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THE ALZHEIMER'S SURVIVAL GUIDE FOR CAREGIVERS

Practical Tips on Caring for Your Loved One



THE ALZHEIMER'S SURVIVAL GUIDE FOR CAREGIVERS: PRACTICAL TIPS ON CARING FOR YOUR LOVED ONE

The job of caring for someone with Alzheimer's can be one of the hardest you'll ever have. It's a never-ending juggling act. First, there are the practical concerns. You are constantly on call, making sure that your loved one's daily physical needs are met. Then you have yourself and your family to take care of. On top of that, there's the emotional reality you must deal with: your relationship with this person is undergoing a transformation, and it will never be what it once was.

No guide can cover everything you need to know as you juggle all your responsibilities as an Alzheimer's caregiver, and this guide does not attempt to do so. What this guide does is give you practical information to make some of the everyday situations you're likely to encounter a little easier. Things like:

- When does my loved one need to take care of legal and financial planning?
- What do I do if my mom won't sit down and eat?
- Why won't my dad take a bath – and how can I get him to?
- How do I manage stress and avoid becoming burned out?

As you read through this information, we hope you'll find some useful tips that will make your job as caregiver a little easier.

EARLY STAGE ALZHEIMER'S

During the early stage of the disease, your loved one is likely to be able to live independently and function well on his or her own. This is the stage of the disease where your help is likely to be the most hands-off. As your loved one progresses through the early stages of Alzheimer's, he or she will likely need help with things like recalling names, dates, and words; keeping appointments; and keeping track of his or her finances.

One of the first – and most important – things you can help with is legal and financial planning. This is the time to take care of it – while your loved one is still capable of thinking through these issues, making plans, and expressing his or her wishes and preferences.

INCAPACITY PLAN

Over time, Alzheimer's robs you of your ability to manage your own personal, financial, and medical affairs. Because of this, your top priority should be to make sure your loved one has an incapacity plan in place. An incapacity plan allows your loved one to authorize a trusted individual to make important financial and health care decisions on his or her behalf.

An incapacity plan is made up of these basic documents:

1. *Durable Power of Attorney*: With a Durable Power of Attorney, your loved one chooses a trusted individual to serve as his or her “agent” or “attorney-in-fact.” This person has the authority to manage your loved one’s financial and legal affairs according to instructions and limits specified within the power of attorney document.
2. *Durable Power of Attorney for Healthcare*: A Durable Power of Attorney for Healthcare allows your loved one to select a trusted individual to communicate with his or her doctors and make medical decisions on his or her behalf in case your loved one is unable to make these decisions on his or her own.
3. *Living Will*: With a Living Will, your loved one states his or her wishes concerning end of life care. This document lets doctors and loved ones know whether or not life support should be withdrawn if there is a terminal illness. In some states the Durable Power of Attorney and Living Will are combined into one document called an Advance Health Care Directive.

If your loved one already has an incapacity plan in place, now is the time to review it and make sure it still expresses his or her wishes. If he or she does not have an incapacity plan, it is important to put one in place as soon as possible, while he or she is still able to make legal decisions. Either way, an experienced estate planning and elder law attorney can help make sure your loved one’s plan is complete, effective, and in compliance with current legal requirements.

ADDITIONAL LEGAL PLANNING

After your loved one has taken the crucial first step of putting an incapacity plan in place, he or she will want to discuss additional planning. An experienced estate planning and elder law attorney can help your loved one think through the challenges that Alzheimer’s is likely to bring. Together, they can structure a plan that meets your loved one’s financial needs while preserving as many assets as possible for his or her family.

This kind of planning varies widely from family to family and from individual to individual. Everyone’s needs and challenges are different, so no two plans look exactly alike. However, there are several common themes your loved one will want to discuss with his or her attorney, including:

Estate Planning

Any major life change is cause to meet with an estate planning and elder law attorney to review your Will, Trust, beneficiary designations, and the other components of your estate plan. An Alzheimer’s diagnosis certainly qualifies as a major life change. Now is the time for your loved one to not only make sure that his or her estate plan still reflects his or her wishes, but also that it fits with the financial and long-term care planning he or she is likely to do.

Your attorney will guide your loved one in evaluating his or her needs, wishes, and goals and will help to ensure your loved one's estate plan fits his or her changed circumstances.

Property and Gifting

Your loved one's estate planning and elder law attorney will also likely ask questions about what real estate and other assets your loved one owns and how that property is titled. This review of assets and property titles is important. Making a few simple changes now can ease transitions and protect your loved one and your family in the future.

However, your loved one should not transfer any property or make any substantial gifts without consulting an experienced attorney. A nursing home stay or other forms of long-term care are real possibilities for many patients with Alzheimer's, and paying for long-term care is a concern.

Depending on your loved one's individual needs, qualifying for government benefits in conjunction with a structured gifting program might be appropriate. However, under the wrong circumstances, gifting assets can result in serious legal consequences, including delaying your loved one's eligibility for benefits.

Long-Term Care Planning

Now is also the time to start a conversation about the possible need for long-term care (such as nursing home care) in the future. This kind of residential care is expensive, and most people can't afford to pay for it out-of-pocket. An experienced estate planning and elder law attorney can help your loved one explore all the available options for funding long-term care. This might include creating a plan to qualify for Medicaid which, when done carefully, can be ordinarily accomplished while preserving many or even all of a person's assets. The key to paying for long-term care without going broke is to plan as far in advance as possible.

MIDDLE STAGE OF ALZHEIMER'S

The middle stage of Alzheimer's disease is often the longest. It may last for a number of years. It can also be the most challenging.

As your loved one progresses into "middle stage" Alzheimer's, you as caregiver will find yourself dealing with a new reality. More accurately, you'll find that you're dealing with two realities:

- *Your Own*: the one you've always lived in, with bills to pay, friends and family to keep up with, a home to maintain, and perhaps a job and children to juggle.
- *Your Loved One's*: with doctor's appointments and medications, plus a growing list of symptoms and challenges. Your loved one may need increasing help with bathing, dressing, eating, and other activities of daily living. This is the point at which your

responsibilities as a caregiver increase, and taking care of your loved one becomes more of a full-time, hands-on job. Added to this, he or she may exhibit a variety of new behaviors, like sleep problems, agitation and anxiety, confusion, and delusions. Sometimes, it might seem like your loved one is living in a completely different reality.

As you take on this sometimes daunting job, it's important to remember that you are not alone. Roughly 7 in 10 patients with Alzheimer's are cared for at home. Fifteen million¹ Americans provide care for family members, friends or other loved ones with the disease. As your loved one's life changes, yours will, too.

RELATIONSHIP

One of the more difficult ways in which caregivers find their roles changing is in their relationship to the Alzheimer's patient. If you're caring for your parent who has Alzheimer's, it can be unsettling to find your roles reversed. The mom or dad you grew up looking to for advice and guidance now seems to be regressing. You're taking on a parental role, making sure your parent is fed, clothed, and bathed. And your parent might not be a willing partner; in fact, you might be faced with a mother or father who is confused, agitated, or suspicious of your motives. This can add an extra layer of difficulty to an already stressful situation.

If the person you're caring for is your spouse or partner, the transition may be even more difficult. The person you've looked to for companionship and support is now relying on you to meet their needs. Your relationship has turned into a one-way street.

The task can be draining, both physically and emotionally.

ROUTINE

As your loved one progresses into the middle stage of Alzheimer's disease, one of the most important things you can do is to help provide daily structure and organization. Creating a daily routine helps to reduce anxiety, agitation, and boredom and it can also relieve sleep problems.

First, frame the day around your loved one's sleep schedule. As much as possible, have your loved one wake, nap, and go to bed at the same time each day. Also, try to keep daily meal and snack times consistent.

Once you have this basic framework in place, think about the following:

- What time of day is your loved one at his or her best?
- What activities does your loved one like and dislike?
- What are his or her strengths and weaknesses?
- What was your loved one's schedule like before Alzheimer's?

¹ <https://www.alz.org/media/Documents/facts-and-figures-2018-r.pdf> (2018)

- How much rest does your loved one need?

Then, make a written plan that organizes your loved one's day into short activities, making sure you allow enough time for bathing, dressing, using the toilet, and getting rest.

If you're not sure what types of activities should go on the plan, consider the following:

- Household chores
- Preparing, serving, and eating meals and snacks
- Quiet activities (reading the newspaper, watching TV)
- Outdoor activities (going for a walk, gardening)
- Creative activities (music, arts, or crafts)
- Outings (grocery shopping, medical appointments)
- Social activities (visiting with friends and family)
- Personal care (bathing, dressing, toileting)

Your daily plan does not need to be a minute-by-minute schedule, but it should be regimented enough that it creates a reliable routine for your loved one. For example:

Morning:

- Get up at 7:00am
- Assist with washing, brushing teeth, toileting, and dressing
- Prepare, serve, and eat breakfast together
- Wash breakfast dishes
- Have coffee and read the paper together
- Break or quiet activity (give your loved one a magazine, watch a favorite TV show)
- Help with toileting
- Household chores or outing

Afternoon:

- Prepare, serve, and eat lunch together
- Wash lunch dishes
- Help with toileting
- Nap
- Help with toileting
- Creative activity or outside activity
- Quiet Time
- Creative activity or outside activity

Evening:

- Prepare, serve, and eat dinner together

- Wash dinner dishes
- Play cards, watch TV or a movie, etc.
- Help with toileting; get ready for bed
- Read
- Go to bed at 9:00pm

A routine like this can be very difficult to maintain on your own. Many families arrange for their loved ones to attend an adult day care program on a regular basis. This has a number of benefits. It gives you a break, allowing you to run errands, take care of yourself, and simply maintain your sanity. It helps to give your loved one a variety of activities while keeping him or her on a schedule.

No matter how you choose to schedule your loved one's time, remember that flexibility is key. What works today might not work next week or next month. Pay attention to your loved one's moods and behaviors. If he or she seems agitated, distracted, or bored, it may be a sign you need to make some scheduling changes. Try adding another activity or scheduling in some additional rest time. As your daily routine changes and adapts, always remember to schedule some time for yourself – even if it's just a few minutes to read, go for a walk, or talk to a friend on the phone.

Helping the Day Run Smoothly

Alzheimer's can make even the simplest of activities frustrating and difficult. In addition to sticking to a daily plan, it helps to have some strategies and practical solutions for dealing with the daily problems you're likely to face.

A WORD OF ADVICE: CHOOSE YOUR BATTLES

You're exhausted. You were up until 3:00 in the morning dealing with a teenager who has no respect for his curfew. It seems like no sooner did your head hit the pillow than your alarm clock rang, signaling the start of another long day.

Fast forward a few hours, and here you stand, in your kitchen. Your mother, who has Alzheimer's, has just asked you what time it is...for what seems like the hundredth time in the last fifteen minutes. Now, as you try to coax her into her chair so that she can eat her lunch, she balks. She has been pacing lately, and she hates sitting at the table to eat. Today, she has chosen to flatly refuse to sit down.

You feel like screaming at her, and you wonder if there's some way you could force her to sit and eat...but you know that these actions will just make the situation worse.

So, what do you do?

You take a deep breath, step back, and assess the situation. What's your goal here? You want your mom to eat a healthy meal. At this point, manners aren't really a priority. So, as long as her food isn't a choking hazard, does it really matter if she eats standing up?

You decide to fix her some finger foods for lunch: chicken nuggets, orange sections, and steamed broccoli. Problem solved: she happily eats her lunch on the go, and you've successfully fed your mother a healthy meal.

It's Not Personal

Alzheimer's forces you to re-think your priorities in an extreme way. You're dealing with someone close to you whose behavior may be changing dramatically. Sometimes, it is difficult not to take your loved one's behavior personally.

- Maybe they're telling the same stories, or asking the same questions, over and over again.
- Maybe they're saying things that you know are simply not true.
- Maybe they're refusing to eat, bathe, or dress appropriately.
- Maybe they're behaving in a way that's rude or even aggressive.

Amid all this change, which can be confusing, infuriating, and heartbreaking, there's one thing you need to remember:

Your loved one is not making a conscious, rational choice to behave in this way.

- Every time they tell a story or ask a question, in their mind, it's the first time. They don't realize you've already heard it a hundred (or more) times.
- When they tell you something that doesn't make sense, or that is completely outlandish (or when they're being rude, mean, or aggressive) they're operating from their own reality – one in which they're the one who is perfectly rational.
- When they don't want to eat, bathe, or dress appropriately, there's generally a reason for this behavior. They're not doing it on purpose to annoy you.

The trick to maintaining your sanity and reducing conflict as an Alzheimer's caregiver is to choose your battles. When a difficult situation arises, take a moment to ask yourself what you're really trying to accomplish. Consider whether there's a way to reach your goal without backing your loved one into a corner and making things more difficult for everyone involved.

Eating

Eating can be a big struggle, especially as a person progresses through the middle stages of Alzheimer's. There are a few reasons for this.

One issue is that your loved one's sense of smell and taste may change. This is partly due to perception changes caused by the disease, and partly because our ability to taste naturally decreases as we age.

Another issue is that Alzheimer's may cause your loved one to experience distorted vision. When food is similar in color to the plate it is served on, the food can be hard for an Alzheimer's patient to recognize. These visual distortions can also cause your loved one to become easily distracted if there is too much on the table at one time, or even too much on his or her plate at one time.

A further problem can arise if your loved one experiences communication problems due to the disease. What if the food is too hot or too cold and he or she can't tell you? Your loved one will likely just refuse to eat.

With these issues in mind, here are some tips to help mealtimes go more smoothly:

- Make sure the table, plate, and food are different colors. For example, if you have a white table, don't serve pork chops and baked potatoes on white plates. Instead, consider using a dark green or navy blue plate. This way, the plate stands out from the table, and your loved one will be able to see the food on top of the plate.
- Keep mealtimes simple. Try not to watch television while you eat; remove centerpieces or other table decorations that might distract or confuse your loved one; and try not to serve too many foods at once. If your loved one has an especially difficult time at mealtimes, consider serving foods one at a time.
- Make sure utensils are easy to grasp. Some patients with Alzheimer's have difficulty holding and using regular utensils. If this is a problem, you can get special utensils at a medical supply store.
- Try adding extra seasoning to your loved one's food to make it more flavorful. Be willing to adjust what you serve based on changing food preferences.
- Test the temperature of your loved one's food before serving it.
- Don't worry about manners. Now is not the time to focus on tidiness; making sure your loved one eats a healthy, well balanced diet should be the priority.

Another strategy many caregivers find helpful is to eat as many meals as possible together as a family. Make mealtimes a social activity that everyone looks forward to, and your loved one may be more willing to participate.

Hydration

Hydration is an essential part of good nutrition. Without proper hydration, a person's skin can become thin, dry, and papery, and can tear easily. Dehydration can also play a part in the development of bedsores.

One of the most important things you can do is to offer your loved one water or other non-caffeinated, low-sugar beverages throughout the day. If staying adequately hydrated is a problem, you can also offer foods with high water content, such as cucumbers, watermelon, oranges, and other fruits, as well as soups or smoothies.

BATHING AND HYGIENE

"Let's get you in the bath, Dad," said Mary, dreading the response. "I don't *need* a bath! I just had one *yesterday!*" came the indignant reply.

In fact, it had been more like five days since Mary's dad, Joe, had bathed.

Mary knew her dad was not trying to drive her crazy, but at times like this, it sure felt like he was.

One of the most common complaints from caregivers is that it's nearly impossible to get their loved ones to bathe, brush their teeth, or perform other tasks to maintain their hygiene. Often, cognitive or perception problems are to blame for this behavior.

Sometimes, a person with Alzheimer's simply doesn't remember the purpose of bathing or brushing their teeth. In this situation, calmly talking your loved one through the reason for your request can help. You can even say something like, "They won't let you go to adult day care if you don't take a bath and brush your teeth."

In other situations, perception is to blame: the person doesn't see things the way he or she used to. Most bath tubs are white. When a white tub is filled with clear water, and a person with Alzheimer's is asked to step over the side of the tub, the experience can be disorienting. Here are some tips:

- Install hand rails and a non-slip tub mat.
- Consider using bubbles or colored bath salts so your loved one can see the water.
- Consider filling the tub with a few inches of water, helping your loved one get seated, and then filling the tub the rest of the way. Sometimes, this causes less anxiety than stepping into a tub full of water.
- If your loved one prefers to shower, consider using a bath chair.

It's important to stick to a routine, scheduling bath time at the same time every day. It is also important to allow plenty of time for bathing, and to be careful to make sure your loved one is comfortable. As people age, they tend to become cold easier. This is especially true of people who have circulatory problems. If your loved one has difficulty communicating, the source of bath time tensions could be that he or she is too cold, and simply can't tell you.

If you are a parent, these bath time struggles might remind you of when your children were very young. However, it is important to keep in mind that you are dealing with an adult. For this reason, it is essential to protect your loved one's dignity and privacy. Here are some tips:

- If at all possible, have a person of the same sex help with bathing. Ideally, this person should be familiar to your loved one.
- Keep your loved one covered with a bath blanket, robe, or towel while dressing and undressing.
- Let your loved one help with disrobing, filling the tub, and washing, even if "helping" only means holding a washcloth.
- Make bathing a slow and gentle process.

In between baths, you can help maintain your loved one's hygiene by offering sponge baths, or by using non-rinse soap products. Several times a day, it's a good idea to offer your loved one a warm wash cloth to clean his or her hands and face. Not only does this feel nice and soothing, it is a great help in maintaining cleanliness.

Dental Hygiene

As the disease progresses, your loved one might forget how to brush his or her teeth. Be prepared to give step-by-step instructions, or to model proper tooth brushing technique. If brushing becomes a problem, you can visit a medical supply store. They often stock oral swabs for cleaning the mouth.

Watch out for signs of mouth pain. If your loved one refuses to eat or makes strained expressions while eating, check for mouth sores and contact your dentist.

DRESSING AND GROOMING

Dressing and grooming can become sources of frustration during the middle stage of Alzheimer's disease. Your loved one may forget how to dress himself or herself. Or you may find that too many choices may cause your loved one to become overwhelmed and frustrated.

On another note, you may find yourself surprised and even a little embarrassed by the clothing ensembles your loved one chooses. It is not unusual for an Alzheimer's patient to want to wear several layers of clothing, so your husband might insist on wearing three shirts or two sweaters. There are three rules of thumb when it comes to what your loved one should wear: it should be comfortable; it should be safe; it should be sanitary.

This means that as long as your husband won't overheat in three shirts or two sweaters, it's probably best to let him wear what he wants. Here are some additional clothing tips:

- If your loved one is easily overwhelmed by clothing choices, offer him or her limited choices. Then, lay out his or her clothes in the order they should be put on.
- If your loved one insists on repeatedly wearing the same outfit, consider buying multiples of each item.
- Make sure your loved one wears comfortable shoes with non-skid soles.
- Choose comfortable clothing that is easy to put on and take off.
- If your loved one is prone to wandering, you should add a nametag to his or her clothing. Every morning, attach a note with your loved one's name and address and your name and phone number to the back of his or her shirt. This way, your loved one can't remove it.

DECIDING WHEN TO GO OUT

Outings, whether they are to the doctor's office or to the grocery store, can become particularly challenging as Alzheimer's progresses. Taking your loved one away from home can cause more anxiety and stress than enjoyment – for everyone involved. As outings become more stressful for you and your loved one, you'll want to begin asking yourself these three questions before scheduling an appointment or an excursion:

1. Do we need to do this?
2. What time of day should we go?
3. How should I prepare in case of problems or an emergency?

Do we need to do this?

Some outings, like a trip to the doctor's office, are a necessity. Others, like going to church, out to dinner, or shopping, don't have to be done with your loved one in tow. Often, you can make arrangements for your loved one to stay home with another family member, or perhaps a respite caregiver, while you go out.

When you are deciding whether or not to include your loved one on an outing, try to determine whether the trip will add value to his or her life, or whether it will simply cause anxiety.

What time of day should we go?

Try to schedule necessary outings for your loved one's best time of day. If your husband is most alert and easygoing during the mid-morning hours, schedule his doctor's appointments or other trips at this time. This way, you have plenty of time to get ready before the appointment, and you can look forward to a relaxing lunch and perhaps a nap for your husband when you get home.

No matter what time of day you schedule appointments, be sure to allow plenty of time to get ready and get out of the house. Rushing will only cause your loved one anxiety and add to your stress.

How should I prepare in case of problems or an emergency?

Before you leave the house, think through what items you want to have on hand in case your loved one becomes anxious or upset while you're out. Do certain pictures or familiar items calm him or her? Does your loved one become upset when he or she is hungry or thirsty? Be sure to pack whatever comforting objects you think you'll need, as well as a snack and a drink for your loved one.

MANAGING DOCTOR'S VISITS

When you are healthy, doctor's appointments tend to be a somewhat passive affair. The doctor examines you, gives you some advice, maybe prescribes a medication...and you do what he or she tells you to do and carry on with your life.

When you're dealing with a disease like Alzheimer's, and particularly when you're helping to manage a loved one's care, it pays to take a more active role. This helps you keep track of everything that happens during multiple medical appointments – often with multiple doctors. It also helps you ensure that your loved one gets the best possible care. Here's how to do it:

- *Take Notes:* Keep a single location, such as a notebook, where you maintain notes of each doctor's visit. Write down what was discussed; any questions you asked, along with the answers that were given; any new instructions; and any new medications or dosage changes.
- *Ask Questions:* If you are not sure about something or don't understand what a doctor tells you, speak up! Likewise, if one doctor says something that seems to contradict what another doctor has said, refer to your notes and point it out. Health care is a business and, as the customer, you are entitled to good customer service.
- *Keep Track of Medications:* Your loved one is likely to be on multiple medications, and those medications are likely to change. It's important to keep an updated list of medications and dosage, as well as notes about how to administer your loved one's medicine. You'll want to keep this list in an easily accessible place, in case of an emergency.

MAINTAINING YOUR SANITY

The role of caregiver is an overwhelming one, to say the least. Taking care of yourself is a necessity – not a luxury. If you neglect your health and become sick or succumb to caregiver burnout, who will take care of your loved one?

Here are some suggestions for maintaining your health – and your sanity:

- *Accept Help When It Is Offered:* Make a mental note (or even a written list) of the things you could use help with. Maybe it's cooking or cleaning. Maybe it's hands-on help with your loved one so that you can have a few hours away from the house. When friends or family members ask if there's anything they can do to help, say "Yes!" and let them know what you need.
- *Know Your Local Resources:* Find out about adult day care centers, home health care agencies, and other resources in your area. Then, as your financial means allow, take advantage of these resources. Enrolling your loved one in adult day care or hiring a home health aide – even if it's only for a few hours a week – can give you valuable time to run errands, see a movie, play a game of golf, or just sit by yourself and relax.
- *Join a Support Group:* It helps to know you're not alone. A support group gives you a place to vent your frustrations, share tips and suggestions with other caregivers, and be among people who can understand what you're going through. The Alzheimer's Association, www.alz.org, offers online message boards and chat rooms for their online community of caregivers. Additionally, in most areas of the country, they offer local support groups for caregivers and others dealing with the disease.
- *Take Care of Yourself:* When you're so focused on taking care of someone else, it can be easy to neglect your own health. Try not to neglect the basics: eat a healthy, balanced diet; get some exercise every day; try to get enough sleep; and see your doctor and dentist on a regular basis.

LATE STAGE OF ALZHEIMER'S

As the disease progresses, your loved one will develop more serious physical needs and will likely require around-the-clock medical care. During the final stages of Alzheimer's, patients usually lose the ability to talk and often lose the ability to walk on their own. This is the stage in which nursing home care or hospice care becomes a necessity for many families, if the patient with Alzheimer's is not already in residential care.

Deciding when to look at alternative care is difficult. When you have focused so long and hard on keeping your loved one at home, it can be difficult to make the shift to looking at nursing home care. Your loved one's physical health will play a large part in your decision, but it is only one part of the equation. You'll want to consider a number of factors, including:

- *Safety:* Is your loved one becoming too physically frail to be safe at home? Does he or she wander away from your home? Is your loved one physically aggressive to the point that he or she is a danger to you or others in your home?
- *Your Health:* Are your caregiving duties causing you to become physically ill or exhausted?

- *Your Family:* Is caring for your loved one causing undue stress on your family?
- *Doctor's Recommendation:* Has your loved one's doctor recommended nursing home care?

While no one wants to place a loved one in a nursing home, the time may come when this is the best decision for your loved one as well as your family as a whole. And the truth is, there are excellent nursing homes with special care units specifically for patients with Alzheimer's.

We hope the information this guide has been helpful to you. For more information on caring for a loved one with Alzheimer's disease, you can contact the Alzheimer's Association (www.alz.org) or talk to an estate planning and elder law attorney.