



Toolkit

for effective caregiving

How to help your loved one, while taking care of yourself



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What's inside

Introduction	3
Managing caregiver stress	4
Overcoming obstacles	7
Staying active and safe at home	10
Planning ahead	13
Working with professional care providers	14
Resources for caregivers	15



More.

That's a word that often comes up when caregivers are describing their experience.

When you're a caregiver, you may be more exhausted, more depressed and more challenged than at any time in your life. You need more hours in your days. More days in your weeks. More energy. More focus. More patience.

Resources for new and seasoned caregivers

The good news is that there's support available to help you become a more effective caregiver—and take care of yourself at the same time.

Start here, with this toolkit from Fallon Health. It's filled with tips, resources and checklists with practical information for caregivers, especially those caring for older adults.

Celebrate successes

Before you go to the next page, take a moment to consider the positives of what you're doing. That's not always easy to do.

While you don't want to sugarcoat a situation, focusing on a small improvement or accomplishment can help you reframe it. Give yourself credit for those successes and the effort you're putting in. Find some joy in those moments.

Find the resources for the times ahead

Remember that there are supportive people and organizations who can supply some of the "more" you need. Ask for their help.

It may take some effort to find the best fit for you and your loved one. You may have to ask directly, maybe more than once. But the time you spend to connect with them is an investment that will soon show its value.

Now, read on for some helpful resources and information.

Managing caregiver stress

Take care of yourself first

The stress of caregiving can affect your physical and emotional health, but you may be able to counteract some of those negative effects with better nutrition, more exercise and mindfulness.

If you feel that taking time for yourself is taking time away from the person you're caring for, remind yourself that taking care of yourself supports your ability to be an effective caregiver.

Benefits of eating well

Ever feel like you can't find time to eat? Do you grab unhealthy snacks on the go instead of having balanced meals?

Everyone does once in a while, but it can be especially difficult for caregivers to find time to plan, prepare and sit down to eat—even though good nutrition is fundamental to taking care of your body.

Regular, nutritious meals can increase your energy level, improve your mood and immune system, and help you get to or maintain a healthy weight.

You don't have to make major changes to see those benefits. Here are some ideas to get started:

- Learn the food groups and general guidelines for good eating. [ChooseMyPlate.gov](https://www.choosemyplate.gov) information to refresh your memory.
- Eat a healthy breakfast. It really is the most important meal of the day.
- Add a nutritious food, rather than taking away a less healthy version. For example, add veggies to your pasta sauce, but still allow yourself some dessert.
- Make nutritious substitutions—whole grain bread instead of white, [healthy snacks](#) instead of chips.
- Have fewer [highly processed foods](#). Avoid foods and drinks with added sugar.
- Drink eight to 10 glasses of water daily.
- Learn how to read the [nutrition labels](#) on packaging.
- Habits take time to develop. Set a goal you'll be able to meet. Then slowly try some [more suggestions for healthier eating](#).



Appreciate the moment

Practicing mindfulness is a way to focus on the present, rather than worrying about the past or the future. This is especially important when you're spending a lot of your time in a caregiving role—you need time to relax your mind and your body.

Here are some tips for getting started. You can choose just one to focus on or add several to your daily routine at once.



- Pay attention to your thoughts and feelings throughout the day. Are there repetitive thoughts that come to mind several times in a day? Consider writing them down or beginning a journal.
- While driving, turn off the radio and put your phone away.
- Go for a walk, and notice things around you: newly planted flowers, children playing in a yard or the sun's warmth.
- Sit in silence for five minutes or longer. Practice mindfulness exercises to calm your mind.
- At meal times, pay attention to how much and how fast you're eating. How does the food taste? What is the texture?
- Carve out at least 10 minutes during the day to do something just for you. Go for a walk, play with the dog or read.
- Take deep mindful breaths, in through your nose and out through your mouth with a sigh. With each exhalation, let go of all the thoughts occupying your mind.

The benefits of this practice will begin to spill over into other areas of your life and help decrease daily stress. Learning to accept both positive and negative experiences can help you move forward with a more balanced life, even while you're providing care for someone else.

You can [find more ideas for practicing mindfulness](#) on the Caregiver Connection blog.



Exercises to relieve stress

You don't have to do a long or strenuous workout to get some relief from stress. **Fortunately, three 10-minute activity breaks are just as effective.**

Choose an activity you'll look forward to and feel motivated to do consistently. Any form of physical activity can improve your mood and relax your mind.

Even getting your heart pumping for a few minutes at a time will be a help. You'll be happier, healthier and better able to provide the attention and care your loved one needs.

How can you use the ideas below? Jot down your thoughts as you go along.

Make a commitment to yourself.

Schedule time for exercise, just as you would any other appointment.



List ways you can increase your activity levels by doing everyday tasks.

A walk at lunchtime? Taking the stairs? Doing squats while folding laundry? Parking farther away from entrances while shopping?



How can you make it easy to stay on track?

Don't give yourself an extra excuse to skip exercise.



Who would join you for a walk, a jog or a fitness class?

The added benefit is you get time to catch up and enjoy each other's company.



Overcoming obstacles

Keep lines of communication open

If you're just beginning to notice changes in someone you care about, you may be struggling with how to bring up your concerns. Or maybe you're seeing worrisome signs in someone you've been helping for a while. It can be hard to talk about those, too.

Yet open and honest conversation is often the best way to ensure that hesitance doesn't become inaction.

Changing roles and getting established as a caregiver

Making a relationship work well takes a lot of give and take. The same is true of the relationship between a caregiver and a person receiving care.

What does a caregiver need to do? Every situation is different, but a good first step is to talk with your loved one about the care needed. It could be a long heart-to-heart or many shorter chats. (If there's any cognitive impairment involved, try to choose a time when your loved one seems relaxed and clear.)

Tips for starting the conversation

While you'll want to be sensitive to your loved one's feelings, being direct about the topic of caregiving make for a smoother transition.

If your loved one doesn't want to talk, try again another time. Here are some questions and issues to consider:



- What are your loved one's thoughts and feelings about receiving help? Stress? Frustration? Embarrassment? These common feelings about needing to rely on others can affect attitude and behavior.
- Would it be easier for your loved one to accept help with a certain task from a friend, family member or paid professional caregiver?
- Do you and your loved one agree on what help is required for personal safety?
- How can you help your loved one maintain a sense of dignity, even when extensive help is required?

Because care needs and expectations change over time, it's good to make this an ongoing conversation.

- **Check in** regularly.
- **Ask** the person receiving care for clear feedback. What does and doesn't work?
- **Accept feedback** without reacting defensively.

By being open, respectful and practical, you can get through these tough conversations and difficulties that may be on the path ahead.



Dealing with resistance

If you've discovered that your loved one strenuously resists your help and suggestions, you're not alone.

The following behaviors are common among people who are experiencing physical or cognitive decline. Does your loved one show any of them?

- Pushes away their family and friends
- Ignores medical advice
- Keeps doing things that are no longer safe for them
- Says hurtful or inappropriate things

Your loved one's resistance can make it more difficult for you and other people who want to help. Here are some tips for managing the situation and your response to it:

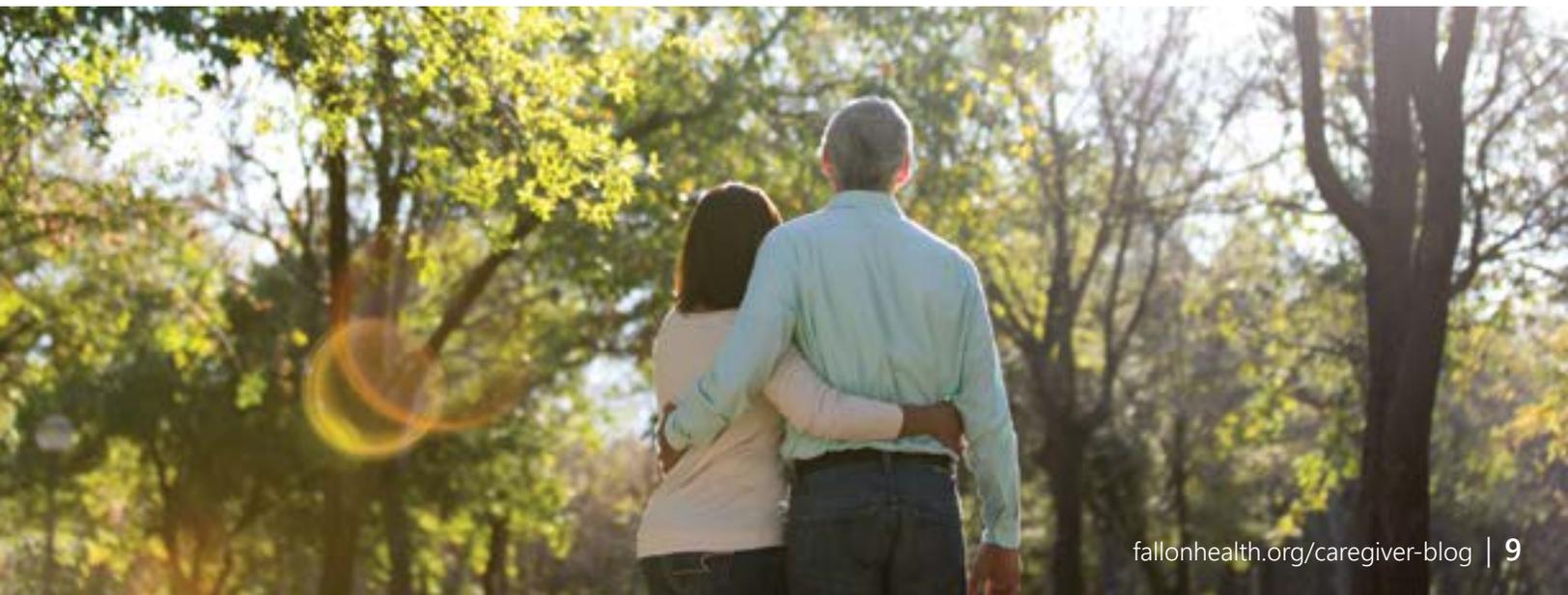


- **Try to see their side.** The difficult behavior you see could be your loved one's attempt to keep control, maintain a sense of autonomy or avoid feeling like a "burden" to you.
- **Offer choices whenever possible.** Remember that your loved one wants to be respected and have control over decisions.
- **Enlist the help of friends and family.** Your loved one may reject your advice but accept the same advice from someone else.
- **Ask your loved one's health care providers** for suggestions.
 - Could health issues or medical treatments impact behavior and attitude?
 - Is your loved one being aggressive or physically abusive? If that's the case, contact their primary care provider right away.

Caregiving from a distance

Do distance, competing responsibilities or other factors make it difficult for you to help in person on a regular basis? Here are **five ways to make it easier to be engaged in caregiving from afar**.

- 1. Ask about your loved one's wishes and expectations for care**, not only their health issues. While this is good practice for all caregivers, it's especially important when you don't have regular in-person opportunities for checking in with each other. Have an initial conversation and then follow up regularly.
 - **Define your role.** Ask what they'd like you to do. What isn't being done now? How can you help? Which decisions do they prefer to make independently and which you could make on their behalf (with final approval by them)? What's realistic?
 - **Discuss long-range wishes.** For serious health conditions, plan ahead and [take the necessary legal steps](#) in case your loved one may not be able to make their own decisions.
- 2. Keep in touch.** Take time to talk about more than your loved one's health. Use an app like [Skype](#) or [FaceTime](#) for a video chat. Seeing your loved one may help you identify any issues not mentioned over the phone.
- 3. Ask your loved one** for permission to talk with health care providers and access medical information remotely. A HIPAA form is required.
- 4. Build a network of contacts near your loved one** to provide social opportunities and updates on changes in health or behavior.
- 5. Be present when you visit.** Don't spend the entire time going to appointments, doing chores and errands, and checking in with people at home. Do something you can enjoy together. Watch a favorite movie, play cards, go through old pictures. If your loved one's physical or cognitive condition has changed, you may need to [adapt the activities you do together](#).



Staying active and safe at home

When someone has physical, emotional or cognitive changes—or some combination of them—some aspects of life at home may also need to change.

Checklist for preventing falls



According to the National Council on Aging, 75% of falls take place in or near the home. Use this checklist to help ensure that your loved one's living space is free of common hazards.

Floors

- Position furniture to create clear walking paths.
- Remove throw rugs.
- Eliminate anything that could be a tripping or slipping hazard.
- Reposition and coil cords so they can't be tripped on.

Stairs

- Fix steps that are loose, broken or uneven.
- Make sure stairs are well-lit and clear of clutter.
- Attach carpet to steps—or remove it and add nonslip rubber treads.
- Install sturdy handrails on both sides of stairs.

Kitchen

- Position often-used items in easily reachable cabinets.

Bathroom

- Get a rubber mat or nonslip strips for the floor of the tub/shower.
- Install grab bars in the tub and next to the toilet.
- Use a shower chair so your loved one doesn't have to stand in the shower.

Bedroom

- Keep a lamp within easy reach of the bed.
- Use nightlights.

Outside the home

- Have your loved one use a shoulder bag, belt pack or backpack to keep both hands free.
- Use baskets or bags with walkers.
- Check your loved one's glasses. Bifocal or trifocal glasses can cause issues with steps or curbs, and a single-prescription pair may solve the problem.

Helping your loved one stay engaged

What activity or hobby is important to your loved one? How can you adapt it to your loved one's current abilities? You can focus on a piece of it to incorporate into a ritual for your loved one or make it into something you do together.

Here are some examples:

- An avid outdoor photographer may like taking pictures of houseplants, flowers or people inside—and then sharing them.
- For a birder who can no longer get outside easily, a window with a view of a birdfeeder in winter and a flowering garden in the spring could be a solution.
- A home cook who used to make big meals for company may be able help with a dinner menu or preparation of an easy dish or dessert.

Your best source of ideas is your loved one. Basing activities, whether modified or not, on what he or she has always liked to do, is a good bet for sharing time that is meaningful for both of you.



Dining out

Going out to dinner can be overwhelming for someone with dementia, vision or hearing impairment, or another physical or cognitive condition.

Restaurants in the [Purple Table Reservations](#) program have staff trained to help make your experience more enjoyable.



Meeting new people

Look for a [Memory Cafe](#) near you. These social gatherings are for people with memory issues and their caregivers to have time together with others who are having similar experiences.



When you should help with medication

When someone's been managing their own medication for their entire life, it can be difficult to acknowledge that it's become too complicated. While you don't want to hurt your loved one's pride by questioning their capacity to continue managing their medications, making a mistake can have serious or even deadly consequences. How do you know if your loved one is taking medications correctly?

Look for these signs. If your loved one is experiencing any of them, you may need to step in to help with medication:



- Forgets things they used to know, such as names, faces, where they live, etc.
- Gets confused easily
- Struggles to open pill bottles and blister packs
- Can't read the labels
- Doesn't know what prescriptions are for or how to take them
- Has out-of-control health conditions
- Has expired drugs
- Leaves pharmacy bags unopened
- Mixes and keeps assorted medications together in bags or other containers
- Uses numerous OTC medications and dietary supplements not recommended by a medical provider
- Has duplicate medications, or uses multiple remedies that contain the same drug as one of their components (e.g., plain Tylenol tablets combined with a multi-ingredient medication that also contains Tylenol)

Tips for offering to help with medication

If you do have concerns, give some thought to how you'll bring up the topic. Here are some approaches to starting a conversation about medication management:



- Present your help as a way to take the task off your loved one's plate.
- Emphasize safety. Taking the wrong pills or forgetting to take them can cause [falls](#), depression, confusion, hallucinations, malnutrition or other serious situations.
- Alert the primary care provider if your loved one clearly needs help but still declines.
- Find out if your loved one's health plan offers a [medication management program](#).

Turn to pharmacists and medical providers for advice

Managing medications is a challenging role for any caregiver. [Ask your loved one's pharmacist and/or medical providers for help](#). They can provide information and insight to make medication management simpler for you—and help you ensure your loved one gets the right medications at the right time.



Planning ahead

Advance planning for your loved one—and for you

Advance planning involves thinking about and writing down preferences for care and representation. Has your loved one done this? Have you? This type of planning gives family and care providers the ability to follow someone's wishes in the event that the person becomes unable to express them. This can help protect you and your loved ones, as well as financial assets.

Permission granted?

No matter what you've arranged informally, you need written permission to talk to your loved one's medical providers directly.

- **Ask your loved one to sign a HIPAA** (Health Insurance Portability and Accountability Act) form at each medical provider's office, so you can talk directly with your loved one's providers.
- **Consider a [health care proxy](#)**, so your loved one can name a health care agent. The agent would make medical decisions if your loved one becomes unable to make or communicate his or her health care decisions. A health care proxy must include a signed HIPAA form to be valid.

- **Call your loved one's health insurance plan**, to find out what documentation is required for the company to share information about your loved one with you.

Learn more about [essential documents to formalize caregiving arrangements](#).

Prioritize your own planning

People often find it difficult to talk about the possibility of something happening to prevent them from making their own health care decisions.

Many caregivers fall into this category. You tend to focus on your loved one's care, not on your own future.

But it's important to create and review plans of your own. Sometimes younger people name their parents or siblings as agents for their [health care proxy](#) (to make health-related decisions) and [durable power of attorney](#) (to act on their behalf for any financial matter)—but they never update the documents. After decades pass, the person listed may have died or may no longer be competent for the role.

That can put your family in the difficult position of trying to guess what you would have wanted. You can avoid these situations by creating and regularly reviewing these documents.

Working with professional care providers

When your loved one goes to rehab

If your loved one is hospitalized, there are specific steps you can take to ease the transition **as they move on to a rehab** or skilled nursing facility:



- **Identify one person** in the family as the main contact person.
- Ask to communicate with the **person in charge**.
- Give the staff **background** on your loved one.
- **Tell the staff** about your loved one's personality, sleep/wake times, medications, anxiety triggers, communication barriers and motivations.
- Don't wait to **ask about the discharge plan**. The day of admission is the day to begin planning for discharge.
- Identify rehabilitation goals.
- Be clear about your expectations for communication.

Someone at the rehab facility may ask to do a home evaluation to ensure that discharge is as safe and successful as possible.

Choosing a home care agency

A home care agency can help you better manage care at home as your loved one's needs become more intense or complex. Professional caregivers can also help during transitions between care settings—for example, from a rehab back to home.

When you're looking for an agency to provide any type of home care for your loved one, don't sign on the dotted line until you take these important steps:

- **Find out what your loved one's insurance coverage includes.** Health insurance plans—including Medicare plans—may have copays or other cost-sharing and limit services.
- **Ask for references from people you know and trust.**
- **Interview the agency.** Are the company and its staff insured? Reachable 24/7? How are employees screened? How are complaints managed?
- **Check out the [Home Health Compare](#) website.** It has patient survey results and Medicare ratings for Medicare-certified home health agencies.

Finding the right agency and care providers can take time, but the extra support will help you better care for your loved one at home.



What to look for in a nursing home

When you're looking at a nursing home, stop by without an appointment the first time. That way, you get a true picture of its everyday operation.

Look for signs of how well the residents are cared for. Can you check off all these boxes during your visit?



- Residents look well-kept and seem as happy as they can be.
- There's a variety of activities for the residents—and they're encouraged to join in.
- The CNAs (certified nursing assistants), RNs (registered nurses) and other staff seem happy and interact respectfully and patiently with the residents.
- Cleanliness.

Make an appointment before a second visit. Ask questions of the other people you meet—staff, families, other nursing home residents—in addition to the person giving you the tour.

Resources for caregivers

[Caregiver Connection](#): a Fallon Health blog for caregivers

[Senior care programs](#): health plans for adults who are independent or need more/complete coordinated care

[Caregiver support groups](#) in Massachusetts, sponsored by Fallon Health

