

Six Steps to Living Well While Caring for Aging Parents



AGING (i)fe CARE™
A S S O C I A T I O N

The experts in aging well.

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We all strive for balance in our lives – nimbly tossing all those balls in the air and navigating their trajectory. When one of those balls is caring for our aging parents, our sense of personal balance is challenged. If we have children ourselves, we enter the sandwich generation zone where we are soon overtaxed and stressed out.

A reminder may be in order that equilibrium is the key to living well as we divide our time among the needs of our parents, children, partners, jobs and ourselves. The pull to care, or over care, often knocks that balance off its feet.

For example, is it easy to skip your gym or yoga class because Mom needs a prescription picked up, or Dad wants you with him when he sees his cardiologist? Do you rush from work, to your daughter's soccer game, to checking in on a sick parent? Has it become a way of life to spend a day cooking for your aging parents while consuming unhealthy fast food yourself, no time for your own home-cooked meal?

The good news is, you can tackle these challenges and create a more balanced life. Friends and family are often a great resource. In addition, gathering a team of professionals in the aging network to be your navigation guides can bring clarity and relief. Don't be fearful of bringing in skilled experts because of the cost – consider the fees you pay as an investment in everyone's well-being. The professional guidance will set you on a successful path so you won't be derailed by caregiver stress, and can actually save you money in the long run.

In this article, we will provide you with information you need in order to prepare for and effectively manage potential crises and demands. We'll show you how to defuse your crises and steer things back into control. As adult children caring for our parents, we may not be able to reverse the inevitable end-of-life issues our parents are facing, but we can prepare ourselves with information ahead of time so there are fewer surprises.

Dealing with the emotional challenges in a healthy way can help us avoid losing the things in our lives that bring us joy, give us purpose, and keep us connected to those we care about most. You can attempt to avoid becoming exhausted physically and emotionally by planning well and prioritizing yourself, as well as the needs of others.

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Establish Connection Through Honest Conversation

The goal here is to gather information about your parents regarding the present and the future. The first conversation about these important issues may be uncomfortable; it may take a few conversations before your parents are willing to give up a little control and plan with you for their future. Your goal is to get your parents' answers to all the "what if" questions now, so you can all reduce any confusion and indecision during an actual crisis.

1. Planning the Conversation

- If other siblings will be involved in the conversation, it's best to have a conference – phone or in person – ahead of time to discuss primary issues and goals you'd like to address. Pick a point person to lead the conversation.
- Make a list of your concerns. Base them on your own observations and those of others who are close to your parents' situation. Prioritize the list with what you see as the most important issues at the top.
- Take another look at the list and prioritize it the way you think your parents would – what are their most important concerns? What do they care most about? Do they generally ask for or accept help?
- Plan your approach. Take into consideration your parents' style, values, and decision-making history. How do they normally react to change? Be sensitive.

2. Starting the Conversation

The approach you take with your parents is key to having a successful conversation. Think through your points very carefully and write them down to help you keep on track and grounded. The goal of your conversation is to engage your parents in a meaningful conversation about what supports they might accept now and what they might consider in the future. Here are a few pointers:

- Stay calm, genuine, and respectful. Remind them of how much you love and care about them. Be as supportive as you can. If you begin to feel tense, take a slow, deep breath or step outside for some fresh air, rather than engaging in an argument.
- Assure your parents that you respect their desire to take care of their affairs without any outside help. Discuss situations that could change that balance, such as a sudden illness, which would necessitate your stepping in to act as their advocate. Knowing how they'd like things managed ahead of time will help you know what decisions to make on their behalf if a crisis occurs.

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SAMPLE LEAD IN: “Mom/Dad, we respect your autonomy and dignity. We are concerned though, that if there is a medical crisis or some other crisis, we won’t know how to help you if we don’t know your desires. Beyond that, in a crisis we’d need to have information about your insurance, your finances and your long-term care plans. Can we take a few minutes to talk about that?”

- Be ready to stop the conversation at any time if things become too tense. Conversely, don’t be surprised if your parents welcome the conversation! You may find that your parents have been anxious to discuss these issues but didn’t want to impose on you.
- Progress might be gradual. Remember that giving up control, even a little bit, is scary and hard for many aging people. Usually the best outcome is having your parents slowly begin to accept small increments of help that don’t overwhelm them. Conversely, cornering your parents will usually lead to their resisting all of your suggestions.
- Safety first. That said, if you have serious safety concerns, or think that your parents might be considered a danger to themselves or to others, you will need to take bigger, more dramatic, and immediate steps. Usually this involves making a report to your county’s Adult Protective Services office where they have professionals who can help assist in emergency situations.
- Hiring professional assistance. If your parents reject the idea of even having this conversation, consider hiring an Aging Life Care Professional™ to help you. Frequently, having a skilled, professional, and objective third-party can help to get your parents talking. You can find a highly qualified Aging Life Care Professional by going to aginglifecare.org.

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3. Goals by Necessity

As mentioned above, it might take a few conversations before your parents are ready to be co-planners with you. The following are the most important issues to cover in that first, or a subsequent conversation:

- **Insurance information** – Make copies of your parents' Medicare, Medicare supplement, and prescription cards. Do they have a long-term care policy or a life insurance policy? If so, make a copy or ask where they keep the policies.
- **Medical information** – Get the names and contact information of all of your parents' medical doctors and specialists, and any current diagnoses for which they are being treated. Make a list of their current medications and get the name of their pharmacy.
- **Legal information** – Do your parents have a Durable Power of Attorney? Advance Directive (Living Will)? Have they completed a POLST (Physician's Orders for Life Sustaining Treatment) form with their doctor? Where are these documents kept? Make copies of everything.
- **Financial information** – Tread lightly but do your best to get information about your parents' income and assets. Where are their investment accounts and what is the contact information for their financial representative? In which bank(s) or credit union(s) do they have their accounts?
- **Day-to-day issues** – Do your parents need help with managing home upkeep, gardening, shopping, bill paying, or driving? Who are the people helping them with these things now?
- **Emergency call information** – Do your parents have an emergency response call system? If so, do they know how to use it? Do they wear the device 24/7?
- **Social information** – How often do your parents go out? How do they get there? What are their social interests? Who are your parents' closest friends or helpful neighbors? Try to get the contact information for the people who are nearby and would help in an emergency. Do your parents drink alcohol, and does this negatively impact their lives or safety?
- **Cognitive information** – Ask your parents if they have any concerns about their memory. Their response may give you an idea of whether or not they are aware of what you might have observed. If they express concern about their memory, reassure them that there are medical assessments available, and sometimes medications that might be able to help.

4. Follow Up

The results of this first, or subsequent conversation might lead you to do some research for your parents on things they'd like to know more about. However, even if you think the best first step is to visit an Elder Law attorney, and they think getting gardening help is more important, go with their flow. An Aging Life Care Professional can be a great resource for finding local, vetted service providers.

Take the time to organize all of the information you've collected and provide a copy of everything to your parents. Keeping the information up-to-date will make it a good source in case of an emergency.



step|two

Assemble Your Team

A family member who tries to fly on their own as a family caregiver can bring on some unintended danger to their own health and the health of their parents by not knowing the right approaches to take or resources to use. You need a “home team” approach to reduce the likelihood that you will suffer from “burn out,” lose wages, sacrifice your career or your marriage, or miss out on activities that you hold dear and that keep your own engine revved.

A team helps maintain balance in your life. This is a good time to engage that team.

- 1. Family and sometimes friends:** Often, siblings come together for a family meeting where everyone commits to taking on a certain task(s). These tasks might include calling or visiting your parents once a week, helping to manage their finances, or overseeing medical issues and appointments.
- 2. Skilled caregivers:** In addition to family members on the team, consider bringing in skilled caregivers. Choose a home care agency that is fully licensed, insured, and bonded. Licensed agencies train and supervise their employees and pay all necessary payroll taxes. A “client-centered” Plan of Care should be written by the agency’s Registered Nurse and provide step-by-step instructions for an aide to follow in the personal care of your parents. Fully licensed agencies provide ongoing supervision of the aide by their Registered Nurse.
- 3. An Elder Law Attorney:** This kind of attorney specializes in the type of financial planning necessary to prepare someone for the cost of long-term care. A list of qualified Elder Law attorneys can be found at www.naela.org.
- 4. An Aging Life Care™ Expert:** This kind of professional’s contribution to the team is providing ongoing management and oversight of your parents’ care needs within their budget. A list of qualified Aging Life Care Experts can be found at aginglifecare.org.
- 5. Financial help:** If your parents have a low income, you can look for services through some of the following nonprofit agencies, some of which provide low cost care management services.
 - Catholic Social Services
 - Jewish Family Services
 - Lutheran Family Services
 - Your Local Area Agency on Aging – www.eldercarelocator.gov will lead you to an office near your parents
 - Community organizations and services for low-income residents



step|three

Protect “Your” Health

Without a sound body, successful family caregiving can be seriously derailed. The stress from caring for older parents can challenge every aspect of your life – work, parenting, exercising, partner relationships, and more.

Guidelines for caring for you

- 1. Have annual physical examinations.** This includes general health checkups, as well as dentistry, eye care and any other specific areas of concern to you. Consider your family history when speaking with your health care professional(s) about preventive care and testing, such as mammograms, prostate screenings, and colonoscopies. Follow up with necessary visits, tests, and any medications.
- 2. Stick to, or adopt, a healthy diet.** Life can run us ragged, and the rigorous journey you are on needs fuel! So don't skip meals, and avoid junk food.
 - With your doctor's approval, try to include whole grains, fruits and vegetables (five to eight servings each day), healthy sources of protein, such as organic milk and free-range, grass-fed meat, and healthy fats, like olive oil, avocados, and nuts.
 - Your health care provider can tell you if you should be taking vitamin supplements. The human machine needs good hydration, so aim for five – six glasses of water each day.
 - Your time is precious, so you might want to invest in a new “slow cooker” and a healthy slow cooker recipe cookbook! These recipes are often hearty and can last for more than a few meals.
- 3. Sleep well.** (Yes, it is easier said than done!) Sleep is when our bodies heal and replenish themselves, preparing us for the day ahead. Busy, active minds or tired bodies can prevent us from relaxing into that deep R.E.M. sleep our bodies need. If you struggle with getting a good night's sleep, it can exacerbate existing health conditions and actually contribute to weight gain, grumpy moods, depression, and anxiety. Not a good thing for someone trying to juggle lots of balls at the same time!

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Finding your perfect formula for a good night's sleep takes experimentation. Be a scientist and try a few of these suggestions to see which ones work for you:

- Try to have a quiet hour before bedtime – no computers, cell phones, games, or television.
- Listen to relaxing music, read a good book, or meditate.
- Avoid drinking fluids for about two hours before bedtime so you are not awakened with an urgent need to go to the bathroom!
- Avoid sugar and caffeine in the evening hours.
- Do some form of mindfulness exercise (more on that, below).
- Try taking a warm bath with lavender oil and Epsom salts.
- If you normally exercise in the evening, try moving it to the morning. Over-stimulation can interfere with sleep.
- Avoid alcohol. It might make you sleepy, but once it wears off, you could wake up during the night and be restless.
- Go to sleep in a cool room with light blankets. This often facilitates a better night's sleep.
- Turn off all the lights and close your bedroom blinds or curtains. You might want to try installing "black out shades" on your windows to really keep the light out and create a dark environment.

- If possible, try to avoid using over-the-counter sleep aids or prescription sleep medication. They generally only work for a short time and can expose you to unwanted side effects. However, there may be times when you might just need a little boost to get the sleep you need, so talk with your health care professional.

4. **Get moving.** To keep yourself healthy, you need to move your body. Healthy exercise can make you feel good, free you from negative thoughts, and help you feel refreshed and renewed.
 - Find a form of exercise you enjoy and do it for up to 200 minutes each week. If you are currently not exercising, try starting with just a short 15-minute walk every day, then gradually work up to the 200 minutes.
 - Some exercise ideas include walking, swimming, running, biking, playing tennis, and hiking.
 - Working around the house can be a form of exercise, especially working in the garden, on a home improvement project, or a physical task where you can see the results more quickly. Some people love to wash windows – they find it somewhat meditative and it brings instant gratification.

If you are doing a task only because it has to be done, but it does not feel rewarding to you, it might cause you to feel resentful, frustrated, or some other negative feeling. This is not good for your health! In fact, it causes your body to release stress hormones that can negatively affect your heart and brain! Marshall the troops and see if you can find someone else to do that task, and lighten your load.



step|four

Maintain Positive Mental Health

Everyone on the team who is helping and caring for your parents needs to have a good sense of self and be open to working well with each other. You all possess different gifts and skills, so sorting out who can/will do certain things helps everyone. But even cooperation doesn't shield us from many of the feelings that arise when caring for others.

Even if we see ourselves as mentally healthy, and our lives as well balanced, we need a way to express our emotions in order to maintain a positive existence. It's normal to experience times when we feel a little sad, confused, angry, depressed, or disappointed in ourselves or in others. Here are some helpful skills to cultivate.

1. All of your emotions are valid. Acknowledging how you feel is the first step toward overcoming negative feelings or accepting occasional negative feelings as part of the caregiving process. Once you acknowledge and deal with your feelings, it is easier to get back on track. And sometimes those feelings are a beacon of information, a message that something isn't working well and needs to be changed or adjusted.
2. Learn to accept those negative or difficult feelings as normal and temporary. You might find yourself wanting to say, "I'm sad because I am losing a little of my mother to her dementia every day." Instead, try to frame it in a more positive way, such as, "I am sad that I'm losing my mother to her dementia, but I am happy to be able to give her a little of the care that she gave me all of my life." Simply reframing thoughts and feelings in this way can give you a more positive, balanced outlook on the same situation.
3. If the burden of sadness is overwhelming for you, it might be time to see an Aging Life Professional or a Licensed Mental Health professional. These practitioners can help you explore your feelings and adjust your outlook by helping you balance the negative and positive. For instance, learning to also focus on the things in life that bring you joy, such as the love you have

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for your children and/or grandchildren, the support and caring you receive from your partner, or even the simple beauty of nature, can help you better manage the hardships you might also be facing.

4. It can be easy to get swallowed up in the pain of loss and become isolated. Life is both joy and loss, not just one or the other. The journey you and your family are on can be a challenge. Reach out to friends and skilled professionals to help you “right your ship” and sustain you through the journey.
5. Those caregivers who ask for help are better able to balance caregiving, family, career, and self-care than those who do not. Bringing in a select variety of people to help you with your caregiving duties can actually give the person being cared for more people with whom to interact. This can improve their quality of life. Asking for help becomes a win-win situation!
6. Support groups provide an extra layer of support as a place to listen to others in a similar situation. You are encouraged to share your feelings with the group as well. Support group meetings are held throughout the country – you can even find groups online. Getting ideas from other people dealing with the same issues is very helpful and can help you transition from a place where you’re feeling like you’re the “only one” to a place where you know you are not alone. No one wants to fly solo! An Aging Life Professional or Local Area Office on Aging can tell you where to find support groups in your area.



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Use Mindfulness to Create and Sustain Balance

Mindfulness activities are those exercises that help you get your mind to a place of relaxation, temporarily disconnected from the thoughts of everyday living. The exercises are purposeful and done with the intention of renewing your mind and body. Some of the exercises take just a few moments while others might last an hour or more.

Fans of traditional medicine have now embraced the importance of doing mindfulness activities for mental well being. Studies at Stanford University and the University of California, San Francisco show that these practices can improve brain functioning and body healing. They can also be a deterrent to brain dysfunction – rebuilding “telomeres” (the ends of chromosomes) damaged by stress.

Some different ways to practice “Mindfulness” include:

1. Meditation.
2. Prayer.
3. Yoga.
4. Nature walks.
5. Guided meditation (you can purchase or download CDs and DVDs online).
6. Relaxation Exercises – systematically relaxing each part of your body – feet, legs, belly, etc. – with breathing, while focusing on a place of peace and renewal (the beach, mountains, your garden, etc.).
7. Some forms of massage can be accompanied by “mindfulness” exercises.
8. Using a simple “mantra” – something you say internally as you take a sip of any fluid, such as, “peace is filling my mind and body” (an example of one of the “one second” exercises suggested by one of the Stanford researchers).
9. Very portable relaxation and mindfulness exercises are breathing exercises – there are many forms and they can be incorporated into your prayer time, nature walks, meditation time, or anytime your mind needs a “break.” Focusing on your breath – the inhale and the exhale – helps keep your mind from wandering to the “to-do list.”

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“The 4-7-8 (or Relaxing Breath) Exercise” from Dr. Andrew Weil

This exercise is utterly simple, takes almost no time, requires no equipment, and can be done anywhere. Although you can do the exercise in any position, sit with your back straight while learning the exercise. Place the tip of your tongue against the ridge of tissue just behind your upper front teeth, and keep it there through the entire exercise. You will be exhaling through your mouth around your tongue; if this seems awkward, try pursing your lips slightly.

1. Exhale completely through your mouth, making a whoosh sound.
2. Close your mouth and inhale quietly through your nose to a mental count of four.
3. Hold your breath for a count of seven.
4. Exhale completely through your mouth, making a whoosh sound, to a count of eight.

This is one breath. Now inhale again and repeat the cycle three more times for a total of four breaths.

Notes about the “4-7-8 exercise”

1. Note that you always inhale quietly through your nose and exhale audibly through your mouth. The tip of your tongue stays in position the whole time. Exhalation takes twice as long as inhalation. The absolute time you spend on each phase is not important; the ratio of 4:7:8 is important. If you have trouble holding your breath, speed the exercise up but keep to the ratio of 4:7:8 for the three phases. With practice, you can slow it all down and get used to inhaling and exhaling more and more deeply.
2. This exercise is a natural tranquilizer for the nervous system. Unlike tranquilizing drugs, which are often effective when you first take them but then lose their power over time, this exercise is subtle when you first try it but gains in power with repetition and practice.
3. You cannot do this exercise too frequently. Do it at least twice a day. HOWEVER, do not do more than four breaths at one time for the first month of practice. Later, if you wish, you can extend it to eight breaths. If you feel a little lightheaded when you first breathe this way, do not be concerned; it will pass.
4. This exercise cannot be recommended too highly. Everyone can benefit from it. Once you develop this technique by practicing it every day, it will be a very useful tool that you will always have with you. Use it whenever anything upsetting happens – before you react. Use it whenever you are aware of internal tension or use it to help you fall asleep.

It is important for us to “relax” even more so when we are family caregivers. “Taking five” (5 – 20 minutes a day to separate your thoughts from the daily tasks and planning can actually give you more energy and extend the length of your life. Try it – start slowly and try to work up to 30 minutes a day (this can be two 15-minute sessions).





step|six

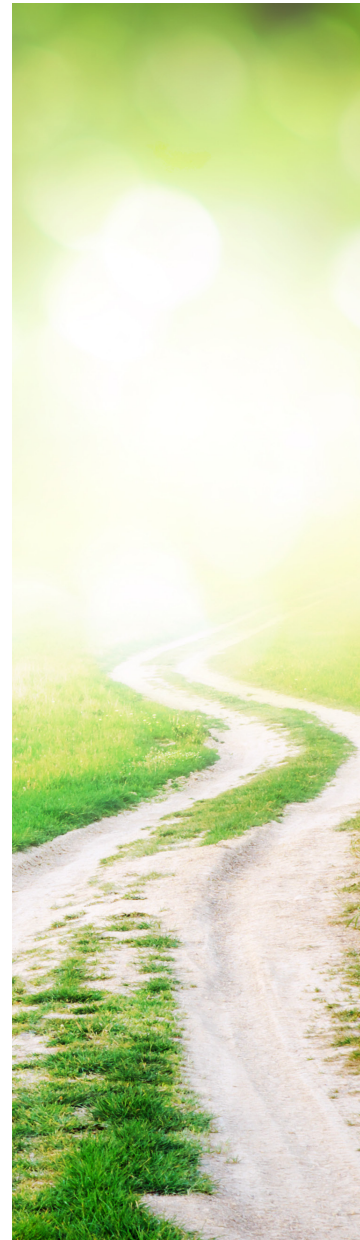
Maintain Your Gains

Hopefully you have reached some significant milestones: 1) You have had meaningful conversations with your parents and created an equitable plan with them, 2) you have assembled your care team and set your plan in writing, and 3) you have learned the tools you'll need to keep yourself healthy and your life in balance. Your newest task is to maintain all your gains. Like any new habit or program we start in our lives, it's easy to slip up and fall back onto old habits if we don't make a conscious effort to stay on course.

A crisis can happen with your parents at any time. It might be a medical incident, an environmental issue (such as a blizzard, hurricane, or earthquake), or a financial stumbling block. Avoid the escalation of problems and stress by maintaining control and being ready to act in any emergency.

1. In order to be fully ready at all times, you need to stay connected to the team you have assembled. Set up reminders, checks and balances throughout this journey. Keep up the support group activity, professional counseling, self-care and updates with your Aging Life Care Professional.
2. Periodic check-in visits by the Aging Life Care Professional are very helpful to keeping things stable. If your parent(s) suffers with extreme memory loss or disorientation, remember that dementia is a bit of a moving target; you need professional oversight to make sure that you are addressing small issues as they come up, instead of waiting for a crisis. An Aging Life Care Professional will look for signs that might topple your progress, and address them before they become a more serious threat.
3. In addition to helping you maintain both medical and safety balance with your parents' care, your Aging Life Care Professional is also up-to-date on entitlement program changes as well as new services and technology. Periodic check-ins will assist you in keeping abreast of what is new, what is good, and what is locally available.

As you work through your thoughtful, well-designed caretaking plan, you may eventually find yourself facing the death and loss of a beloved family member. You will need a place to express and contain your pain. Build that place now.





WHEN THE SUN SETS

The journey of a relationship never ends. You will carry the memories – good and bad, funny and sad, the things you have worked through together, and those things left unresolved – all the days of your life. Your role as the caregiver at some point ends, but can begin again in the future, for another person in your circle of friends or family. The quest is always to find the balance in the caregiving by taking care of yourself as part of that equation. Self care is crucial for taking care of others.

If you find yourself having difficulty recovering from the loss of a loved one, or discover that you have become addicted to the caregiving role, find a professional therapist who can help you sort out your feelings. Life is short! The caregiver in many of us can provide care from a healthy place, and yet some of us still need to flip the switch in order to release ourselves into a space where we can tolerate less burden and feel more alive.

May your journey be guided by your heart, supported by a caring team, and rewarding in ways you never imagined.

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A S S O C I A T I O N

The experts in aging well.