

TIPS & RESOURCES

Strategies for Caregiving Challenges

Dementia caregiving

Dementia-related illnesses, such as Alzheimer's, can involve more than just memory loss. Changes in personality and behavior and can make these conditions even more difficult for loved ones. It's important to get as much information and support as possible to help you deal with the extra challenges.

Tips from caregivers who have walked this path

- › **Your loved one can't change, but you can.** Understand that you will have to adapt to their changing/worsening condition.
- › **Take the path of least resistance.** Imposing rigid schedules and pushing your agenda sets you up for extra stress. Maintain soothing routines, but learn to let go of expectations and to go with the flow.
- › **Take note of what works.** What do they enjoy? What helps them feel calm? And, conversely, what makes them upset? Help other caregivers understand what works.
- › **See the world through your loved one's eyes.** Imagine not knowing the people around you or even where you are. Use this thought to trigger patience and reassurance.
- › **Live in the moment.** Resist the impulse to micromanage the future or second-guess the past. Accept the realities of the here and now.
- › **Be gentle.** Frustration can make you act abruptly or speak in angry tones. Try your best to lead with a gentle touch, simple gestures and a soft tone.
- › **Keep touchstones to the past nearby.** Photos of happy days in the past and other memorabilia can help start conversations and act as a reminder of who they were before symptoms began.
- › **Find good, ongoing sources of respite** from your caregiving duties. Taking regular breaks and recharging your spirit by doing things for you can help you be a better caregiver and avoid burnout.
- › **Release the stress.** Figure out what helps you let go of stress. Whatever it is – exercise, meditation, the outdoors, getting lost in a movie – schedule time for it as often as possible. It's not selfish, it's how you recharge.
- › **Focus on the positive.** Be open to the idea that there can be good moments so you will be ready to enjoy them when they come.

Dementia resources

National Institute on Aging

www.nia.nih.gov/health/topics/dementia

Alzheimer's & Related Dementias Education and Referral Center (ADEAR)

www.nia.nih.gov/alzheimers

COVID-19, Alzheimer's and Dementia

www.alz.org/alzheimers-dementia/coronavirus-covid-19

For caregivers

Dementia Caregiving

www.caregiver.org/caregiver-resources/health-conditions/dementia/

Caregiver's guide to understanding dementia behaviors

www.caregiver.org/resource/caregivers-guide-understanding-dementia-behaviors

Alzheimer's Association: Alzheimer's and Dementia Caregiving

www.alz.org/help-support/caregiving

Alzheimer's Navigator – Personalized Action Plan

www.alzheimersnavigator.org

National Institute on Aging: Helping Children Understand

www.nia.nih.gov/health/helping-children-understand-alzheimers-disease

Long-distance caregiving

Not having direct oversight and the worry of what might go wrong can be a major source of stress. Proactively addressing some variables can make a big difference. Regular check-ins and visits can help.

- › When you visit, do a walk-through of each room, including the basement and garage. Look for potential hazards. Some examples include poor lighting, trip hazards, non-working detectors, and need for grab bars.
- › A home safety evaluation done by an occupational therapist may be helpful in identifying issues and solutions.
- › Check the refrigerator and cupboards for expired or spoiled food. Look for changes in cleanliness of the home.
- › Review medications and their system for taking them.
- › Connect with neighbors, friends, faith community and others that may be able to act as a support safety net and alert you if issues develop.
- › Identify availability and contact info for area services that may be needed now or later, such as meal delivery, transport services, home help or health aides.
- › If possible, meet with their doctor, attorney, banker and other professionals. Discuss your role in their care and need for oversight of their medical/financial information, as appropriate to their situation.

Resources that may be helpful

Guide to Community Resources

www.caregiver.org/resource/caregiving-home-guide-community-resources/

Do Not Call Registry

www.donotcall.gov/default.aspx

Opt Out of Junk Mail

www.consumer.ftc.gov/articles/how-stop-junk-mail#mail

Meals on Wheels

www.mealsonwheelsamerica.org/find-meals

American Association of Daily Money Managers

www.aadmm.com

Geriatric Care Managers

www.nia.nih.gov/health/what-geriatric-care-manager

Resources for all caregivers

Area Agencies on Aging and Eldercare Locator

eldercare.acl.gov or call 1.800.677.1116

National Respite Network and Resource Center

<http://archrespite.org/respitelocator>

National Adult Day Services Association

www.nadsa.org/consumers

Family Caregiver Alliance

www.Caregiver.org

AARP Family Caregiving

www.aarp.org/caregiving

Home Safety Checklist

www.nia.nih.gov/health/home-safety-checklist-alzheimers-disease

Home modification

https://eldercare.acl.gov/public/resources/factsheets/home_modifications.aspx

Assistive Technology

www.caregiver.org/resource/assistive-technology

Power of Attorney overview

www.legalzoom.com/articles/what-is-a-power-of-attorney

HIPAA overview

www.nextstepincare.org/uploads/File/Guides/HIPAA/HIPAA.pdf

Find a caregiver support group

www.aarp.org/caregiving/life-balance/info-2021/support-groups.html

www.aplaceformom.com/caregiver-resources/articles/caregiver-support-groups

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HOW CAN I HELP?

Strategies for Caregiving Challenges

It's natural to want to help when a person we care about becomes stressed. But the “dance” of offering, asking for, and accepting help can be surprisingly awkward. Caregivers are encouraged to have a to-do list ready when others ask, “Is there anything I can do?” Even better, potential helpers can share their availability and ideas of how they might help. Keep in mind that you don't want your help to make life harder for the caregiver. Along with offering your ideas, ask them to tell you what they really need. Some suggestions:

Practical support:

- › Propose a regular break. Offer as much time as you are able. Make sure you can honor your offer so the caregiver can count on this time off.
- › Fix a meal. Consider dishes that can be frozen for later. Ask about dietary restrictions. If it's possible for you, offer to prepare a meal on a regular basis. For example, have them choose two days a month.
- › Do laundry, wash dishes, vacuum, or do any needed chores. Be respectful if anyone is resting.
- › Run needed errands. Pick up prescriptions, get groceries, fill the car with gas, etc.
- › Do research on behalf of the caregiver. For example, home medical equipment or geriatric care managers. Offer your time and focus to figure out options, learn about costs, and look into reviews and credentials.
- › Offer help with organization. There are a lot of moving pieces in caregiving. Ask if you could help set up a system of some sort. It might be putting up a dry erase calendar to track appointments. It could be coordinating a group of helpers, creating a filing system, or some other way of creating efficiency.
- › If your budget allows, consider the gift of a massage. Touch can release tension and emotions in a way that talking cannot.
- › Consider texting periodic messages of support – no response required.

Emotional support:

- › Let them know you're available. You might ask if there is a good day or time to stop by or call. Be prepared to reschedule as needed. Keep checking in. Caregiving can feel very isolating.
- › It may feel stressful to ask about what they are dealing with and how they feel, but it's important to get past any discomfort. Being open, direct, and willing to follow their lead tells them you care.
- › Some caregivers may feel that they need to appear strong and capable. They may keep hardships to themselves. Gently invite them to open up: “I honestly can't imagine how you do this. It must get very hard some days. What is it like for you?”
- › Listen. Allow them to share and vent. Validate what they are feeling.
- › You don't have to fix anything. You don't have to be a source of advice or inspiration. Just being there, being sensitive and responding to what the person needs is a valuable form of support.
- › Don't take reactions personally. Exhaustion and worry can make a person irritable or not themselves. Let it roll off of you.
- › Often the work caregivers do is not recognized. Offer genuine, specific, unqualified praise for the job they're doing. “I know it isn't easy. Your strength amazes me.”
- › Don't minimize what they're dealing with, but be open to injecting some humor and laughter into your conversations, if appropriate. It can be refreshing to also talk about something other than caregiving.

HEALTH CARE PARTNERS

Strategies for Caregiving Challenges

The medical management aspects of caregiving can prove to be some of the most stressful. Developing strong partnerships with health care professionals can provide invaluable assistance. They can help you set realistic expectations, guide decision-making, and be a source of supportive resources.

Find a fit

If the person you're caring for doesn't have an established relationship with a health care provider/team or if it's not a positive one, it can be worth the effort to seek out a good fit. Along with exploring network status and other variables with their insurance company, consider the following:

1. Review online information for the doctor(s) recommended as part of your loved one's care team. If possible, interview several until you find one who inspires confidence, is caring, and communicates well.
2. On your first visit, ask questions. Try to get a good sense of the course of treatment they would pursue and why. Ask about pros and cons.
3. Notice your response to the plan. Does it make sense to you? Does it align with what your loved one wants in a treatment plan?
4. Notice your loved one's response to the provider's style. Do they and you feel comfortable with this person? Is the provider taking the time to answer questions thoroughly? Do you feel rushed or patronized?
5. Get a second (or third) opinion. Doctors themselves recommend this step. Opinions on the course of treatment can vary widely.

Once the decision has been made about a health care provider and a treatment plan, trust your choices.

Prepare to be an advocate

Medical professionals can be allies when it comes to caregiving challenges, but they have their own goals and perspectives. It's stressful to feel confused or unsure when it comes to health questions. It helps to come prepared.

Before each visit, put together "talking points" you want to cover. The list on page two is a good starting point.

During the appointment, it may be helpful to take notes or ask the doctor if you might record the appointment. You might also ask if they use a medical scribe (note-taker) who could share the appointment notes with you.

Working as a team

Good communication supports a good partnership.

You can do your part by being open and honest about your situation. Take an active role in decision-making and encourage the person you care for to do the same.

Ask questions. This might feel uncomfortable. Some people worry that they might not seem smart or that there isn't enough time. What matters is that you have a clear understanding of your loved one's condition and the treatment plan. Use open-ended questions to avoid getting basic answers. For example, instead of: "Is the pain a bad sign?" ask: "What does it mean when mom has this pain?"

It's okay to ask them to weigh in on different approaches. You can bring up new treatments or research that you may have learned about or alternative approaches used in other cases and ask for their take on it.

Be assertive. If the doctor recommends a course of treatment, you can ask why. What are the pros and cons compared to other choices? If you feel that your loved one isn't getting the health care they should, discuss your concerns openly. Give the doctor a chance to explain their goals. If you're still not satisfied, you may want to renew the search for care provider who better suits your needs.

Share non-medical concerns. Challenges such as transportation, housing, isolation and respite care can affect stress levels and the physical and mental health of your loved one. For example, if finances are tight, they might not be able to afford certain medications. The treatment plan will make the most sense when all facets of well-being are considered.

When you accompany your loved one to appointments, you want to make sure all questions are addressed fully. Some of the concerns below may not apply to your situation. These are just some ideas to help you get started. Add questions that focus on what's important to you and the person you care for.

Treatment plan

What are the treatment options? _____

Which plan do you recommend and why? _____

What medications are you considering and why? _____

What side-effects can we expect? How do we manage them? _____

What other options exist? _____

Are there any alternative treatments that could help? _____

What does the treatment timeline look like? _____

What is the next step if we go forward with this plan? _____

Symptoms

We've noticed: _____

These symptoms started: _____

We're currently managing them by: _____

What else could be helpful? _____

Concerns

We are worried about: _____

What concerns you about this case? _____

What can we expect long-term? _____

Non-medical issues we're having include: _____

Are you aware of supportive services that could be of help? _____

What is the best way to reach you if we have questions? _____

Other items:

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TENSION RELEASE

Strategies for Caregiving Challenges

Self-care is a vital part of maintaining balance as a caregiver, but the realities of the role mean it can be hard to find the time and energy for it. If stress is overtaking you, take a few minutes to review your week. Ask yourself the following questions to identify targeted self-care moves:

- › What are my signs that stress is having an impact?
- › What factors contributed the most stress?
- › What helped or could help bring that pressure down and help me recharge?
- › How can I incorporate those moves into next week's schedule?
- › Who could help?

Tension release tools

Along with your own personal de-stressors, keep some simple mind/body practices in your toolbox to release physical and mental tension. The exercises below are easy to learn. They can be done "in the moment" when stress builds, during a time out, or at the start or end the day to allow your mind and body to feel more calm and centered.

Mental visualization

Mental visualization is a method in which you use your imagination to direct your thoughts to a peaceful, relaxing, safe place. Because of the way the mind and body are connected, when you use your senses to imagine a scene, you respond as if it were real—you relax. Nature scenes can be especially calming. You can practice and lead this exercise yourself or follow a guided recording. Many are available online or as an app. Here is a sample practice:

- › Find a comfortable place to sit or feel free to lie down. Close your eyes. Take a few gentle, deep breaths and let your body relax.
- › Picture a setting that's calm and peaceful for you. It might be a tropical beach, a mountainside, a quiet meadow, a cool dense forest, a sparkling stream, or any other place that is pleasing and relaxing.
- › As you imagine this scene, think of what it would feel like to be there – all the sensations in this peaceful setting. Add some detail. For example, is there a breeze? What does the sky look like? Is it clear, or are there clouds? What do you see, hear, smell, feel?
- › Try picturing a path. What do you notice as you move slowly forward on the path? Imagine what you would experience via your five senses.
- › Take a few minutes to feel the calm in this relaxed and pleasant space. Breathe slowly and naturally.
- › When you're ready, take a nice deep breath, count to three, exhale and open your eyes.
- › As you go back to your day, see if you can retain some of that sense of calm.

Progressive muscle relaxation

This technique relaxes the body by first contracting, and then releasing, each of the main muscle groups of the body. This point-counterpoint procedure helps you relax more deeply and quickly than just releasing the muscles.

To do progressive relaxation you can create your own recording to help you go through all the muscle groups, or you can just learn the procedure from the table below and work through them from memory.

- › Choose a place where you can stretch out comfortably, such as a carpeted floor or an exercise mat.
- › Inhale and tense each muscle group (hard but not to the point of cramping) for 5 to 10 seconds, then exhale and suddenly relax the muscle group completely. Give yourself 10 to 20 seconds to relax, and then do next group.
- › When you are finished with all the muscle groups, return to alertness by counting backwards slowly from 5 to 1.

| Muscle group | What to do |
|----------------------------|--|
| Hands | Clench them in fists. |
| Wrists and forearms | Extend them, and bend your hands back at the wrist. |
| Biceps and upper arms | Clench your hands into fists, bend your arms at the elbows, and flex your biceps. |
| Shoulders | Shrug them (raise them toward your ears). |
| Forehead | Wrinkle it into a deep frown. |
| Around eyes/bridge of nose | Close your eyes as tightly as you can. (Remove contact lenses or glasses before you start the exercise). |
| Cheeks and jaws | Smile as widely as you can. |
| Around the mouth | Press your lips together tightly. |
| Back of the neck | Press the back of your head against the floor. |
| Front of the neck | Touch your chin to your chest. (Try not to create tension in your neck and head). |
| Chest | Take a deep breath, and hold it for 5 to 10 seconds. |
| Back | Arch your back up and away from the floor. |
| Stomach | Suck it into a tight knot. |
| Hips and buttocks | Press your buttocks together tightly. |
| Thighs | Clench your thighs together tightly. |
| Lower legs | Point your toes toward your face. Then point your toes away, and curl them downward at the same time. |

You can also use a “quick release” version in stressful moments. An example would be to start at the top of your head and move down your body tensing all your muscle groups, one after the other in rapid succession as you breathe in. Hold all for about 5 seconds, then whoosh out your breath and release all the tension. Let muscles go limp, drop your arms and shoulders, let your mouth go slack, feel the sense of relaxation. Take a few calm breaths and return to task.

Breathing exercises

Breathing exercises are one of the simplest ways to relax. This is partly because breathing slowly and rhythmically makes your body feel like it does when you are already relaxed, and this sends a message to your brain to calm down and relax. It also relaxes you by clearing the mind of other thoughts, as you focus on your breathing.

Belly breathing

Belly breathing is quick and easy. It's a good one to start with. Once you've got the technique down, it becomes a good in-the-moment way to feel more calm and controlled.

- › Sit in a comfortable position.
- › Put one hand on your belly just below your ribs and the other hand on your chest.
- › Take a deep breath in through your nose, and let your belly push your hand out. Your chest shouldn't move.
- › Then exhale through your mouth, letting your belly hand go back in.
- › Do this 5 to 10 times. Take your time with each breath.

4-7-8 breathing

This exercise also uses belly breathing, plus a longer exhale to help you relax. You can either sit or lie down.

- › To start, put one hand on your belly and the other on your chest as in the belly breathing exercise.
- › Take a deep, slow breath from your belly, and silently count to 4 as you breathe in.
- › Hold your breath while you silently count from 1 to 7.
- › Breathe out slowly as you silently count from 1 to 8. Try to get all the air out of your lungs by the time you get to 8.
- › Repeat 3 to 7 times or until you feel calm.

Morning breathing

This can be a good exercise to do first thing in the morning to relieve muscle stiffness. But it's also helpful for re-energizing and relieving tension throughout the day.

- › From a standing position, bend forward from the waist with your knees slightly bent, letting your arms dangle.
- › As you inhale slowly and deeply, return to a standing position by slowly rolling up, lifting your head last.
- › Hold your breath for just a few seconds in this standing position.
- › Exhale slowly as you return to the position of bending forward from the waist.
- › Repeat several times.

More resources

Assorted guided practices:

www.helpguide.org/articles/stress/relaxation-techniques-for-stress-relief.htm

Reference

Healthwise. (2021). *Stress management: Relaxing your mind and body*. <https://www.cigna.com/individuals-families/health-wellness/hw/medical-topics/stress-management-uz2209>

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