturing demeanor, in spite of the disease, or she may start exhibiting uncharacteristically selfish behavior. Your husband's sense of suitable behavior may stay intact, or it may become warped, causing him to make inappropriate sexual and racial remarks in public.

A few things, however, become relatively certain when Alzheimer's invades your life:

- **Your role will change—and it won't be easy**
  Cognitive decline in your loved one may happen fast or slow, and it will likely be unpredictable. One minute, your wife may be chatting away, happy as a clam, and the next, she may become violent, lashing out for no apparent reason. Like your loved one's mood, your role as a caregiver will always be in flux. In the beginning, you might be mostly called upon to help out with simple tasks—laundry, shopping, cooking. As your loved one's cognitive abilities decline, you might eventually need to provide more hands-on care with activities such as bathing, dressing and going to the bathroom. There may also come a time when you and the rest of the family will have to seriously consider placing a loved one with Alzheimer's into an assisted living community or nursing home. The variability of your journey as a caregiver will cause emotional, relational and financial stress, which you need to prepare for properly. (Strategies to help you attend to your personal needs as a caregiver will be covered in greater depth in Chapter Seven of this eBook.)

- **You're in it for the long haul**
  Nearly one-third of Alzheimer's caregivers provide assistance to their loved ones for more than five years, according to statistics from

the Alzheimer's Association's "2014 Alzheimer's Disease Facts and Figures Report." When the billions of hours of unpaid care provided by relatives are divided evenly amongst the millions of informal Alzheimer's caregivers in America, the typical family member will look after their loved one for about 22 hours each week.

- **Your loved one won't be the same**
  Alzheimer's disease causes the death of neurons and the shrinkage of brain tissue. Depending on which areas of the brain are impacted, an individual's personality can become permanently altered. There may come a day when your wife of 40 years no longer remembers who you are, or your once-loving father starts screaming at you every time you walk into the room. When faced with these heart-rending situations, the only way to cope is to give yourself permission and time to grieve the loss of the loved one you once knew, and try to make peace with who they are right now.

- **You won't be the same**
  As any long-term caregiver will tell you, caregiving can change your personality. AgingCare.com Expert Carol Bradley Bursack says these changes may be either positive or negative. "Much depends, of course, on personal insight, general openness to change, feelings for the person you are caring for and your own physical and mental health. In the end, whether the changes that remain with you are positive or negative may rest with how you view life in general."

Living in Their World

The following is an excerpt from Rick Phelps' post, "What Can I Do?"

> *"I think the most important thing to remember is how your loved one was, not how they are now.*
>
> *Chances are, they belonged to the generation that was a proud, patriotic and private generation. Hardly ever complaining. Used to doing things themselves. Hate asking anyone for help, and certainly didn't want to be a burden on anyone.*
>
> *But all of this goes out the window when you reach the mid-to-late stages of this disease.*
>
> *As an emergency responder, I used to make life and death decisions, sometimes in seconds. Now I stand in front of my sock drawer for minutes, thinking: 'Which pair?'*
>
> *I cannot stress enough how everything changes with this disease. Most family members and caregivers see this change, yet treat their loved one as things once were. It's natural but, in the end, it won't work.*
>
> *So the answer to 'What can I do?' is always: nothing. Nothing—meaning you can be there for them, you can assist them with daily things, you can be their caregiver...but you can't change what is happening.*
>
> *Try to learn all you can about what is happening to them, but understand that you can't fix it. As bad as things are today, today may very well be the best day they ever have again."*

Standing Tall Against the Stigma of Dementia

We fear Alzheimer's. We fear becoming the stereotypical dementia patient: slumped in a wheelchair, staring out the window, our minds as blank as our gaze.

From this fear, a powerful and pervasive stigma is born. A stigma fueled by a lack of legitimate knowledge about the realities of the disease. A stigma with a crippling ripple effect that contributes to the isolation of those with Alzheimer's and their families.

Even longtime friends can vanish when an individual is diagnosed with Alzheimer's. They may feel uncomfortable in the presence of a person with cognitive impairment, they may not know what to say, or be worried that they might do something to upset them.

This abandonment, benign or not, can take a toll on family caregivers:

> *"My 'friends' have pretty much disappeared. No phone calls, not even an email. It's a lonely life."*
>
> *"Now that Mama lives with me, I have to initiate gatherings with my friends—they seldom call me anymore."*
>
> *"Friends are hard to find, or they act like they don't even know me—it's as if my entire life is a stigma and they don't want to be seen with me."*

These are the typical laments of family members of those with Alzheimer's; and the situation is no less frustrating for those diagnosed with the disease. "Feelings of isolation are what I fear the most and what, I suspect, many with Alzheimer's suffer greatly from," says AgingCare.com blogger, David Hilfiker.

What can you, as a caregiver, do to combat and cope with this stigma?

- **Make peace with reality**
  Regardless of the truth (or lack thereof) behind the belief, Alzheimer's has become synonymous with a loss of identity. There will probably always be some form of fear-fueled stigma attached to the disease. There will be people who won't understand why your mother makes inappropriate comments in the grocery store, or why your husband won't stop repeating the same story over and over. Harboring anger against these individuals isn't helpful and will only serve to increase your stress (and consequently, your loved one's stress, as well).

- **Seek out opportunities to educate**
  Instead of holding on to resentment, try gently educating those who don't know much about Alzheimer's on the realities of the disease. The term 'teachable moment' may border on the cliché, but it's an accurate way to describe those instances when a friend or family member's misunderstanding of Alzheimer's can be transformed into an opportunity to spread knowledge and awareness.

- **Don't allow yourself to be silenced**
  In order to reduce the power of "the scarlet A," AgingCare.com Expert Deanna Lueckenotte says caregivers have to "let go of the fear that surrounds you and reach out to your community. Chances are, you'll not only discover a surprising amount of support, but you might also be able to help others overcome their own fears." Sharing your experiences with the disease in an open, honest manner can indeed encourage others to do the same.

Remember, your loved one is going through a similar ordeal, compounded by the confusion and other cognitive difficulties of this particular type of dementia. It will not always be easy for them to articulate how the disease is affecting their mind, so they may need your help and encouragement when speaking about their Alzheimer's.

"When people ask me, 'What do you miss the most?' My answer is always, 'Everything,'" says AgingCare.com blogger, Rick Phelps. "Because once you have this disease, nothing is the same."

Alzheimer's Caregivers Face Unanswered Questions

Hindsight may be 20/20 but, when it comes to being an Alzheimer's caregiver, foresight is essentially non-existent. There are many things that seem obvious after you've gone through them with a loved one who has the disease, but that you'd never have considered, prior to experiencing them.

What do most caregivers wish they'd known when they began their journey with their loved one? An illuminating AgingCare.com survey offers some insight:

"I wish I'd known…

how to wave my magic wand and have family understand what's happening to Mom."

how to place Dad in a home without them taking him to the cleaners."

how difficult taking care of an Alzheimer's patient really is. Had I really known what I stood to lose, I never would've taken this on."

how to find the right doctor."

that I'd soon miss the days when Dad would tell the same story over and over again; now he can't even talk."

that a loved one doesn't have to be put in a nursing home if they don't want to be."

how to keep him healthy and engaged as his mobility and memory declines."

how hard it really is to be a caregiver. What 24/7 really meant. How to deal with the day-to-day craziness."

what's the best medicine to help them sleep through the night."

how to ease their anxiety and frustration."

when it's time to move them into a facility, and how to get them to go if they don't want to."

that I'd have to eventually accept that, no matter how active and alert and precise Mom used to be, this is her now. "

how to get him to take a shower."

what to expect as Alzheimer's progresses."

how to get help."

how long this will last."

Some of these questions have answers; some don't. Some answers are simple; others are complex.

Even the world's leading experts in Alzheimer's don't know everything there is to know about the disease. In fact, very little is certain when it comes to the ailment's causes and underlying pathology.

Top 7 Alzheimer's Myths

1. **Alzheimer's and dementia are the same thing**
   Dementia is the overarching term used to describe conditions that cause cognitive difficulties. Alzheimer's is a type of dementia.

2. **Memory loss is a normal part of aging**
   Occasional slips may become more common with age, but the severe memory loss associated with Alzheimer's is not normal.

3. **Alzheimer's is preventable with diet and exercise**
   Healthy lifestyle habits are important for successful aging, but nothing has been shown to successfully prevent Alzheimer's.

4. **Alzheimer's only affects old people**
   Approximately five million Americans have Early-Onset Alzheimer's Disease (EOAD), which can occur in people in their 30s, 40s and 50s.

5. **There's an "Alzheimer's gene"**
   The APOE4 gene may increase EOAD risk, but it doesn't guarantee a person will develop the disease.

6. **Coconut oil can cure Alzheimer's**
   Individual reports of the benefits of coconut oil for people with Alzheimer's exist, however, there is currently no cure for the disease.

7. **Brain puzzles can slow down Alzheimer's**
   Puzzles may help keep a person's mind active, but they can't effectively prevent or slow down the progression of Alzheimer's.

CHAPTER TWO:

The Daily Challenges of Alzheimer's

Managing the difficult behaviors caused by the effects of Alzheimer's on a person's brain can be challenging. Whether it's getting a loved one to stop repeating the same question over and over, or calming them down when something triggers an outburst, responding in a productive way is essential to maintaining the sanity and safety of all involved.

This chapter will describe how to see the world through the eyes of someone with Alzhemier's, highlight communication strategies, outline ways to minimize the fallout from behavioral outbursts and offer tips to manage sleep disturbances caused by Alzheimer's.

Articles in this chapter include:

- The World Looks Different With Dementia
- 10 Tips for Talking to Someone With Alzheimer's
- When It's Okay to Lie to a Loved One
- How to Stop Repetitive Remarks
- Bathing Tips for People With Alzheimer's
- Diffusing Difficult Behaviors
- Sundowners and Other Sleep Issues

The World Looks Different with Dementia

Variances in temperament and life experience cause everyone to see the world slightly differently, but people with Alzheimer's and other dementias often encounter a significantly altered state of reality.

Hallucinations, delusions and delirium may seem like interchangeable terms, but they are actually three distinct issues. Alzheimer's caregivers need to know the differences between these terms in order to understand how their loved one's disease is affecting their perception of the world around them.

HALLUCINATIONS

A hallucination is a multi-sensory experience that occurs while a person is conscious and awake. These episodes look, feel, smell and sound real, but they are actually mental fabrications.

Hallucinations can be caused by a variety of ailments, including: Alzheimer's and other dementias, medications, schizophrenia, eyesight and hearing issues, dehydration, drug and alcohol abuse, and certain infections. A person with dementia is most likely to experience hallucinations that are visual (e.g. seeing ants crawling all over the walls of the bedroom), but may also hear voices or music that doesn't exist, feel as though their skin is infested with bugs, or smell phantom scents.

For people with Alzheimer's, hallucinations can be frightening or comforting. For instance, hearing and seeing children playing around the house may conjure up happy memories in your loved one, but perceiving the dark-colored bath mat in front of the shower as a bottomless pit can be terrifying. Comforting hallucinations don't necessarily have to be addressed; indeed, allowing a loved one to be happy in their world, in that moment, may be the best thing for them.

When hallucinogenic episodes become so extreme that they interfere with a person's safety and well-being, antipsychotic medications may be prescribed. However, it's important to bear in mind that the debate surrounding the question of "Should someone with Alzheimer's be given antipsychotics?" is ongoing, with experts' opinions falling on either side.

There are non-pharmaceutical steps you can take to minimize the chances of a loved one experiencing hallucinations, such as removing or covering up mirrors (self-reflections can seem like a stranger to a person with Alzheimer's), and being aware of sights and sounds that could be confusing (e.g. air conditioner noise, shadows cast by furniture).

DELUSIONS

A delusion is an untrue belief that is firmly held, despite the fact that it isn't supported by reality or seems highly implausible. Delusions are often the result of paranoia—a pattern of irrational thoughts fueled by anxiety and fear.

A common delusion of people with Alzheimer's is that their caregiver (or another family member) has stolen something from them. If a special object has been misplaced but the person with Alzheimer's can't remember where it is, they may believe that someone took it from them, as their mind attempts to fill the holes left by memory loss.

Depending on the delusion, distractions and reassurances are often the most effective ways for calming a loved one. If your mother insists you've stolen her favorite necklace because she can't find it, tell her that you'll help her look for it after dinner. Chances are, by the time the meal is over, your mom won't remember the accusation.

DELIRIUM

Marked by confusion and rapidly changing mental states, delirium can arise due to anything from dehydration to a urinary tract infection. Unlike hallucinations and delusions—which can be caused by more permanent issues, such as Alzheimer's—delirium is often a short-term, easily-reversible condition.

However, it is important to note that even when delirium is caused by a treatable condition—such as a urinary tract infection—extreme declines in cognitive abilities in people with a pre-existing dementia can occur. Thankfully, treating the underlying condition will almost always result in the restoration of the person's former level of functioning.

A person with Alzheimer's will likely cycle through various hallucinations, delusions and episodes of delirium during the course of the disease.This makes it essential that you, as their caregiver, learn how to view the world through their eyes.

Looking Through Dementia's Lens

Rick Phelps and Harry Urban have each been battling Alzheimer's for years. As advocates for the millions of men and women with the disease, the two men travel around, speaking about how the condition has changed their lives.

Here are their responses to the most common Alzheimer's questions:

> ***Q: Are you scared?***
>
> ***Phelps:*** *Yes, I'm scared of the unknown. I don't know if I have six months to communicate, or six years. I worry about going to bed at night and whether I'm going to be as bad tomorrow. This disease is with you 24/7. It's in my brain and I can't get away from it—it is a scary thing."*
>
> ***Q: What daily challenges do you face?***
>
> ***Phelps:*** *It's probably better for me to tell you what I can do as opposed to what I can't. I can mow the grass—I just love it. It probably sounds trivial, but it's a godsend for me. I even like to go and mow the yards of my older neighbors. I'm not allowed to touch anything that you plug in. I have good intentions, but I can't recognize what's wrong until it's too late. I remember trying to hang a television on my niece's bedroom wall. I forgot to find a stud, so it fell off and ripped a huge hole in the wall.*

Q: What frustrates you?

Urban: *Making a decision on something. Even if I have strong opinions about something, if you give me choices, I get frustrated. Going to a restaurant and being faced with so many options, I get annoyed. Driving [is frustrating]—because I get so confused—I don't know which lane to be in, whether to go left, right or straight. If you take me shopping, I will go crazy because of all the voices and the strange people all talking at the same time.*

Q: Why do you forget things? Become argumentative? Exhibit bad judgment?

Phelps: *It's important to understand that I don't understand. I don't have any idea why I forget some things and remember others. It's not intentional—I just don't have the ability to realize what I'm doing is wrong.*

Urban: *You can't argue with me, I'm too headstrong. If I think it's one way, you're not going to convince me otherwise, and the only one who's going to get frustrated is you. But, I'm not being nasty—it's just that this is my world. For example, I always have to walk behind my wife when we go out. At first she wanted me to walk beside her, but I have a fear of getting lost, so I want to keep her in my eyesight. If someone is talking to me and I'm quiet or I don't acknowledge them it's because sometimes we need to go to our faith place. We're so stressed out by this disease that we need a place to go in our mind to get away from Alzheimer's. But, you should always talk to us; we're still in there. You have to know that you've reached us, even if we don't look at you or respond.*

Q: How do you deal with the bad days?

Phelps: *You deal with them because there's no other way to deal with them. On my difficult days I can tell everything isn't what it should be. It's worse during the winter. I get sundowners when I'm caged up in the house. It's almost like a migraine; I know something isn't right and I hope it doesn't last long. On those days, I stay away from the computer and I don't go out.*

Urban: *You would not believe how many hours I sit on my bench outside and think about how I used to do so much. I used* *to be on top of the world, but I can't think like that. I have to focus on what I can do. I'm here for a reason.*

Q: What advice would you give to caregivers?

Phelps: *Accept this disease and accept what's coming down the road. One of the most important things I've learned is that if you or your loved one thinks you might have a problem, then you probably do. Check in to long-term care insurance before you're diagnosed because it's prohibitively expensive afterwards. This disease will devastate you financially. Try to look at the positive in everyone and everything. As bad as this disease is, we've found friends and support.*

Urban: *Learn what you can about this disease. I'm not telling you to pick up a book and learn about the different stages. I'm saying that you need to try and learn why your loved one does the things they do. You have to learn to live in our world, because we can't live in yours—it doesn't exist for us anymore.*

10 Tips for Talking to Someone with Alzheimer's

The mental changes that accompany Alzheimer's not only impact a person's ability to recall past events, they can also dramatically alter their capacity for communication.

"People with dementia tend to use language that more directly links to their emotions and what they really want to say than the rest of us do," says Susanna Howard, AgingCare.com Expert. "They use words that wouldn't typically be used in an 'ordinary' conversation."

Here are ten tips to keep conversations with a cognitively impaired loved one positive and productive:

1. **Face-off:** Establishing friendly eye contact and using a person's name are good rules of thumb to follow during any kind of dialogue. When speaking to a person with Alzheimer's, make sure you get their attention by saying their name. Assure them that they have your full attention by facing them and looking them in the eye.

2. **Diminish distractions:** Background noise from a television, radio or a fan can distract your loved one during a conversation, making them more likely to lose track of what the discussion is about. Finding a quiet place where the two of you can converse in peace will result in a more fulfilling dialogue.

3. **Converse one-on-one:** The more people who are involved in a discussion, the more complicated it becomes. Whenever possible, try to keep talks with a person who has Alzheimer's one-on-one. Even small groups of three or four people could make your loved one confused and anxious.

4. **Keep things simple:** Comments and conversations should be kept simple and to the point. Always refer to nouns by their actual name (i.e. when pointing out a pretty bird on a walk, say "bird" instead of "it"). Being faced with too many choices can be frustrating for

someone with Alzheimer's, so steer clear of open-ended questions. For example, if you're having a discussion about what outdoor activity your loved one wants to do, don't say, "Where would you like to go today?" Instead, it's better to ask, "Would you like to go to the park?"

5. **Avoid conflict:** Don't argue with a person who has Alzheimer's—you won't win and it will only make both of you more agitated. Avoid inflammatory comments such as, "I just told you that," and "You're wrong," and learn to recognize when giving in and walking away from a brewing feud is the best course of action.

6. **Extra points for patience:** Be patient when talking to a loved one with Alzheimer's. Resist the temptation to complete their sentences—it won't help them remember and it's likely to be more frustrating to them than anything else. Instead, try asking a question that might jog their memory. For example, if they are wandering around the kitchen and saying, "I want…I want," you can ask, "Are you hungry? Would you like something to eat?" Howard advises caregivers not to shy away from silence, even if it seems awkward. "Give your loved one time to respond and offer them quality attention," she says. "Embrace silence and being."

7. **Enter their world:** Pledge to temporarily live in your loved one's reality—which can be much different from yours. Depending on what stage of the disease they are in, your loved one may believe their deceased spouse is still alive, or that they themselves are an accomplished concert pianist. As long as living in their reality isn't hurting anyone, it's best to just play along. If this makes you feel guilty, remember that their mind has been hijacked by disease and no amount of persuasion on your part is going to convince them that they are wrong. Providing support and validation will go a long way towards easing their anxiety and brightening their mood.

8. **Clue into visual cues:** Body language is a powerful conversational tool, no matter who you're talking to, but physical indicators are especially important when you're trying to communicate with someone whose cognitive ability is diminished. Your loved one may not be able to verbally articulate their happiness or frustration, but paying attention to their facial expressions and body positioning can help you better determine their disposition.

9. **Get creative with communication:** If words aren't sufficient enough to get your point across, don't be afraid to experiment with different types of communication. Use verbal, visual and auditory cues to help your loved one understand what you are saying. For example, if you want to know whether they would like turkey or ham on their sandwich, pull out and point to each option as you ask the question.

10. **Just keep talking:** Even if your loved one has limited powers of speech (or can no longer talk at all) never underestimate the power of conversation. Talking to a person with Alzheimer's who is nonverbal will let them know how much you support them, not only as their caregiver, but also as someone who loves them.

Living in Their World

The following is an excerpt from Michele DeSocio's post, "Living Proof that Alzheimer's Can't Steal Love:"

> *"Mom mostly stares and sleeps, but she can put some words together and knows me. I visit often and she lights up when she sees me. Sometimes she is confused who I am, but I learned to look her in the eye and tell her my name. Her response is, "I'm so happy, I love you, and you are beautiful." She can, to my amazement, recite the Lord's Prayer and remembers many songs from way back when.*
>
> *Today I was not feeling well, but I stopped in to visit mom. There was a live banjo show, but mom was sleeping. I gently woke her and brought her to a quiet family room they have.*
>
> *I brought her favorite cookies—Fig Newtons—and a Coke. I played her favorite tunes and we sang together.*
>
> *Out of nowhere, mom said "I am worried about you." I hugged her and reassured her I was okay. Mom has not been able to ask me questions for a long time now. I did not tell her I was not feeling good.*
>
> *This is not the first time she has surprised me with saying something that mothers often say to their children, out of the blue. It's always something I need to hear.*
>
> *I had my mom back today just for a moment.*
>
> *I held back the tears until I got in the car. I miss my mom, but I know that she is there and that she know what's going on. I believe this is love.*
>
> *Love is not a memory it's a feeling in the heart and soul, never to be forgotten. This disease can take away almost everything, but not the love."*

When It's Okay to Lie to a Loved One

From infancy, most of us are told that it's never right to lie. As we grow older, and the line between truth and falsehood begins to blur, this directive becomes increasingly difficult to follow. By the time a person becomes a caregiver, they're likely to be well acquainted with the concept of the "white lie"—a fib told to protect a loved one's dignity, sense of pride, etc.

It's an unfortunate truth, that family caregivers are often called upon to be untruthful with their loved ones.

A whopping 73 percent of people have lied to their elderly family members, according to a recent AgingCare.com survey. Forty-three percent of these men and women find themselves fibbing on a weekly basis.

Most lie about their feelings in an effort to shield their loved ones from additional stress. But those whose family members have Alzheimer's must often engage in a particular form of benign deception—called "validation therapy" or "therapeutic lying"—in order to keep their loved ones calm.

Say, for example, that it's the middle of the night and your Aunt Megan won't go to sleep because she believes her recently deceased husband, Carl, will be coming home from work soon. If you insist that Uncle Carl is dead, you'll not only upset Aunt Megan in the present, but she'll likely soon forget what you told her and the cycle will repeat itself. However, if you tell Aunt Megan that Uncle Carl might be a bit late coming home and he didn't want her to stay up waiting for him, you may be able to calm her down enough to get her to go back to bed. In the morning, Aunt Megan probably won't recall what transpired during the night.

Though there is still some debate about the ethical nature of therapeutic lying to people with dementia, many professional health care workers adhere to the practice. A recent survey of British nurses, published in the journal "Nursing Standard," found that 98 percent of them had lied to a patient with dementia.

It may seem disrespectful to lie to a loved one; almost like you're treating them like a child. But AgingCare.com Expert Carol Bradley Bursack has this to say about the practice of validation therapy:

"If we, as caregivers, continually 'correct' their thinking, we are chipping away at any self-esteem that they have managed to retain during their slide into dementia. Constant correction can be demeaning—even cruel—though it's generally not meant as such.

Validation is not about treating someone as a child. It's about respecting the person with dementia as he or she sees the world. It's about overcoming our own bias. It's about adding some dignity to the last years of our elders' lives by accepting that maybe there is more than one way to see the world."

Living in Their World

The following is from Marlis Powers' post, "Dementia Fixations and White Lies:"

> *"I have a friend whose Alzheimer's plagued husband insisted that he had an appointment in Boston, a two-hour drive from home. He told her this day after day. She assured him that, no, he did not have an appointment in Boston.*
>
> *Finally, one day, out of frustration she put him in the car and headed south to Boston. After driving about twenty miles it occurred to her to tell him that she just received a phone call that cancelled the trip. She turned around and drove home and that was the last she heard about the Boston appointment.*
>
> *These incidents may seem funny to those who may not have experienced something similar. But to those of us going through daily fights over ridiculous things that are causing our loved ones distress, it can be enough to make us question our own sanity.*
>
> *Sometimes deceit is necessary to quell the patient's obsession with something.*
>
> *Don't feel like you are being sinful in telling them a "white lie." The lie may be in their—and your—best interests."*

How to Stop Repetitive Remarks

Memory loss and anxiety can cause a loved one with dementia to repeat themselves—asking the same questions over and over, or regaling those around them with the same story, multiple times a day. When this happens, you may be at a loss as to how to get them to stop.

Teepa Snow, an occupational therapist and dementia education expert discusses how to respond to four of the most commonly-repeated phrases:

> ***Repeat #1:*** *Do I have a doctor's appointment today?*
>
> ***Response:*** *Yes you do. I'm sorry, I thought I said something, but maybe I didn't. (Pause for response—if they say something, use some of their words to affirm their feelings, then add a new thought pattern.) In the meantime, can you help me clip these coupons?*
>
> ***Explanation:*** *Alzheimer's interferes with a person's ability to process and store new information. Some days, your loved one will be able to remember recent events, such as doctor's appointments. On other days, as Snow says, "their wiring won't work." When your loved one is repeatedly asking the same question, it's because they're having trouble with their short-term memory. In these cases, you need to do two things: let them know that it's okay that they are having trouble (by saying "sorry"), and get them out of the pattern of repeating. A good way to break the cycle is by giving them something else to do. Simple tasks that enable your loved one to be successful—like clipping coupons—will offer them something else to think about while making them feel good because they are helping you out.*

Repeat #2: *When are we going to my doctor's appointment?*

Response: *I just spoke with him on the phone and he says he doesn't need to see you again anytime soon.*

Explanation: *In this scenario, avoid telling your loved one that they've already been to the doctor's. "The key is to let them know that the doctor doesn't need to see them again, without confronting them when their brain is saying that they haven't been to the doctor," says Snow. Arguing with a loved one who has Alzheimer's will only amplify their anxiousness. They will begin to feel as though they cannot trust themselves and will be even more likely to ask you things repeatedly in the future.*

Repeat #3: *Where are we going again?*

Response: *We're going to the doctor's. Hey mom, I made a CD for us to listen to, it has some of your favorite songs on it. See if you can recognize the artists.*

Explanation: *Being trapped in a car with a loved one who keeps asking you where you're going (or when you'll get there) can be exceedingly frustrating, but it's important to avoid lashing out in these situations. The key to handling this scenario is to respond to your loved one and engage them in doing something else. Activities that involve music are often most effective, since music is one of the few retained skills in people with Alzheimer's. It's a good idea to use older music that will be more familiar to them.*

Repeat #4: *Have I ever told you about that time…?*

Response: *Really? Tell me about it!*

Explanation: *While repetitive litanies can be obnoxious to caregivers who've heard the same tale dozens of times before, Snow says such stories are an important communication technique for someone who is losing their memory. Your loved one wants to engage with you, but may feel stupid or frustrated because you're always in control of the conversation. They will pick old stories they know they can remember so that they can have a dialogue with you instead of being talked at all the time. Encouraging them to "tell me about it" is a supportive method* *that lets your loved one know you want to talk with them. Even if you're hearing a story for what seems like the millionth time, Snow says it is also a good idea to document the tale in some way. As their Alzheimer's progresses, your loved one will gradually lose their ability to tell you that story, but the narrative is a good reference tool because it may tell things about them that will be helpful in the future. Listening to (and recording) the tales of your loved one's life will help you get to know them better so, as Snow says, "as they lose themselves, you can help them reestablish the connections."*

Bathing Tips for People with Alzheimer's

The challenge of getting a person with Alzheimer's to bathe is not uncommon. Caregivers often lament that their loved ones are either scared of the bathing process, or don't even see a need for it.

Here are a few reasons your loved one may resist taking a bath or shower, and how to handle them:

- **They think they just took a shower**
  It may have been over a week since your loved one's last shower, but memory issues can make it seem like they just took a bath a few hours ago. In these instances, it may help to offer some sort of enticement—perhaps a midday outing to their favorite lunch place—to get them to clean up.

- **They don't understand what it is**
  There may come a point when your loved one will no longer be able to comprehend the showering process. They don't understand why water is pouring on their head and soap is being rubbed on their body. This can lead to anxiety and emotional outbursts. To cut down on their fear, keep the water and air temperature warm (but not hot)

and consider using a hand-held showerhead that will allow your loved one to see where the water is coming from. Approach the process gradually, in a step-by-step fashion; help them remove their clothes.

- **They are afraid**
  If your loved one is in the advanced stages of Alzheimer's, they may have a visceral fear of water, which can make bath time difficult. Sponge baths can be a viable alternative to showers, just make sure to go slowly and communicate where you're going to put the cloth or sponge next, so as to avoid surprising them. For those who are afraid of slipping in the shower, consider installing a grab-bar or shower seat to keep them steady.

- **They are embarrassed**
  If your loved one requires assistance to bathe, they may become embarrassed to the point of refusing to let you help them. Especially when an adult child is taking care of a parent of the opposite gender, it's common for a sense of shame to creep in for both parties. Be mindful of your loved one's desire for privacy, and know that hiring a specially-trained professional caregiver to perform these more intimate tasks may help preserve your loved one's modesty and dignity.

Bear in mind that a daily shower isn't necessary—or beneficial—for a person with Alzheimer's who is resistant to the act. Dry shampoos and soaps can help keep your loved one clean in between baths.

Above all, understand that forcing a resistant loved one to bathe will only result in conflict, and accept that it's enough to simply do your best to keep them clean and healthy.

Diffusing Difficult Behaviors

The disorientation and confusion caused by Alzheimer's can make a loved one more prone to aggressive outbursts. The disease also often damages the mental filter that adults develop to determine the difference between appropriate and inappropriate behaviors.

This confluence of symptoms can make for some embarrassing and dangerous situations, especially if you are out in public. Say one morning you decide that taking mom with you to the grocery store is a safe, easy way to help her get some exercise and social stimulation. The two of you are walking up and down the aisles of the recently renovated store when, without warning, she releases a profanity-laced tirade that's foul enough to make you want to crawl under the shopping cart and pretend to be invisible.

That's clearly not an option, so what do you do?

- **Keep your cool:** Remaining calm is the key to handling aggressive behavior in a loved one. A level-headed approach will enable you to think more rationally and your calm demeanor may rub off on them as well. A recent "University of California, San Francisco" study found that people with mild forms of mental impairment (including Alzheimer's) often have an increased sensitivity to the emotions of those around them, and may copy those emotions—a phenomenon called "emotional contagion."

- **Move along, there's nothing to see here:** If you're in a public place, try to draw onlookers' attention away from your loved one; explaining, if you can, that they have dementia and cannot help themselves.

- **Perform a search and rescue:** Try to figure out what could have ignited your loved one's outburst. If you are able to isolate the root cause, it may help you prevent another episode in the future. You can also attempt to distract your loved one, drawing them away from the source of their frustration by giving them a simpler task that will bestow a sense of accomplishment, once they complete it.

- **It's not them, it's their disease.** A person with Alzheimer's faces a crushing amount of confusion and frustration that can manifest in unseemly outbursts. This fact may, at times, be difficult to keep in mind, but maintaining this perspective will help you cope more effectively with inappropriate behavior.

These same strategies apply regardless of whether an outburst occurs at home or in public. Staying composed and searching for the trigger of your loved one's aggression are essential to helping them calm down.

Sundowners and Other Sleep Issues

Sleep issues are a well-documented side effect of most manifestations of dementia, but are especially common in those with Alzheimer's disease. This presents a problem for caregivers, since, if a loved one isn't sleeping, neither are they.

"Quite often, the lack of sleep is what first causes a caregiver to look at placing a loved one in a facility," says Maureen Bradley, LPN, CDP, director of the Alzheimer's care programs at several skilled nursing facilities run by the Royal Health Group.

Many sleep-deprived caregivers are plagued by the same questions: How do I get my dad to sleep through the night? Why does grandmother sleep all day? Why does my mom get so anxious at night?

A group of Alzheimer's experts weighs in on six common sleep questions:

1. **Does Alzheimer's cause sleep problems?** Yes, Alzheimer's can wreak havoc on a person's ability to fall (and stay) asleep. Suddenly adopting an irregular sleep schedule and sleeping more than usual are both typical side effects of the disease, according to Emerson Wickwire, PhD, Sleep Medicine Program Director at Pulmonary Disease and Critical Care Associates. "As Alzheimer's progresses, a person's circadian rhythms tend to become desynchronized. They may become prone to dozing intermittently throughout the day, then experience difficulty sleeping at night."

2. **Is my loved one "sundowning?"** Sundowning refers to the collection of behaviors exhibited by someone suffering from sundowners syndrome, a dementia-related disorder that causes anxiety and agitation to increase as night falls. Experts believe that anywhere between 25 and 66 percent of people with dementia experience this condition. If your loved one is sundowning, they may become restless, pace around, shadow you or wander off. These behaviors

typically start to occur sometime between 3 p.m. and 7 p.m. and may continue throughout the night, according to Bradley.

3. **Why do people with Alzheimer's have unusual sleep cycles?** The precise cause of sleep problems in those with Alzheimer's is currently unknown, though many factors likely play a role. Wickwire says the disease alters the areas of the brain that regulate hormone secretion, appetite and cognitive functioning. Messing with any or all of these elements can result in restless nights. Bradley adds that other contributors to unusual sleep cycles (e.g. lack of activity during the day and an inability to recognize a familiar environment, such as a bedroom) can also cause issues.

4. **Is it okay to let someone with Alzheimer's sleep all day?** This is a tricky question. People in the later stages of Alzheimer's disease may spend much of the night lying awake in bed. These sleepless nights translate to drowsy daytimes. According to Bradley, boredom is another big contributor to daylight lethargy. "Caregivers are often afraid to upset a loved one, so they just let them sleep," she says. But, this can spark a vicious cycle; letting a loved one lie in bed for too long during the day makes them more prone to waking up in the middle of the night. Bradley suggests trying to keep an individual with Alzheimer's engaged and active during the day. It doesn't have to be anything special: adult day care activities, physical exercise, special outings, even simple errands can keep your elderly loved one engaged and active. If they do need rest, Wickwire recommends scheduling 20-30 minute naps during the day—long enough to be refreshing, but short enough not to interfere with nighttime sleep.

5. **What about sleeping pills?** "I don't like sleeping pills," says Bradley. "They put a person at risk for falls and cause them to feel hung over the next day." Indeed, research consistently indicates that, for older adults, the risks associated with prescription sleep aids often outweigh the potential benefits.

6. **How can I help my loved one sleep through the night?** Expecting someone with Alzheimer's to get a solid night's sleep may be a pipe dream, but that doesn't mean there aren't strategies caregivers can try. In addition to keeping a loved one active and engaged during the day, sticking to a routine, and avoiding caffeine and alcohol can also

reduce sleep problems in people with Alzheimer's. Drawing the blinds to block out nighttime darkness, making sure a loved one gets some sun exposure during the day and crafting a sleep-inducing bedroom environment (i.e. proper temperature, comfortable bedding, etc.) are additional recommendations for getting a person with Alzheimer's to sleep more soundly. If your loved one does wake up in the middle of the night, don't encourage them to try and go back to sleep. Bradley says it's better to get them started on a task, such as folding laundry or reading a book, rather than trying to get them to stay in bed.

3 Strategies to Help Someone with Alzheimer's Sleep Soundly

- **Stay calm**
  People with Alzheimer's tend to mimic and feed off of the behavior of those around them. Keep your cool. Don't raise your voice and don't argue with your loved one.

- **Stick to a schedule**
  A consistent nightly routine can have a calming influence on someone who becomes anxious at night.

- **Provide a peaceful environment**
  Draw the curtains so your loved one cannot see the darkness outside. Turn up the lights, play soothing music and keep them away from a lot of activity.

CHAPTER THREE

Managing Alzheimer's Medical Care

Medical knowledge is minimal when it comes to the facts of Alzheimer's disease. The cause and cure of the ailment remain elusive, and effective therapies and treatments are hard to find. This lack of concrete knowledge, combined with the anxiety and desperation engendered by Alzheimer's, can make managing a loved one's medical care extremely challenging.

In this chapter, you will learn the basics of Alzheimer's disease (including which medications may help), how to decipher Alzheimer's news and research with a critical eye, and how to be an effective healthcare advocate for your loved one.

Articles in this chapter include:

- Alzheimer's Disease: Just the Facts
- Medication Management Strategies
- What Every Caregiver Should Know About Alzheimer's Research
- How to be an Effective Healthcare Advocate

Alzheimer's Disease: Just the Facts

The complex arena of Alzheimer's medical care will require you and your loved one to interact with a variety of doctors and specialists: Geriatricians, gerontologists, geriatric psychiatrists, geriatric nurse practitioners, neurologists and neuropsychologists, to name a few.

The key to being able to engage in productive conversations with these medical professionals is to increase your overall knowledge about the disease (e.g. which medications are prescribed to people with Alzheimer's, what other therapies are available, whether people with Alzheimer's are more susceptible to acquiring other health conditions, etc.), and make sure you stay up-to-date on important news about Alzheimer's research and care.

There are few things that are known about Alzheimer's disease:

- **Age increases your risk**
  After age 65, a person's risk for developing Alzheimer's increases twofold, every five years. About 50 percent of people 85 and older deal with symptoms of Alzheimer's or some other form of dementia, according to the Centers for Disease Control and Prevention.

- **There is no cure**
  Nothing can cure, stop or delay the advancement of Alzheimer's. However, in some individuals, medications may temporarily slow the symptoms of cognitive decline.

- **Healthy body, healthy mind**
  Research consistently shows that maintaining a healthy body is an important part of maintaining a healthy mind. Hypertension, obesity and cardiovascular disease have all been linked to an increased risk for developing dementia. Eating a well-balanced diet and avoiding excessive alcohol consumption and smoking can help when attempting to stave off Alzheimer's disease.

THE EXTREME COSTS OF ALZHEIMER'S MEDICAL CARE

Alzheimer's and other dementias are costly ailments for government programs such as Medicare and Medicaid, as well as for those with the disease and their families.

In 2013, Medicare beneficiaries with dementia incurred an annual average of $9,970 in out-of-pocket costs alone, according to the Alzheimer's Association's latest report. Yet this is only a fraction of the total costs associated with caring for the disease—an estimated $46,669 each year, per patient.

People with dementia have several resources to help cover these costs: Medicare (the federal government-run health insurance program for Americans over 65), Medicaid (the state-run health insurance program for low-income individuals), private health insurance plans and long-term care insurance.

PRESCRIPTIONS FOR ALZHEIMER'S DISEASE

There is currently no way to prevent, cure or slow the biological progression of Alzheimer's.

Medicinal therapies for the disease do exist. There are currently five FDA-approved drugs on the market for individuals with Alzheimer's: Cognex, Exelon, Aricept, Razadyne and Namenda. These prescriptions deal only with the symptoms of the disease, and fall into one of two categories: Cholinesterase inhibitors (Cognex, Exelon, Aricept and Razadyne) and NMDA receptor antagonists (Namenda).

Cholinesterase inhibitors work by helping the brain access and use acetylcholine, a neurotransmitter important for cognition and proper memory functioning. NMDA receptor antagonists defend neurons against damage caused by glutamate—a chemical that is greatly increased in the brains of people with Alzheimer's disease.

These prescriptions may work for up to a year, temporarily forestalling some of the more severe symptoms of cognitive decline; however, their effectiveness is limited.

Antipsychotics, such as Seroquel, Abilify, Risperdal, Zyprexa and Haldol, are sometimes prescribed to reduce agitation, aggression and anxiety in those with dementia. Use of these medications is controversial, due to potentially harmful side-effects, which include confusion, dizziness, incontinence and a decreased ability to move and speak.

Research into new drugs is ongoing, but despite countless headlines that hail, “New Alzheimer’s Drug Shows Promise…,” most experts estimate that a medication to combat the disease is still at least a decade away.

Medication Management Strategies

For a person with memory problems caused by Alzheimer’s, adhering to a consistent medication regimen can be tricky. Caregivers often express that not only is it a challenge to get a loved one to remember to take their prescriptions, it’s also hard to convince them they need medication in the first place.

Pill organizers with an alarm to remind your loved one to take their medications (and that will send you a warning via email, text or phone call if they don’t) may be helpful. However, the drawback of such devices is that they can be unplugged or turned off.

If your loved one is living at home, you can hire a professional caregiver to come and help them with their medications, just keep in mind that not all in-home caregivers can legally administer medications, only registered nurses. If your loved one resides in an independent living or assisted living community, staff members may be available to help with medication management.

Here are some additional strategies that the caregivers on the AgingCare.com caregiver forum have used to get their loved ones to take medications:

- "Try a reward system—want a special treat before bedtime? Take your medication first."
- "I take the meds that are available in liquid form and mix them with a sports drink and serve in a glass as the only thing to drink with meals. Those in pill form are crushed and mixed with peanut butter and served on a cracker. Mom thinks it's a treat and gobbles it up."
- "As each new challenge arises, it helps to accept that Mom's Alzheimer's is progressing and I am in charge of her well-being since she can't be. Confrontation certainly doesn't work, does it? So we just have to out-maneuver them."
- "Try putting the pill in some pudding, ice cream, anything they really like to eat."
- "Ask them why they don't want to take the medication, sometimes fixing those reasons can help. For example, if a pill is too large and uncomfortable to swallow, ask their doctor if they can switch to an easier-to-ingest brand."
- "The array of pills can be daunting and a reminder of how sick and old you've become. Sometimes you have to prioritize. If she doesn't want to take a cholesterol-lowering pill, maybe that's not as bad as skipping the diabetic control drug."
- "For swallowing issues, sometimes taking pills with a thicker liquid helps. Also, some pharmacies have products you can spray into their mouth before the pills, to make them go down easier.

What Every Caregiver Should Know about Alzheimer's Research

When it comes to ailments that inspire desperation, Alzheimer's disease definitely tops the list.

Scanning the headlines, it may seem as though there is a revolutionary Alzheimer's screening method or a new drug that is supposed to delay the disease's effects discovered every day. But media coverage of hot-button diseases can be misleading to those who don't know how to spot an overly-dramatic report.

The unfortunate truth is that actionable information about Alzheimer's diagnosis, treatment and care is uncovered far less often than the general public is led to believe.

EVALUATING THE SIGNIFICANCE OF ALZHEIMER'S RESEARCH

For caregivers who want to stay current on Alzheimer's news, but don't want to be duped by deceptive hype, there are ways to determine whether a particular research study is really relevant:

- **Is the study conducted on humans, animals or in a test tube?**
  Unless the study featured humans as the primary test subjects, the discovery isn't likely to change how Alzheimer's is dealt with in the near future.

- **How many people are involved?**
  An impactful study will likely include a diverse group of hundreds or thousands of people. The results of a study with fewer than 30 individuals generally cannot be applied to a larger population.

- **Is there FDA approval?**
  A new drug or therapy that has garnered FDA approval should be considered pretty important. FDA approval requires that a significant volume of information about the test or treatment be gathered, and indicates that the new drug will be available within a year or two.

- **Who's footing the bill?**
  The results of studies funded by private companies should be taken with a grain of salt. The conclusions can certainly be valid, but the possibility for bias and excessive marketing may make a study seem more important than it actually is.

How to Be an Effective Healthcare Advocate

An increasingly popular movement in the healthcare community is the concept of "shared decision making," which encourages doctors, patients and caregivers to engage in collaborative dialogue about medical conditions, tests and treatments. While these kinds of discussions are beneficial—regardless of age or circumstance—they are especially important for families dealing with chronic, terminal illnesses like Alzheimer's.

When a caregiver is involved in the medical decision-making process, it's often because a patient is too ill to make important choices regarding their care. As an Alzheimer's caregiver, your role in the shared decision-making process will be primarily dependent on the cognitive capabilities of your loved one.

If your mother is in the middle stages of Alzheimer's and is diagnosed with breast cancer, pursuing aggressive radiation and chemotherapy may not offer her the highest quality of life in her remaining years, but she may not mentally be able to weigh the pros and cons and make the decision on her own.

This all-too-common scenario illustrates why it's essential to not only become aware of a loved one's wishes regarding their medical care, but also to prepare the documents (called advance care directives) that will give you the authority to make decisions for them, based on their previously stated desires.

It is best to arrange these documents before you loved one's disease has progressed too far. If a lawyer deems a person incapable of signing legal documents, gaining control over their finances and healthcare will require intervention from the courts to grant conservatorship and guardianship.

An advance care directive—sometimes called a "living will"—details the medical treatments an individual does and does not want to undergo to prolong their lives, should they become physically or mentally incapable of communicating with their healthcare providers. Often prepared along with a living will are a durable power of attorney (POA) and a do not resuscitate order (DNR).

A durable POA enables an elder ("the principal") to appoint a trusted person ("the agent" or "attorney-in-fact") to manage their affairs. The "durable" designation is especially important for families dealing with Alzheimer's disease because it means that the document's commands continue to remain in effect, even after the principal becomes cognitively incapacitated. There are two main types of POA: financial and healthcare. A financial POA bestows control over a person's finances, while a healthcare POA grants permission to make medical decisions on their behalf.

A DNR is a legally-binding document, signed by a patient or their healthcare POA, which instructs medical personnel not to perform cardio-pulmonary resuscitation (CPR) or advance cardiac life support (ACLS) on a person in the event that their heart stops or they stop breathing. DNRs only deal with circumstances that would require CPR or intubation. Even with a DNR, a person can still receive other treatments, such as antibiotics and chemotherapy, if they wish.

The notion that a family member may one day become incapable of making their own decisions is a topic that patients and caregivers alike would rather avoid. But having a discussion about a loved one's goals and wishes for future medical treatment is an essential step to take when they have been diagnosed with Alzheimer's disease.

Living in Their World

The following is an excerpt from David Hilfiker's post, "We're Invisible in the Medical System, Too:"

> *"The ignorance [of Alzheimer's disease, in the medical community] is shocking, but it's also completely understandable to me as a former physician because I know how little training medical people receive in recognizing and treating cognitive impairment.*
>
> *We learn in our training to take care of the seriously demented, but not to care for people with less severe levels of cognitive impairment, especially the early stages.*
>
> *Let me guess what was going through the doctors' minds when my friend told them that her husband has Alzheimer's.*
>
> *They take one look at him sitting on the examining table, responding normally to their questions, looking like everybody else. "Looks okay to me," they tell themselves. So they essentially ignore her comment, perhaps not even mentioning it to the nurses. Nothing is done to determine the level of his impairment and how his care needs to be tailored, because they aren't skilled in it or perhaps don't even recognize the need for it.*
>
> *Later, he has some difficulty with his medications. She explains again about the Alzheimer's, and the nurses spring into the kinds of action they've been trained in: put the side rails up, accompany him everywhere, talk slowly in loud voices, spoon feed him, and all the other things they believe appropriate to a severely demented person.*
>
> *As a person with early Alzheimer's, he is invisible within the medical system.*

> *Most of the nurses and doctors literally don't know how to recognize him, much less care for him. I don't blame the individual medical people; they've not been trained, and they are subject to all the same constraints of fear and embarrassment as the rest of us.*
>
> *Nevertheless, it's simply bizarre that most medical people don't know how to deal with a disease more common than heart disease and more common than all the cancers taken together."*

THE POLITE WAY TO QUESTION A DOCTOR

For many people, questioning a physician can be a daunting proposition. But consider this: Doctors have access to over 3,500 different diagnostic tests and countless forms of medication and surgical treatments. As such, there are few scenarios where only one course of action will work, particularly when it comes to Alzheimer's.

If you feel your loved one's treatment plan isn't working, it is important that you become comfortable with having an honest, open discussion with their physician. As you do so, try to keep the following things in mind:

- **You're allowed (and should be encouraged) to question**
  As a family caregiver, one of your essential roles is to be the best advocate you can be for your loved one's health. Finding the right course of treatment for them is more than worth some personal discomfort or any hurt feelings on the part of their doctor.

- **Keep it positive**
  Even when you're calling a physician's judgment into question, it's best to begin by offering them a sincere compliment. For example, "Doctor, you've been looking after my mother's health for so long and we really appreciate all you've done, but I do think Mom needs a specialist. I may be overthinking the situation, but do you know of someone you could refer her to for a second opinion?"

- **Talk to other professionals**
  Concerns about prescriptions can be discussed with a doctor or you can also seek counsel from your loved one's pharmacist. A pharmacist isn't likely to openly disagree with a doctor's recommendation, but they may be able to spot problematic drug interactions and offer a perspective that can open the door for further dialogue with your loved one's physician.

- **Write it down**
  Take notes on your loved one's reaction to a change in therapy or medication. Is their new prescription alleviating their symptoms or making them more disoriented? Do they seem to respond well to a dose given at a particular time of day? Not only are you more likely to remember these changes if you write them down, but the doctor also will see that you've put in the effort to track your loved one's condition, which can give more authority to your claims.

5 Questions to Ask Before Every Medical Procedure

- **Why should my loved one do it?** It's essential that you understand why the physician has ordered a particular test or procedure. Getting a loved one's doctor to explain the logic behind his or her decision will either serve to put your mind at ease, or raise a red flag about the validity of their suggestion.

- **What other options are available?** Sometimes there is more than one way to conduct a diagnostic test, or a viable alternative to surgery. Asking a physician about all of the possibilities will allow you and your loved one to make a more informed decision.

- **What's next?** Understanding the follow-up procedures and care involved after a test or procedure can help you determine whether it's worth the hassle and/or risk. For instance, some experts feel early diagnosis of prostate cancer may not always be helpful to men because, in certain instances, detectable tumors never become serious enough to have a negative health impact. In these cases, the physical and mental stress of subsequent tests and surgeries to remove the tumor may far outweigh the benefits.

- **What if they do it?** Every medical procedure, no matter how innocuous, carries the potential for complications. Having knowledge of these hazards and their possible effect on the health of a loved one is essential to making an informed decision about a test or procedure.

- **What if they don't do it?** It may seem as though you're playing devil's advocate, but you shouldn't hesitate to ask the doctor what could happen if your loved one doesn't undergo a test or have a procedure performed.

CHAPTER FOUR

Living an Active Life with Alzheimer's

Alzheimer's may be currently incurable, but that doesn't mean that those with the disease can't still experience moments of mental, emotional and physical well-being. It's vital that caregivers learn to recognize the opportunities that exist for improving their loved ones' day-to-day lives.

In this chapter, you will discover how a daily routine can help keep your loved one calm, learn how to plan meaningful activities for a person with Alzheimer's and uncover strategies to help them maintain their physical and mental health.

Articles in this chapter include:

- How a Daily Routine Helps Alzheimer's
- Engaging Activities for Every Stage
- Habits for a Healthier Life

How a Daily Routine Helps Alzheimer's

Whether it's indulging in a morning cup of coffee or going for a lunchtime walk around the block, daily routines provide us with a sense of comfort and control over our otherwise hectic existences.

The relieving nature of a regular routine is even more potent for people with Alzheimer's disease and other forms of dementia.

Individuals who are experiencing memory loss "thrive on familiarity," says Holly Hart, LVN, director of residential health services at Claremont Manor, a CCRC (continuing care retirement community) in Claremont, California. "Familiar faces, a familiar environment, even familiar food—anything they can use as a touchstone."

The comforting effect of familiarity is so powerful because dementia gradually impairs a person's ability to plan, initiate and complete an activity.

People with Alzheimer's often experience great difficulty when attempting to do new things, according to Jed Levine, executive vice president and director of programs and services for the New York City Chapter of the Alzheimer's Association. But a predictable routine can prevent someone with the disease from becoming distracted and forgetting what they are doing. "Even if there is little or no conscious awareness of time, routine helps ground them," Levine says.

A daily agenda may even be able to help a person with Alzheimer's cope with the short-term memory issues that are typically some of the first symptoms of the disease.

Hart argues that establishing a predictable pattern of events can help transfer the schedule of a daily routine into the long-term memory portion of the brain, helping a person retain their ability to perform activities of daily life, such as brushing their teeth or fixing a snack.

TIPS FOR STARTING (AND STICKING TO) A ROUTINE

When coming up with a regular routine for someone with Alzheimer's, the overarching goal should be to tailor it as much to your loved one's preferences and past activities as possible.

For example, Levine recounts the story of one caregiver who was forced to put her mother in an assisted living facility. Living in assisted living was extremely stressful and anxiety-producing for the older woman, until her daughter suggested the staff give her mother a "New York Times" newspaper on Sundays. Though Alzheimer's had diminished the older woman's ability to understand the articles like she used to, the paper helped by giving her a benchmark with which she could establish a sense of time. "On some level, she was aware it was Sunday and, once she got the paper, she calmed down and enjoyed reading the various sections," says Levine.

The more you can include activities that resonate with your loved one's pre-dementia life, the better. Did they have a favorite television program that they liked to watch at a certain time? Did they enjoy listening to a particular radio talk show? Did they meet up with their friends for a game of checkers on Sunday nights?

Levine offers suggestions of other, more generic, activities that are also important to include in a daily routine:

- Medication administration
- Meal times
- Toileting
- Bathing and showering
- Brushing of teeth and hair
- Leisure activities
- Exercise

The more you can schedule, the easier it will be for you and your loved one to establish a familiar routine.

STICKING TO A PLAN WHILE GOING WITH THE FLOW

Once a daily procedure is in place, Hart says it's important to try and follow it as often as possible.

Disruptions in daily routines (such as those caused by holiday visits to other family members' houses) can elevate your loved one's anxiety and make it harder for them to get back to a normal schedule once the disturbance is over.

Of course, schedules will change, depending on doctor's appointments, unexpected illnesses, an elder's changing mood and the progression of their disease. In these instances, Levine says caregivers should, "remain flexible and go with the flow; do not insist on routine if the person with dementia is resistant." Try to learn how to recognize when your loved one is becoming agitated or stressed by a routine, then modify the schedule to fit their changing needs.

Taking care of a loved one with dementia is a continual process of trial and error. One day, your loved one might enjoy going for a midday stroll in the park, the next day they may not even want to set one foot out of the door.

That's why both Levine and Hart echo that cardinal rule of family caregiving: make sure you look after your own needs, not just the needs of your loved one.

"Caring for a relative with dementia is difficult and challenging, and most people are not prepared for it," says Levine. "It's critical that the caregiver learn how to care for themselves."

Engaging Activities for Every Stage

A multitude of research studies touting the benefits of keeping people with memory disorders physically and mentally active have been released in recent years. But coming up with the right activities to keep a loved one with Alzheimer's engaged in life can be tricky.

There are a few key things to keep in mind when brainstorming potential pastimes. First, as your loved one begins to forget who they are, it's all the more important that you remember, and present them with meaningful activities that echo their previous interests and talents.

It's also essential to keep in mind that for many individuals with Alzheimer's, the desire to accomplish significant things doesn't vanish. Activities that can give an elderly loved one a sense of triumph may help stave off anxiety and depression—as long as you don't make achievement the sole aim. Instead, try to focus on the enjoyment of the activity.

Concentrate your efforts on the faculties that remain with your loved one, not the ones that have been lost. There are, after all, many things that people with cognitive impairment can still do:

- **Help out:** It's possible to turn mundane daily tasks into activities that someone with Alzheimer's can assist with. Even simple tasks, such as helping measure ingredients for a recipe or folding the laundry, can give your loved one a sense of purpose and feeling of accomplishment. Just remember to keep instructions straightforward and simple.

- **Tell stories:** Encouraging a person with dementia to reminisce about their past may end up confusing and embarrassing them if they can't recall every detail of the experience. But a creative storytelling technique, developed by Anne Basting, director of the Center on Age and Community at the University of Wisconsin, may enable your loved one to exercise their imagination and become a storyteller without the pressure to remember. First, pick a thought-provoking photo that seems staged or has something obviously out-of-place—an image that appears to have some kind of story behind it. (See examples at the end of this eBook) Next, ask your loved one open-ended questions about the photo, like "What do you want to call him/her?" and "Where do you want to say this takes place?" Write down your loved one's response, regardless of whether it makes sense, then read it aloud in recognition of their contribution. Once you and your loved one have created a storyline, you can share it with friends and family. Creative storytelling helps "bring people out of isolation and helps care partners connect with each other in a meaningful, positive way," according to Basting. Through the practice of this activity, people with dementia "are allowed to be creators of something. They gain trust again in their ability to communicate, to make meaning," she says.

- **Listen to music:** The power of music to help individuals with Alzheimer's remember people, places and events from their past is well-grounded in both scientific and anecdotal evidence. A Helsinki University study found that participating in a 10-week long singing and music class can enhance memory, mood, orientation and overall cognitive abilities in individuals with dementia. Another investigation, led by researchers from George Mason University, uncovered a similar result after exposing people with dementia to classic numbers, such as "Somewhere Over the Rainbow" and "The Sound of Music." The bonus for caregivers? Listening to music and singing also proved beneficial to their memory and overall well-being.

- **Stay social:** Interpersonal interactions are often touted as an effective way to keep people with Alzheimer's mentally sharp, but finding social outlets can become difficult, due to both the stigma of Alzheimer's and the behavioral changes that often accompany the disease. Leaning on loyal family and friends, attending local support groups and connecting with patients and caregivers on online forums are all good options for fortifying social connections.

- **Volunteer:** Devoting time to help other people can provide immense satisfaction to both you and your elderly loved one. Volunteering can involve something as simple as collecting school supplies, toys, canned goods, etc., and taking them to a local shelter or food bank. People who can't leave the house can also assist with sorting, wrapping and taking inventory of collected goods.

- **Stick to simple pleasures:** Keeping things simple and straightforward is often the best course of action when coming up with activities for people with Alzheimer's. Going to a local park to feed the birds and fish, collecting stamps, taking turns reading a favorite book aloud, doing a craft, playing a game, putting together a simple puzzle—anything that allows the two of you to stay in (and savor) the present moment.

- **Activities for advanced Alzheimer's:** When a person enters the late stages of Alzheimer's, their ability to touch, see, feel and hear may become severely impaired. In these instances, gentle activities such as a hand massage with scented lotion, or running their hands through a box of sand or rice, can provide your loved one with pleasing sensory stimulation.

Living in Their World

The following is an excerpt from Marlis Powers' post, "A Sense of Purpose Can Keep Depression at Bay:"

> *"Depression in senior citizens is one of the most under-recognized and under-treated medical illnesses.*
>
> *In the general population, 12 percent of deaths are attributed to suicide. That statistic rises to 16 percent for those aged 65 and older. Depression can be caused by many things; the death of a loved one, loneliness, chronic illness or failure to adjust to retirement.*
>
> *In Charlie's case I think it is due to lack of purpose and the physical inability to participate in things that used to give him pleasure.*

It is imperative to reach out and help someone who is showing signs of depression, by inviting them on outings or encouraging them to re-start a favorite activity.

Many older people increase their alcohol consumption as a means of coping. This will only lead to further depression. Exercise classes such as strength training or Tai Chai can help by enhancing balance, improving core strength and preventing falling.

Insomnia should be remedied by reducing caffeine consumption and keeping to regular bedtimes and wake up schedules.

Now that my knee is healing, Charlie and I are back at our strength training classes. One more reason for him to get out of bed!

Senior citizens should be encouraged to carry family photos with them or keep them nearby, make new friends, and even get online to keep in touch with family and friends. This has been an especially helpful exercise for me – it's the reason I started blogging.

Seniors need to find a purpose in their life.

Sometimes adding a pet to the household will give a person suffering from depression motivation and pleasure. Just be sure that the pet will not cause unwelcome complications, such as tripping, financial burden, allergies, etc.

George Bernard Shaw said, "We don't stop playing because we grow old. We grow old because we stop playing."

Depression may be part of growing old but we need not let it define us. Recognize the warning signs of depression in the elderly, whether yourself or others, and look for ways to overcome it or, at least, keep it under control."

Habits for a Healthier Life

Making sure a loved one adheres to healthy eating and exercise behaviors becomes even more critical when Alzheimer's is involved. Unfortunately, cognitive impairment often also makes it even more challenging to coax them to take care of themselves.

THE 30-30-30 RULE

Experts recommend the following easy-to-remember rule for promoting health in a person with Alzheimer's. Each day, they should participate in:

- 30 minutes of moderate exercise
- 30 minutes of listening to music
- 30 minutes of talking with friends and family

THE BENEFITS OF PHYSICAL EXERCISE

Much is made of the mental declines brought on by Alzheimer's, while little attention is paid to the physical deterioration that goes along with the disease. But the death of neurons can also cause serious mobility issues, making it difficult for your loved one to walk, talk or even get in and out of a chair or bed.

Physical activity has been shown to promote brain health, increase ability to perform everyday tasks, decrease fall risk and enhance physical functioning in individuals with Alzheimer's disease.

A group of Finnish researchers recently discovered that participating in a customized, home-based workout program twice a week could slash fall risk in cognitively impaired individuals by 50 percent. The exercise intervention also significantly slowed their functional decline.

There appeared to be an additional monetary bonus to adopting a regular workout regimen, even if it meant having to hire a physical therapist to make a home visit.

The yearly cost of caring for a person with Alzheimer's was greatly diminished when they participated in an individualized exercise program—$25,112 for those with specially-tailored programs versus $34,121 for those who did not exercise regularly.

EXERCISE TIPS FOR PEOPLE WITH ALZHEIMER'S

- **Talk to their doctor:** Your loved one's physician should always be notified of any major changes to their routine. He or she may be able to offer some suggestions for physical activities that would be good for your loved one to do.

- **Find something they enjoy doing:** Despite the undeniable benefits of physical activity, your loved one may be resistant to exercise. You can't force them to work out. You can, however, look for activities they enjoy doing that also involve working up a sweat. Perhaps your mother has always loved baking; the two of you could make a from-scratch batch of whole grain bread, sans electric appliances. All that mixing, kneading and standing will get her blood flowing and you will have a delicious loaf of bread to enjoy afterwards.

- **Start slow and simple:** Be sure to introduce the idea of exercise slowly to your loved one and avoid overly-complex activities. People with Alzheimer's are prone to becoming anxious and fearful if they are exposed to an unfamiliar situation. This anxiety may cause your loved one to act out, or refuse to participate at all. Kick things off with a casual stroll or a simple game of catch.

- **Avoid perfectionism:** If you progress to more complicated activities—such as tennis—keep in mind that, depending on the day, your loved one's disease may cause them to forget the rules or even how to do the activity all together. It's not about perfection, it's about engagement.

- **Watch out for warning signs:** Keep an eye out and make sure your loved one isn't overexerting themselves. A cognitively-impaired individual may not realize when they're doing damage to their body.

MAKING MEALTIME EASIER

As Alzheimer's progresses, mealtimes can become an increasing struggle for those with the disease and their caregivers.

In the beginning, your loved one may not remember how to fix their meals, or forget that they need to eat and, as time goes on, other eating issues will begin to appear:

- **Anger and agitation:** Cognitive decline may cause an individual to become agitated during mealtimes. They can also lose their sense of proper table manners—eating too much, taking food from other people's plates, making rude comments about the meal. Maintaining a calm demeanor, no matter what your loved one says or does, and taking your time with the meal can help them relax.

- **Anxiety and confusion:** Anxiety and confusion can be avoided by making the eating process as straightforward as possible and reducing distractions. Keep the dining space quiet, clean, well-lit and free of clutter. Solid-colored serving dishes and placemats are best. Putting just one type of food at a time on a loved one's plate can also cut down on confusion. If they have trouble maneuvering with forks and plates, spoons with large handles and bowls may be easier options.

- **No appetite:** Alzheimer's, age and even certain medications can decrease a senior's appetite or impair their ability to taste food. They may also begin to lose their sense of taste and smell, making them less likely to enjoy the eating process. Consult with an elderly loved one's doctor if you suspect that their medications are making them less inclined to eat. You can also try enhancing the flavor of foods with ingredients such as vinegar, onions, garlic and olive oil.

- **Problems chewing:** A person may have difficulty chewing due to a variety of factors: cognitive impairment, ill-fitting dentures, tooth loss and mouth sores. Feeding your loved one soft foods can help alleviate this issue. Substitute canned and frozen fruits and vegetables for fresh produce and turn to foods such as peanut butter, cooked beans and eggs to replace sources of protein that are harder to chew.

- **Choking:** The muscles in an older adult's esophagus are not as strong as they once were and Alzheimer's can cause them to work improperly. Aspiration, when a piece of food gets sucked into the windpipe and lungs, can cause pneumonia in a person with Alzheimer's and is a contributor in the death of many people with the disease. Chopping and shredding a meal into easier-to-eat pieces can cut down on the chances of choking and aspiration. Fruit smoothies made with protein powder can also offer important nutrients, while reducing the strain on the digestive system.

7 HEALTHY FOODS FOR PEOPLE WITH ALZHEIMER'S

Ruth Frechman, RD, spokeswoman for the American Dietetic Association, offers the following list of easy-to-make healthy foods:

- Canned soup (low-sodium)
- Canned fruit (in its own juice, or sugar-free syrup)
- Oatmeal
- Yogurt
- Frozen vegetables
- Peanut butter
- Cottage cheese (sodium-free)

CHAPTER FIVE

Finding Professional Alzheimer's Care

As their family member progresses down the path of cognitive decline, Alzheimer's caregivers often find themselves in need of professional help to take care of their loved one. There are a variety of choices for outside care, depending on how much assistance your loved one needs and how the family plans to pay for it.

In this chapter, you will learn more about the professional care options that are available for people with Alzheimer's—including in-home care and senior living communities—as well as how to choose which situation best suits your loved one's needs.

Articles in this chapter include:

- Evaluating Your Loved One's Care Needs
- Aging-in-Place With Alzheimer's
- Alzheimer's Care in Assisted Living
- Alzheimer's Care in a Nursing Home

Evaluating Your Loved One's Care Needs

Before examining the various Alzheimer's housing and care categories, it's best to first list all of the daily activities that your loved one needs help with. This will give you the guidance necessary to select the option that best attends to those needs.

There are two main categories of daily activities that aging adults need help with: Instrumental Activities of Daily Living (IADLs) and Basic Activities of Daily Living (BADLs).

IADLs deal with the day-to-day maintenance of a person's environment and include activities such as cooking, doing laundry, housekeeping, driving, financial management, medication management and using the telephone.

BADLs involve attending to a person's hygiene, mobility and bodily care needs, including bathing, dressing, toileting, eating, walking, and getting in and out of bed or a wheelchair.

The type of care that is best for your loved one will largely depend on which activities they need assistance with.

For people with Alzheimer's who wish to stay at home, professional home care providers can help with everything from minor tasks such as grocery shopping and preparing meals, to providing assistance with eating and bathing.

For those considering care at a facility, assisted living communities are generally geared towards people who need minimal to moderate help with IADLs, whereas nursing homes offer more advanced assistance with BADLs and medical care.

The quality of memory care will vary widely from facility to facility and provider to provider. It's essential to thoroughly research and vet all of the options for your loved one's care before making a decision.

Aging-in-Place With Alzheimer's

It is the stated desire of many adults to be able to continue living in their home (or the dwelling of a family member) as they grow old, rather than move to an assisted living community or a nursing home. Unfortunately, Alzheimer's can throw a life-size monkey wrench into even the most well-prepared plans to age-in-place.

Staying put in their home can turn into an extremely unsafe prospect for your loved one as they progress down the path of cognitive impairment. Forgetting to turn off the stove, neglecting to take a bath or wash their clothes on a regular basis, and leaving food in the refrigerator so long that it rots are just a few of the dangerous scenarios that can occur when a person with Alzheimer's lives by themselves.

Especially for long-distance caregivers who live far away from their loved ones, determining when a person's level of impairment has reached the point where they can no longer live in their home safely can be a tricky endeavor. Here are a few questions to help you analyze the situation:

- Are they socially isolated? Do they regularly interact with friends?
- Are they exhibiting signs of depression?
- Are they capable of bathing and grooming themselves?
- Are they properly performing regular chores (cooking, cleaning, laundry, grocery shopping) on their own?
- Are they paying their bills on time?
- Are they (and should they be) driving?

If these queries send up red flags that a loved one shouldn't continue living independently, moving them into your house may be a viable option, provided you keep a few things in mind.

- **Other family members matter**
  If it won't just be you and your loved one with Alzheimer's in the house, it's essential to examine the impact the move may have on other family members, specifically your significant other and your children. So-called "Sandwich Generation" caregivers—those looking after an elderly parent, while taking care of their children—often find themselves pulled in several different directions. Alzheimer's behaviors can also create a great deal of confusion for young children to understand why their elderly uncle suddenly starts screaming and hitting them for no apparent reason, or become frightened when they come across grandma as she roams the house at night, muttering to herself. A spouse can also feel neglected or betrayed when their husband or wife devotes much of their time and attention to an elder with Alzheimer's.

- **Finances matter**
  If you decide to move a loved one into your house, it's best to hammer out monetary arrangements in advance. Will you apply to receive payment as their primary caregiver? Will they contribute money to pay for household expenses? Since looking after a loved one with Alzheimer's will require certain financial and career sacrifices by the rest of the family, the question of "How can I get paid for being a caregiver?" is one of the most commonly asked queries of prospective (and current) caregivers.

- **Your needs matter**
  As a caregiver, you can only handle so much when it comes to both the emotional and practical aspects of caring for a loved one with Alzheimer's at home. Wrestling with a husband who is 70 pounds heavier than you are while trying to get him to take a shower is not something you're going to be able to do on a long-term basis. If sundowners is causing your mother to constantly get up and wander around in the middle of the night, robbing you of hours of sleep, there's no way you can continue to safely provide care for her on your own. Identifying and attending to your own needs is a must-do for every Alzheimer's caregiver.

ADULT DAY CARE PROGRAMS FOR PEOPLE WITH ALZHEIMER'S

Adult day care programs typically receive a bad rap; branded as glorified babysitting services that compromise the independence and dignity of aging adults, but day care programs can offer a much needed source of respite care for Alzheimer's caregivers who need a break.

Research from the University of Pennsylvania concluded that adult day care may guard against caregiver stress in those looking after a loved one with dementia. Study authors found that caregivers who take advantage of adult day care services for their cognitively impaired loved ones had lower stress levels.

"There's a shift that needs to take place in terms of how society views adult day care," says Debbie Stricoff, director of adult day services at the Visiting Nurse Service of New York (VNSNY) CHOICE Adult Day Center. "People are not aware of all of the cognitive stimulation and health benefits that people can get. This is a wellness center; a place where people can improve their functioning."

Adult day care programs are typically offered by hospitals, senior centers, nursing facilities and local religious organizations. Some adult day care centers are regulated by the state, but the quality and type of services provided by each particular program can vary greatly, making research a must before signing up a loved one.

Stricoff recommends searching for a facility that is clean, has a staff-to-participant ratio of no more that 1-to-4 (the proportion recommended for dementia day care by the National Adult Day Services Association), offers a wide variety of activities that your loved one would be interested in, can cater to different dietary needs, has transportation to and from the center, and provides personal care services to elderly attendees.

"People can make really strong friendships at an adult day care center. They have the opportunity to develop a whole other support system," says Stricoff. Some programs also allow caregivers to join their loved ones for special celebrations and group discussions.

ADULT DAY CARE AT-A-GLANCE

Cost: *$70 per day **

Payment options: *Private pay, medical insurance, long-term care insurance and Medicaid*

When to seek it: *You want to keep taking care of your loved one at home, but you need a break every once in a while, and they need more activities and social opportunities.*

**2012 average, according to "MetLife Mature Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs."*

NIGHT CARE PROGRAMS FOR DEMENTIA AN EMERGING TREND

Sleep deprivation due to dementia behavior is a driving force behind caregiver exhaustion and burnout. Taking care of an adult with Alzheimer's is much different than taking care of a young child, but the sleep patterns of a person with sundowners syndrome are similar to those of an infant who is reverse cycling, according to Deborah Messina, director of "ElderServe at Night," an innovative dementia care program offered at night by the Hebrew Home at Riverdale, a senior care facility.

These behaviors compel many families to seek alternate living arrangements for a loved one with Alzheimer's. "We had many family members looking at premature placement in a nursing home," Messina laments. "When we asked them why they were considering skilled nursing as an option, the overwhelming response was that the family caregiver couldn't handle the nighttime behaviors of the person with dementia."

When darkness falls, the demons of anxiety, anger, fear, hallucinations and paranoia come out for individuals with Alzheimer's who experience sundowners syndrome. A person in the grip of these issuess is prone to aggressive behavior, shadowing and wandering. As many as 66 percent of people with dementia who live at home suffer from sundowners, according to the Alzheimer's Association.

Hebrew Home's night care program, offered between the hours of 7 p.m.

and 7 a.m., is an initiative aimed at helping caregivers cope with these challenging behaviors. Dozens of adults with dementia gather in brightly-lit rooms where the curtains are drawn to shut out the anxiety-producing darkness. Medical services, such as blood sugar and blood pressure monitoring, are provided for those who need them. Dinner and snacks are served to participants as they engage in activities ranging from cooking groups, to exercise classes, to outings to view local displays of Christmas lights.

“We essentially take their night and turn it into day,” says Messina.

The program is tiered, offering different types of events for different attendees, depending on how far their disease has progressed. The goal is not only to offer participants tasks that engage and challenge them, but to also provide positive, achievable outcomes.

People with less advanced Alzheimer’s may take part in occupational therapy and yoga classes, or splinter off into a discussion group. Individuals with more advanced impairment and those who can no longer speak undergo aroma and touch therapies designed to stimulate their senses and calm their minds.

The social aspects of the program provide an additional benefit to participants, many of whom have few opportunities for outside interaction. “An engaging social environment is difficult to achieve in a home setting,” Messina says. Even dinner is designed to be a communal activity. “Being around others who are in a similar situation offers a level of peer socialization and support that many people with dementia can’t get at home.”

For now, night care programs for people with Alzheimer’s and other forms of dementia are few and far between, so there may not be one offered in your area. But word about the benefits of these initiatives is gaining momentum and the concept may soon become more mainstream.

PROFESSIONAL IN-HOME CARE FOR ALZHEIMER’S

Caregivers of loved ones who want to age-in-place also have the option of hiring professional in-home care providers to offer respite and perform tasks that are too difficult or uncomfortable for family members.

Home health aides provide basic healthcare services such as wound dressing, bathing, medication disbursement and vital sign monitoring. Homemakers provide strictly non-medical assistance such as cooking, cleaning and socialization. Professional caregivers may work for a home care agency, or they may operate as independent contractors. They can provide a few hours of light assistance each week, or 24/7 care for someone who needs round-the-clock monitoring.

10 Questions to Ask When Hiring a Home Care Agency

1. Is this a well-known (and well-referenced) agency?
2. How do they find their caregivers? (Newspaper ads, staff agencies, etc.)
3. What skills do they require prospective employees to have?
4. Are background checks and drug screenings performed on prospective employees?
5. How do they determine what type of care an employee is qualified to provide?
6. Does the agency insure and bond their caregivers?
7. How does the agency train their caregivers?
8. Do they send the same caregiver to an elder's house each time?
9. Will the agency replace a caregiver if they aren't a good fit?
10. How are individual caregivers monitored and supervised?

Regardless of which type of caregiver you choose, it's essential that you inquire about their training and how much experience they've had taking care of people with Alzheimer's disease. The proper training and experience is key, since people with Alzheimer's have different care needs than those who aren't dealing with cognitive issues.

“If the [home care] agency’s caregivers are well trained in dementia care, I think in-home care can be the ideal starting point for people who need extra help with their loved ones, but aren’t ready to think about assisted living,” says AgingCare.com Expert Carol Bradley Bursack.

A professional caregiver should be well-versed in different techniques to keep a person with dementia emotionally and socially engaged. Preferred techniques will vary from caregiver to caregiver and depend on how advanced your loved one’s disease is, but will most likely include some combination of reminiscence, music and art therapy. “Quality of life is often determined by outside stimulation that the senior enjoys,” says Bursack, who touts good communication as a crucial component of successful integration of professional caregivers into a senior’s life. “A good care agency should work with the family so that everyone understands what the professional caregiver is doing with the care receiver and the reason for that approach.”

As the family caregiver, your role will be to find the balance between making sure your loved one is getting the proper care, without stepping on the professional caregiver’s toes. It’s a delicate equilibrium that might take some time to strike, so patience is key.

HOME CARE AT-A-GLANCE

Cost: *$21 per hour **

Payment options: *Private pay, medical insurance, long-term care insurance, Veterans benefits, Medicare, Medigap and Medicaid*

When to seek it: *You want to keep taking care of a loved one at home, but their care has either become too stressful, time consuming or complex to continue doing it all by yourself.*

**2012 average, according to “MetLife Mature Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs.”*

Living in Their World

The following is an excerpt from Marlis Powers' post, "What's a Caregiver to Do When an Elder Won't Accept Outside Care?"

> *"There are several options for someone to look after Charlie while I am incapacitated after my knee replacement; he is rejecting all of them.*
>
> *After years of fighting the GMO labeling/organic food fight I find myself stocking the fridge with TV dinners. The cupboards are overflowing with all kinds of quick fixes for meals.*
> *Won't Monsanto love me?*
>
> *I bought a 'grabber' so I can reach things on the floor without bending over, borrowed a walker (the one Charlie won't use), ordered the HurryCane (don't bother – I can't run any faster than I can with my other cane), and am on the search for a gizmo to raise the toilet seat.*
>
> *But, I still haven't solved the problem of what to do with Charlie.*
>
> *Respite care? It will probably take a straightjacket to get him there.*
>
> *Home Health Care Aid? 'They'll steal everything in sight,' is his response to that.*
>
> *A certain family member was suggested, 'She can't take care of herself. How can she take care of me?'*
>
> *You see where I am going with this? Nowhere!*

Today I talked to the Visiting Nurse that assists our senior living community. She suggested I contact the VA. Charlie has an 80 percent government disability, so they can assign him a caseworker to help figure it all out.

Of course that will mean taking him to the VA hospital – thank heavens there is one about five miles from here. I think maybe, if they tell him what he needs he will listen.

Why is it they always listen better to someone else than the one who is caring for them? Is it just plain stubbornness, or is it their way of showing they still have control of their lives? The latter I think.

It's hard for a person with dementia who is still aware enough to realize they are losing control of their body and their life. They use every means possible to hang on to what little they have left in the way of dignity and pride."

Alzheimer's Care in Assisted Living

If your loved one can't (or doesn't want to) live at home, a memory care unit at an assisted living community might be a viable alternative.

Assisted living communities are designed to make day-to-day living a bit simpler for older adults who can no longer live on their own safely. Transportation services, regular meals, housekeeping and laundry, social activities, exercise programs, and emergency alert services are some of the traditional assisted living offerings. Medical care isn't automatically provided in assisted living, but residents can hire outside caregivers to come and help out with various health issues, such as medication management.

Some assisted living communities also include special memory care wings dedicated to serving the needs of people with Alzheimer's and other forms of dementia. Memory care units are monitored 24/7 and are typically locked to prevent wandering. The help offered to regular assisted living residents is specially-tailored in memory care units to be beneficial for people with cognitive decline.

Due to the fact that Alzheimer's is a progressive disease, memory care unit staff should create a plan to monitor and track your loved one's condition. This plan ought to include regular meetings with you to discuss changes in your loved one's status and any proposed alterations to the initial program.

The range and quality of services offered in assisted living memory care units varies widely from community to community and universal licensing laws do not yet exist, so thorough research is key before making a decision on whether to place a loved one.

ASSISTED LIVING CARE AT-A-GLANCE

Cost: *$4,807 per month* (Use the Assisted Living Calculator to compare your current home costs to the estimated cost of assisted living in your area.)*

Payment options: *Private pay, medical insurance, long-term care insurance (Medicare and Medicaid may cover certain medical-related expenses).*

When to seek it: *Your loved one can't (or doesn't want to) live at home any longer and needs some assistance with IADLs.*

**2012 average, according to "MetLife Mature Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs."*

Alzheimer's Care in a Nursing Home

If your loved one's Alzheimer's has progressed to the point where they are having trouble going to the bathroom, feeding, clothing or bathing themselves, or if they have health issues that demand specialized medical care, then care in a nursing home might be an option.

Nursing home care can be divided into two broad categories: basic and skilled.

Basic care in a nursing home provides help with IADLs and BADLs, and ensures that a person with Alzheimer's doesn't wander off.

Skilled care in a nursing home deals with those tasks that demand a specially trained professional, such as a nurse or occupational therapist, to perform.

Nursing homes also typically offer residents a range of activities to keep them engaged with their environment.

Over the years, nursing homes have acquired a bad reputation that leads many family caregivers to say to their loved ones: "I promise to never put you in a nursing home." While admirable, this pledge is not easily kept when Alzheimer's is involved.

As your loved one's condition deteriorates, you may quickly become overwhelmed with the amount of care you are being asked to provide, and there may come a time when keeping your promise is no longer the best course of action, for you or for them.

"Our healthy parents have visions of nursing homes decades ago, and the very idea of living in one is unthinkable to them," says Agingcare.com Expert Carol Bradley Bursack. But, if you're caring for a family member with Alzheimer's, you have to be able to recognize (and admit) when their needs are becoming too much to handle. Try to let go of the guilt you have over doing the one thing you said you would never do. "When you hit that brick wall of reality and know you must, for your elder's safety and your health and sanity, put them in a nursing home, you have done your best. You cared for them in every way possible before turning to this last option," says Bursack.

Understand that your duties as caregiver don't disappear when a loved one enters a nursing home, they simply evolve. You'll be able to channel your energy into being an effective advocate and spending quality time with your loved one, rather than spending every minute stressing out over their safety.

As with the aforementioned options for Alzheimer's care, it's essential to research and thoroughly evaluate the nursing homes you're considering before choosing the one that's best for your loved one. There are many factors to help you compare nursing home care.

"Caregivers can be dedicated, but that dedication can turn into martyrdom," cautions Bursack. "Frankly, martyrs aren't good caregivers… Honor the spirit of your promises by being the best caregiver you can be. Be a caregiver who knows when to say when."

NURSING HOME CARE AT-A-GLANCE

Cost: *$261 per day for private room, $230 per day for semi-private room**

Payment options: *Private pay, medical insurance, long-term care insurance, Medicare (for short-term stays) and Medicaid*

When to seek it: *When a loved one's cognitive condition has deteriorated to the point where they need help with multiple BADLs and/or require skilled nursing care on a regular basis.*

**2012 average, according to "MetLife Mature Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs*

CHAPTER SIX:

Handling Family Interactions

Solid communication skills are a vital asset for every Alzheimer's caregiver. Being able to politely and effectively discuss difficult dementia issues with the rest of the family can keep relationships strong, in spite of the challenges that arise when caring for an adult with Alzheimer's.

In this chapter, you will learn how to tell friends and relatives that a loved one has Alzheimer's disease, why family members may be reluctant to help out (and how you can convince them to pitch in), and discover methods for handling criticism of your caregiving efforts.

Articles in this chapter include:

- Discussing Alzheimer's With the Family
- Why Family and Friends are Hesitant to Help (And How to Change Their Minds)
- How to Handle Criticism from Family Members

Discussing Alzheimer's With the Family

Whether you've finally decided it's time to tell the rest of the family about your loved one's Alzheimer's diagnosis or you just want to keep them updated on his or her condition, there are a few keys to transforming the traditionally taboo topic of dementia into something that's easier to talk about:

- **Honesty:** Be as open as you can about your loved one's condition, while still maintaining their dignity. The rest of the family doesn't need to know that dad has been making sexually inappropriate remarks about you, his daughter; instead, you can just say that he is exhibiting some new behaviors that indicate his cognitive impairment may be worsening.

- **Knowledge:** The main source of the fear and stigma that surrounds Alzheimer's is the lack of knowledge about the truths of the disease. As your loved one's caregiver, it's important that you aim to become the authority on all things Alzheimer's. Not only will this help you better manage your loved one's condition, it will also enable you to more effectively communicate what you know to the rest of the family so they can better understand the disease.

- **Optimism:** This doesn't mean that you have to (or should) approach discussions about your loved one's Alzheimer's with an excessively sunny demeanor. Rather, optimism means taking a balanced view of the situation, communicating both the negative *and* positive aspects. Encourage the rest of the family to interact with the person with Alzheimer's as much as possible. Let them know some good strategies for communicating such as avoiding a condescending demeanor and tone of voice, and not correcting or arguing with a cognitively impaired individual.

No matter how effective your methods of communication, you won't ever be able to completely prepare the rest of the family to deal with someone living with Alzheimer's disease, or allay all of their fears. But, avoiding such conversations will only add to your isolation and thus be detrimental to the well-being of both you and your loved one.

You may, in fact, be pleasantly surprised by how your friends and relatives rally to your side with offers of help and support after you open up about the situation. You and your loved one don't have to go through this journey on your own; each person in your life is capable of playing a different, yet crucial, role in the caregiving process.

Living in Their World

The following is an excerpt from David Hilfiker's post, "My Grandchildrens' Approach to Alzheimer's:"

> *"After my grandchildren returned home from school one day, I had a chance to talk with them about my Alzheimer's.*
>
> *When we were here at Christmas, I didn't talk with them because I was under the mistaken impression that Laurel (my daughter) was going to wait until my symptoms were more noticeable before telling them about my diagnosis.*
>
> *In fact, after our October conversation in which I revealed my diagnosis to Laurel, she began crying. Eight-year-old Madeline noticed, so Laurel told her and 10-year-old Otto that their grandfather would have increasing trouble with memory.*
>
> *Madeline's two questions were, "Will grandpa forget how to eat?" and "Will he forget how to talk?" Laurel answered, "We'll have to see."*
>
> *So I wanted to talk with them a little about it. I asked them whether they knew about my "memory problem." They said that they did, but they didn't follow up with any questions, so I didn't press any further.*

The children haven't related to me any differently.

When I mentioned something that happened to me in childhood, Madeline—always energetic and inquisitive—asked me why I could remember something from so far back. I told her that most of my loss of memory was for things that happened recently, and she seemed satisfied with that.

When I've had to ask them about things I've forgotten, they've just answered simply without remarking. I've found their matter-of-fact attitude quite refreshing. I feel no sense of embarrassment: This is just one of those things that happen."

Why Family and Friends Are Hesitant to Help

(AND HOW TO CHANGE THEIR MINDS)

Once someone has been diagnosed with Alzheimer's disease, a particular family member may start to stand out as the most natural fit to be that person's caregiver. A spouse is typically the go-to caregiver for their husband or wife, while the number of siblings, proximity, monetary resources and personality type may all factor in when determining which adult child will care for their cognitively impaired parent(s).

No single person can (or should) shoulder all the responsibility for looking after a loved one with Alzheimer's, yet many caregivers lament that their siblings, adult children and other relatives don't help out as much as they should.

"Let me know how I can help," the typical refrain from family members and friends, leaves caregivers stuck in an uneasy limbo where the need for assistance has been acknowledged, but no formal offer of aid has been given.

Caregivers can be reluctant to follow-up on these pseudo-offers by requesting help because they feel personally accountable for their loved one's care. In the rare instance a caregiver does ask for assistance, he or she may be met with a variety of excuses:

- **I can't handle seeing them like that**
  Perhaps one of the more infuriating refusals from relatives is that they can't bear to watch a beloved family member decline into dementia—as if, somehow, you don't feel the exact same way. Former caregiver and AgingCare.com Expert Carol Bradley Bursack sums up this situation beautifully, "Most of us are honored to be able to help our elders through these stages. It's the sadness of coping with their decline that causes our pain. Don't our siblings understand that we, 'can't bear to see him or her like this' either? Probably not. Maybe we are just more 'dutiful.' Maybe we are just, well, on the spot. Whatever the reason, we step up to the plate and do what is required. If we are uncomfortable, we do it anyway. We get over our discomfort."

- **I don't have the time/money**
  The truth is, no one truly has enough time or money to be a family caregiver without experiencing some strain—financial or otherwise. The process of getting paid to be a family caregiver for a loved one is tricky and the out-of-pocket health care costs of a person with Alzheimer's can easily climb into the tens-of-thousands of dollars. Many caregivers also have to quit their jobs or scale back their hours to accommodate their new responsibilities. "Having the time is also relative in that caregiving is emotionally, if not literally, a 24/7 job," Bursack laments. "Most caregivers need a break from the stress of the constant responsibility of being the primary caregiver."

- **You're so much better at it than I am**
  Wrapped within a quasi-compliment, this particular excuse can be challenging to respond to properly. What can you say? "Yes, I am better at it; I am more patient; I am more dedicated; I am more devoted?"

GETTING THE HELP YOU NEED

No matter what the real reason actually is, some family members simply won't be open to helping you with your caregiving duties. But, there are a few strategies that may help you convince those who are on the fence:

- **Be specific**
  One of the factors that can inhibit a person's ability to help out is that they honestly don't know where to begin. Take a moment to think about those tasks you need help with the most. Do you need someone to come over for a few hours each week and watch mom while you go grocery shopping? Would it help if one of your adult children prepared some ready-to-eat meals that could be popped in the microwave after a long day of looking after your husband? Clear, concise requests are the ones most likely to get answered.

- **Be willing to compromise**
  The Rolling Stone's said it best: "You can't always get what you want, but if you try sometimes, well you just might find, you get what you need." If you ask your sister if she could come watch mom for a few hours while you go run errands, she may not be able to come herself, but she might be willing to give you money to hire professional respite care for that time. Be flexible and open to multiple solutions to a particular problem.

- **Be polite**
  No matter how uncooperative your family and friends are when it comes to helping care for a loved one, always strive to stay gracious and polite. It may be challenging to conjure up fuzzy feelings when a person you were sure would support you doesn't offer much assistance (or refuses to help outright), but holding onto resentment will only compound your stress and drain your energy reserves. Accept that certain people won't help—and thank the ones who do show up. Expressing your appreciation might make them more likely to provide assistance in the future.

How to Handle Criticism from Family Members

It's an unfortunate reality of caregiving that the caregiver will always be a potential target for criticism, especially from family members and friends who don't understand what it's like to look after a loved one with Alzheimer's.

If you find yourself in this situation, there are a few strategies you can employ to cope with any sharp remarks:

- **Don't make it personal**
  Try to avoid internalizing any insults you receive, whether they come from the person you're caring for, another family member or a friend. In all likelihood, the source of their sourness has nothing to do with you.

- **Accept that you can't make everyone happy**
  It's cliché, but especially true for family caregivers: Try to please everyone and you will end up pleasing no one. Family members and friends will not always agree with your decisions regarding a loved one's care. While it's a good idea to take into account the viewpoints of others, it's also important to learn how to trust your gut and stand by your choices.

- **Understand that criticism is inevitable**
  No one relishes receiving negative feedback; unfortunately it's an unavoidable consequence of assuming the caregiver role.

- **Turn your frown upside down**
  You've probably heard it before, but research has consistently shown that even a fake smile can provide mood-boosting benefits, and may help you mentally and physically relax.

- **Don't be a pushover**
  Criticism may be unavoidable, but that doesn't mean that you should tolerate abusive behavior. If a family member is hurling hurtful remarks

in your direction, calmly tell them that you refuse to be treated that way and physically remove yourself from their presence.

- **Seek support**
  Receiving a harsh critique—especially when it comes from a family member or close friend—can be difficult to cope with. Many of those who find fault with your caregiving decisions probably don't fully understand the spectrum of emotions and stress that weigh on a caregiver's heart and mind. It's not their fault; they've just never been in your shoes. One of the best ways to cope with criticism is to find an outlet where you can share your experiences and receive honest feedback from men and women who are faced with similar struggles. Online support groups, such as the Caregiver Forum on AgingCare.com, allow you to tap into an ever-present wellspring of encouragement, inspiration and guidance from fellow caregivers.

It may be hard, especially in the beginning, but eventually you will develop your own process for coping with criticism in a healthy, productive way.

CHAPTER SEVEN:

Coping While Caring for a Loved One with Alzheimer's

People caring for a loved one with Alzheimer's must make their own physical, mental and emotional health a priority. It may seem counter-intuitive to the newly-minted caregiver, but a loved one's health and well-being is intimately tied to their caregiver's own health and well-being.

In this chapter, you will learn how to manage the physical and emotional stress of caring for a loved one with Alzheimer's disease, and discover how not to be defined by your role as a dementia caregiver.

Articles in this chapter include:

- The Truth About Caregiver Stress and Burnout
- Self-Care Essentials
- Caregiver Support Isn't One-Size-Fits-All
- Identifying Sources of Support
- Don't Be Defined By Your Role as a Caregiver

The Truth About Caregiver Stress and Burnout

As a caregiver for a loved one with Alzheimer's disease, stress will (to varying degrees) be ever-present in your life. But that doesn't mean that caregiver burnout is inevitable.

People who suffer from caregiving-related stress have a 63 percent increase in their mortality rate, according to a 2003 study conducted by Ohio State University.

10 COMMON SYMPTOMS OF CAREGIVER STRESS

1. *Depression*
2. *Withdrawal*
3. *Insomnia*
4. *Trouble concentrating*
5. *Anger*
6. *Health issues*
7. *Exhaustion*
8. *Anxiety*
9. *Drinking or smoking*
10. *Altered eating habits*

If you feel overwhelmed and find yourself experiencing several of the symptoms of caregiver stress, then it may be time to re-evaluate your approach.

THE STRESS MANAGEMENT STRATEGY EVERY ALZHEIMER'S CAREGIVER SHOULD ADOPT

What if someone told you there was something you could do, right now, that could slow down the mental decline of your loved one with dementia by 37 percent?

Researchers from Utah State University (USU) have unearthed a significant link between the stress-management strategies of caregivers and the mental functioning of the people they care for.

Caregivers who adopt a primarily problem-focused approach to solving common caregiving problems not only experience greater personal health, they are also able to provide better care for their loved ones with dementia, says JoAnn Tschanz, lead study author and USU psychology professor.

She and her colleagues discovered that caregivers who use healthy coping strategies may potentially slow down their loved one's mental decline by as much as 37 percent. Existing research indicates that a close bond with a caregiver who is physically healthy and who can effectively manage their stress levels may help keep a person with Alzheimer's out of a nursing home.

When figuring out how to handle the distress caused by negative dementia behaviors, the strategies caregivers can employ typically fall into two categories: emotion-focused and problem-focused.

- **Emotion-focused coping techniques** emphasize dealing with feelings of anxiety, guilt, shame, anger, etc., caused by a particular source of stress. Strategies include venting, praying, distracting yourself from the stressor and ignoring the stressor.

- **Problem-focused coping techniques** emphasize dealing with the source of the stress directly. Strategies include removing oneself from the presence of the stressor, or seeking to understand and come up with a plan to tackle a stressful situation.

For example, if your loved one suddenly becomes agitated and starts pacing around the house, a problem-focused strategy would begin with research into the possible causes of anxiety and restlessness in someone with dementia. You would then examine whether your loved one was recently exposed to any of these triggers. Your first priority should be to calm them down by either removing the cause of their agitation, or distracting them with another activity. After their anxiety has passed, you would then brainstorm ways to avoid the anxiety-producing situation in the future.

The complex collection of challenges you'll face while taking care of your loved one will require you to employ both emotion-focused and problem-focused coping mechanisms.

Feelings of anger, sadness and guilt must be dealt with properly; you can't just stuff them down. At times, your situation will seem so difficult that the one thing you really need is a support group to listen to you vent.

The ability to successfully meet caregiving's challenges and prevent your emotions from boiling over will have a profound impact on the health and well-being of your loved one. Here are four healthy ways to handle the trials of being a dementia caregiver:

- **Obey caregiving's golden rule:** Take care of the caregiver. Put on your own oxygen mask first. There are countless iterations of this all-important advice. Given the intimate (and scientifically significant) connection between the well-being of the caregiver and the health of the care recipient, it's a maxim that bears repeating. "Taking a problem-oriented approach to caregiving also includes being aware of your own physical and emotional needs," says Tschanz. Schedule 'personal hours.' Ask for help from family and friends.

- **Go with the flow:** "Recognize that everyone has their good days and bad days," Tschanz advises. If your loved one exhibits several bad behaviors in a single day, she suggests trying to identify what might be causing the abnormality. Maybe they didn't have enough to eat for breakfast or their sleep was disrupted. Pinpointing these triggers can help you avoid similar situations in the future. Start keeping a written log that lists the things that seem to affect your loved one in both negative and positive ways. That way you'll have something to refer to when new issues arise.

- **Educate yourself:** Learn everything you can about your loved one's ailment. The more you know about how dementia can affect a person's behavior and abilities, the easier it will be to come up with solutions to dementia-related problems.

- **Seek meaning in madness:** Studies show that caregivers who are able to derive meaning and purpose from their experiences find the burden of caring for a loved one to be lighter than those who view the experience through a predominantly negative lens. If you're having trouble finding the positive, start a journal to chronicle the beneficial experiences and insights you've gained from your caregiving journey.

For additional information on coping with stress, avoiding burnout and maintaining your sanity while taking care of a loved one with Alzheimer's, consult this collection of caregiver support articles.

Living in Their World

The following is an excerpt from Marlis Powers' post, "Find Your 'Stress Busters':"

> *"As we deal with the day-to-day ups and downs of our loved ones, the tension begins to build. There are days when we all want to scream, ignore, tear our hair out, or just get up and walk away – for an hour, a day, a week, forever.*
>
> *We each have to refine our own coping skills and find some way to release the tensions that build, one on top of the other, like a house of matches, ready to collapse at any moment.*
>
> *It wasn't any one thing that set me off today.*
>
> *Sometimes, just the discouragement that comes with watching Charlie deteriorate month after month is enough to make me want to bolt, or at least, stay in bed all day and try to forget this terrible thing called dementia.*
>
> *This morning the people in our community held a breakfast to honor Veterans. As I watched Charlie walk from the car to the meeting place, I couldn't help but notice how much worse his walking has become.*
>
> *His mobility problem is not necessarily related to the dementia; it is a gradually progressing after effect of the paralysis from his airplane crash fifty years ago, and the small strokes he has suffered. It's not so noticeable when he's tapping around the house with his cane.*

But today, as he tried to navigate curbs and walk the short distance to the club dining room, it was very evident that the wheelchair isn't far away. He has a walker that he stubbornly refuses to use.

Watching him try to interact with others at our table was equally depressing. He seldom gets out now in situations where there are people other than family members, and they know not to ask him about things that may be difficult for him to respond to. Not so with strangers.

When they ask him questions about where we came from, service related questions, or other things about his past, they get a blank look from him as his brain tries to come up with an answer. Or, worse yet, he may come up with an answer that is less than the truth as his mind confuses fact with fiction.

Sad.

Every caregiver has to figure out ways to relieve the stress to which they are constantly subjected.

Your release may come from an hour or two of shopping, even window-shopping. It may be sitting in the park people-watching, a walk on the beach, a yoga class once a week, or curling up with a steamy novel while your loved one is napping.

Without stress-busters we all find ourselves taking our frustrations out on our loved ones, including those who are not the patient. Family life is never the same once we become a caregiver.

Whatever it is that gives you some peace, don't feel guilty about taking some time for yourself.

You, the caregiver, are the most important part of the equation. Without you the patient will either end up in a nursing home or in his final resting place. Do whatever it takes to find yourself some moments of sanity from the crazy world called dementia."

Self-Care Essentials

Here are some additional resources to guide you on how to attend to your own physical and mental wellness while caring for a loved one with Alzheimer's:

DIET AND EXERCISE NEEDS

- At-Home Exercises to Help You Stay Strong and Mobile
- 6 Fun Activities That Count as Exercise
- Yoga Can Help Relieve Your Stress and Pain
- 7 Simple Ways to Put Fruits and Veggies Back into Your Diet
- Health Benefits of Mediterranean Diet Foods

WELLNESS NEEDS

- 11 Tips for the Best Sleep Ever
- How Your Thoughts Affect Your Health
- 10 Things That Make You Feel Old—and What to Do About Them
- Medical Tests Every Caregiver Should Have
- Multivitamins May Be a Waste of Money, Say Top Docs

EMOTIONAL NEEDS

- Relaxing: Why It's Hard and How You Can Learn to Unwind
- The Deadly Consequences of Loneliness
- How Caregiving Can Change Your Personality
- 7 Ways Caregivers Can Make Time for Happiness
- The Benefits of Learning to Befriend Yourself

Caregiver Support is Not One-Size-Fits-All

When it comes to assisting dementia caregivers, the traditional "one-size-fits-all" approach to caregiver support may be woefully ineffective, according to a recent analysis.

Support groups, informational seminars, and question and answer sessions with medical professionals and caregiving experts are undeniably beneficial. However, researchers from Rhode Island Hospital have concluded that people taking care of an elderly loved one may derive more benefit from a custom-made style of support.

"Caregiver burden has often been treated as a single construct," says lead study author, Beth Springate, Ph.D.

Springate and her colleagues interviewed more than 200 family caregivers in order to pinpoint the precise sources of their stress. They found that each caregiver's burden was driven by a unique set of factors, which included feelings of embarrassment, frustration, and guilt. Caregivers were also greatly impacted by how the act of taking care of an elderly loved one was impacting their physical and social well-being.

Of her team's findings, Springate says, "We were surprised to see that caregiver burden could be broken down into several different elements, each of which uniquely contributed to the sense of stress caregivers experienced."

SIMILAR TASKS, SINGULAR SITUATIONS

No two caregiver experiences are the same. There may be similarities and common themes, but every person who decides to take care of a loved one will be faced with a singular set of challenges and joys.

Different diseases require different physical, mental and emotional skill sets, and the relationship a caregiver has with his or her family member also has a significant impact on that individual's attitude and approach to caregiving.

For instance, an adult child taking care of an elderly parent with Alzheimer's who abused them while they were growing up will face a very different set of challenges than a wife taking care of her husband with Parkinson's disease.

Indeed, the Rhode Island Hospital researcher found that the men and women who were more emotionally distant from their care receivers typically found the task of caregiving far more challenging than those who shared a close bond with the person they were taking care of. A number of factors likely contribute to this finding, however, Springate hypothesizes that having a positive relationship with an ill relative may enable caregivers to more easily find meaning and purpose in "giving back" to their loved one.

Another interesting conclusion: adult children who were taking care of their elderly parents reported being more burdened by caregiving than spouses who were taking care of their significant other. Again, this conclusion could be caused by a number of factors, however, adult children are more likely to be saddled with multiple caregiving responsibilities as members of the "sandwich generation"—taking care of both elderly relatives and young children at the same time.

RE-DEFINING THE CAREGIVER'S BURDEN

For anyone who has spent time taking care of an elderly family member, the notion that each caregiver's situation is unique is not earth-shattering, it's obvious.

Springate says, "Although there are common themes, everyone's caregiving situation is somewhat different, and our research suggests there is no one approach to reducing caregiver burden that will work for everyone."

The problem is, the concept of "caregiver burden" is too often tackled in a generic manner. Widely-applicable advice on how to relax and reduce stress levels is easily found and can be very beneficial. But, for some caregivers, these strategies alone may not be enough.

The best place to start is by accurately (and honestly) identifying which aspects of caregiving are most challenging for you.

For example, you may be having a difficult time trying to manage the 15 different medications your father is taking, or you may be lost as to how to handle your wife's Alzheimer's-fueled behaviors.

After that, it becomes an issue of seeking out interventions that can help you with your particular set of problems.

Having trouble juggling multiple medications? Try asking your loved one's doctor or pharmacist for strategies to simplify the process. Alzheimer's behaviors becoming too much to handle? Enlist the help of other caregivers for tips to manage and emotionally cope with your loved one's outbursts. A caregiver forum or online support group can be a great way to learn from men and women who've experienced similar situations with their loved ones.

Identifying Sources of Support

"Where can I find support?"

One of the most commonly-asked caregiver questions is also one of the hardest to answer—in part because the response will vary from person to person.

A few lucky individuals can instantly rattle off the names of the men and women in their lives who are waiting in the wings; poised to help them whenever called upon. However, many caregivers find themselves in the opposite position; desperately seeking someone to lend them the proverbial helping hand or sympathetic shoulder.

Kenneth Doka, Ph.D., a professor of gerontology at the College of New Rochelle, shares the following strategy to help you identify and vet your pre-existing support network:

- **Make a list**: Write down the names of the people you interact with on a regular basis. Anyone you could look to for support should go on this list, as well as those who you may not initially consider to be a source of help. (Remember, this is a brainstorming session. Resist the urge to jump in feet-first and strategize or over-analyze. Just dump all of your ideas on to the page.)

- **Categorize**: Once you've compiled your list of names, it's time to categorize each person into one of four groups based on their main strength. The four groups are: Doer, Listener, Respite provider and Critic.

    1. **Doer:** Put a "D" next to the names of the individuals who are the "doers" in your life. These are the people best-suited to help with day-to-day tasks, such as bringing over a casserole if you become so swamped that you don't have time to make dinner, or coming over one day to lend an extra pair of hands to help clean the house.

    2. **Listener:** Put an "L" next to the good listeners on your list; those people who you can call and invite out for a cup of coffee just to vent, knowing they will listen and not overshadow the conversation with their own woes.

    3. **Respite provider:** An "R" goes next to those individuals who could potentially be sources of respite for you. These are the people who will come over and take you out to dinner, or a movie and discuss any topic, except caregiving. Their talent is in helping you re-connect with the other aspects of your life and personality.

    4. **Critic:** Finally, a "C" goes next to the names of those people in your life who are destructive and critical; the negative Nancy's, the complainers and those who drain you of your energy and happiness.

- **Make a plan**: Use your newly-sorted list to formulate an action plan. How can you utilize these various resources to help you cope with the task of taking care of your loved one?

Each caregiver's list will be different. You may find yourself staring at a depressingly-large amount of C's and very few R's and D's.

The goal of this exercise is to identify your ready-made resources and help highlight the gaps in your support network that need to be filled.

By pinpointing and playing to the strengths of your friends, family and acquaintances, you can make sure you get the help you need from the people who are best-suited to each particular task. You wouldn't want to ask a Helper to do the job of a Listener; it would be uncomfortable for them and not as useful to you.

Don't Be Defined by Your Role as a Caregiver

Caregiving: a verb, not a definition.

It should be easy for a caregiver to see themselves as a verb—after all, they're always doing something.

People taking care of a loved one with Alzheimer's disease constantly bounce between dozens of daily tasks: driving an elder to their doctor's appointments, cooking dinner, working a day job, making sure a loved one takes their medications.

A caregiver herself, author Janice Taylor knows how exhausting it can be just to make simple everyday decisions for her mother. What should she eat for dinner? Which of her outfits should be kept and which should be thrown away?

When faced with this never-ending series of tasks, a person's sense of self is often the first thing that gets sacrificed.

Taylor explains that it can be challenging for people taking care of elderly parents to connect with their true selves. "Society tells us what you're supposed to do and how you're supposed to feel," she says, "We're bad people if we don't drive ourselves mad and go deeply into caregiving."

THE WISDOM IN CLICHÉ ADVICE

Set boundaries. Put on your own oxygen mask first. Ask for help.

These statements are the cornerstones of the informal caregiver creed. They also highlight the vital importance of staying true to yourself while taking care of another human being.

Before you can set meaningful boundaries with a loved one, you must decide how much you're willing to give. Before you can ask others for help, you must first be able to recognize (and accept) that you've reached the end of your proverbial rope.

"It's okay to express that you're completely overwhelmed," Taylor says. "You need to define your role as a caregiver and know how much you're comfortable with, based on your own sense of self."

Know yourself. Know your feelings and your limits and don't be afraid to voice them.

PORTRAIT OF A WHOLE PERSON

How do you learn to temporarily subtract the caregiver title from your résumé and tap into who you really are?

It can be tricky, particularly if you've been looking after a loved one for years. Taylor offers some advice for re-connecting with and getting to know your true self:

- **Engage your core:** Think about your core set of inner resources. Define yourself by the things you like to do, not by your relationships to other people. For example, you may be a creative person who enjoys writing, singing and practicing yoga.

- **Talk about yourself:** Engaging in third-person self-talk can help you come up with alternative definitions of who you are. For example, you could say to yourself, "(Your name) is a quilter, attorney and unabashed romance novel nerd." Taylor says this method, "puts you in a place where your mind isn't hijacked by what's going on, where you're more than your thoughts."

- **Connect under the covers:** Re-tooling your self-definition doesn't mean that you have to spend hours sitting alone, meditating on the mysteries of life. Taylor suggests taking a few minutes right after you wake up in the morning to connect with your inner being. "Remember who you are, before you get out of bed," she says.

- **Talk to strangers:** There's perhaps no better way to re-invent yourself than by being around people you've never met before. Look for groups and clubs in your area that are focused on the things you're interested in. This will enable you to explore a personal passion, while introducing you to people who have no pre-conceived opinions about who you are. Conversing with strangers can offer a refreshing change of pace if your day-to-day interactions constantly seem to revolve around one question: "How's mom doing today?"

- **Set some goals:** Most people tend to shelve their own ambitions once they start looking after a loved one with Alzheimer's. But setting personal goals can be a great way to explore and re-ignite your passions. According to Taylor, the most important aspect of goal setting is consistency. Take ten minutes each day to work towards your target, whether it's writing the next great American mystery novel, or growing an herb garden in your backyard.

Looking for more inspiration and advice to help you plug in to your true self while caring for a loved one? Check out the discussion: "More than just a caregiver…"

Conclusion

Being a caregiver for a loved one with Alzheimer's is a singular experience. No matter how long your journey with your loved one lasts, you will likely experience the full range of human emotion, many times over. Learning how to ride the highs and lows is ultimately something that each individual caregiver must figure out for themselves.

Hopefully this guide has provided you with some additional knowledge to help you progress more smoothly down the path of being an Alzheimer's caregiver.

AgingCare.com exists as a consistently-update online resource for people taking care of elderly loved ones; offering information, inspiration and connection to the millions of family caregivers in need of succor and support.

The stigma of Alzheimer's tends to silence those touched by the disease. But with no medical antidote to the epidemic on the horizon, some are fashioning a different kind of remedy, spun from their very own, real-life stories of tragedy and triumph.

The ongoing tales of countless Alzheimer's caregivers appear on AgingCare.com; these are the narratives that inspired "Fade to Blank: Life Inside Alzheimer's," a stirring account of six separate lives, united by one deadly disease. These men and women have offered up their candid tales, agreeing to let the world into some of the most intimate aspects of their lives. Their offering will enable you to gain a better understanding of what life is really like for those faced with the reality of a mind slowly fading to blank.

The strength to care for a loved one with Alzheimer's disease must be drawn from many different sources, but perhaps the most essential foundation of this strength is the knowledge that one's caregiving journey is never a solo one. As one of our members so aptly phrases it, "You are not alone. Always remember that there are many of us out there—and we are all pulling for you."

Additional Reading

CHAPTER ONE SUGGESTED ARTICLES

- Why we Need an 'Alzheimer's Anonymous'
- Top 8 Truths of Dementia Caregiving
- Who is Worse Off: People with Alzheimer's, or their Caregivers?
- The Story of Alzheimer's: Re-Writing the Rhetoric

CHAPTER TWO SUGGESTED ARTICLES

- Who's Telling the Truth: The Person with Dementia, or Their Caregiver?
- Validation Therapy for Dementia: Calming or Condescending?
- 5 Causes of Alzheimer's Outbursts
- Things People with Dementia Say: Common Phrases and How to Reply

CHAPTER THREE SUGGESTED ARTICLES

- Coconut Oil for Alzheimer's: Miracle Cure, or Misguided Myth?
- Patient Advocates: Helping Caregivers Get Healthcare Answers
- Dealing with Doctors who Bully
- How to Get a Doctor's Appointment Sooner

CHAPTER FOUR SUGGESTED ARTICLES

- Seniors Can Find Confidence and Flow in Yoga Practice
- How Music Affects Memory in People with Alzheimer's
- Memory Café Meetings Offer Unique Alzheimer's Support
- The Truth Behind 7 Senior Diet Myths

CHAPTER FIVE
SUGGESTED ARTICLES

- Alzheimer's Presents Unique Challenges for Home Care
- Choosing Housing for a Person with Dementia
- How to Provide a Safe Home Environment for People with Alzheimer's
- Adult Day Care for People with Alzheimer's Disease or Dementia

CHAPTER SIX
SUGGESTED ARTICLES

- Siblings in Denial about a Parent's Declining Health
- 6 Tips for Handling Family Conflict While Caregiving
- How Caring for a Spouse Can Strengthen Your Bond
- Keeping Relationships Strong While Caregiving

CHAPTER SEVEN
SUGGESTED ARTICLES

- Canine Caregivers Change the Lives of Those with Alzheimer's
- The Sneaky Side of Caregiver Burnout
- Thrust into Caregiving: How to Adapt, Survive and Thrive
- The 'Fix It' Mentality and How it Leads to Caregiver Burnout