

13 Essential Tips for Dementia Caregivers

Marguerite Manteau-Rao LCSW, ATR, Mindful living advocate

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The journey of dementia is never easy, and it can be made many times worse if family members do not have the internal tools to take care of themselves and their loved ones. Here, based on years of experience in successfully navigating the dementia care landscape, are 13 tips that may save you a lot of grief as a care partner (caregiver) of someone with dementia.

1. Start your day with a few minutes of sitting mindfulness practice, and end the same way.

Mindfulness practice, even for a few minutes a day, can reduce stress. It is also a good way to start your day from a calm, centered place, which is what your loved one needs most from you. If you're not sure how to practice, simply find a quiet place, close your eyes, sit in an alert yet relaxed posture, take a few minutes to check in with yourself and then turn your attention to your breath. Let your body breathe, and simply watch the in and out flow of your breath. You will notice thoughts and sounds coming and going. That is a normal part of the experience. When that happens, simply return to observing the breath. Sit like this for a few minutes.

2. Incorporate mindfulness into your routines: walking, doing chores, caring for loved one, etc.

The same way you were observing your breath while sitting, you can also pay attention to the sensations of your feet on the ground while walking. You can practice while walking alone or with your loved one -- the slower the better. While washing your hands, you can become aware of the sensations of the water running over your hands. While assisting your loved one with dinner, you can focus on the experience of filling up the spoon, bringing it to the person's mouth and their experience of eating. Remember, it is about being present for the experience in the moment, all of it and regardless of what it is. You may do this as often as you want throughout the day.

3. Practice recognizing and being with your emotions, including difficult ones.

When caring for someone with dementia, you are bound to experience many -- and sometimes difficult -- emotions: grief, anger, boredom, tiredness, fear, anxiety, frustration. A very powerful and simple practice is to simply acknowledge the emotion and its physical manifestations in your body. Where am I feeling it? How does it feel? What are the sensations? Also, recognize whether it is pleasant or unpleasant and feel the whole extent of the pleasantness or the unpleasantness. And when you need a break, focus your attention on the breath and watch it come and go. Lastly, identify the thoughts that come with the emotion and see where you are getting caught. Are there changes you can make in the outside world, or do you need to change your attitude?

4. Practice loving kindness for yourself, and also for your loved one.

When the fear or the anger get to be too much, mitigate with some kind energy of your own. Think about someone, something or a place that is very dear to you. Feel the love and kindness emanating from your heart and send it to yourself. While you may not "believe" in it at first, trust that it will make its way through to you eventually. You are working on rewiring your brain, and it takes time! Quietly say something like this to yourself: "May I be at peace, may I be at ease," and repeat a few times, wishing you

well. You may then send that same kind energy to your loved one, this time repeating the words, "May you be at peace, may you be at ease," wishing him or her well. This is a simple yet very powerful practice if you do it often.

5. Share your mindfulness practice with at least one other care partner.

When led into a sitting mindfulness practice for the first time, caregivers almost always report feeling incredibly at peace and say they wish they could start their days in that way. Then comes the question of: Why not? That's the thing about mindfulness -- simple in principle, yet very difficult to practice and sustain on one's own. Unless you find at least one other person to practice with or who encourages you to practice every day, chances are you will not keep up with it. It could be another family member, the paid caregiver who is helping you or people in your local caregivers support group.

6. Put your emotions out, either in writing, collages or other expressive art forms.

When emotions run strong, and you don't know what to do anymore, one practice is to put your emotions out through simple, expressive art techniques. No need for fancy supplies. You can journal, you can write poetry. You can do self-collages, tearing images that grab you in old magazines and placing them on a sheet of paper, without giving too much thought to it. You are turning off your rational brain and letting your heart speak through words or found images. The point is not to be a poet or an artist -- it is about you literally "expressing" what is inside of you.

7. Share your joys and struggles with other care partners like you.

There are plenty of support groups out there, where you can find emotional relief in the telling of your story and the sharing of your joys and your struggles. You need to guard against the temptation of isolation, however. As a family caregiver, you are at high risk of depression and consequently are more likely to be tempted into retreating and not reaching out to others for emotional support. A good rule of thumb is this: The less you want to socialize, the more you need it for your own sanity and also the well-being of your loved one.

8. Get others to help you.

If it takes a village to raise a child, it takes a whole care team to provide good care to a loved one with dementia. It is not humanly possible for a single person to do this, particularly as the years unfold and your loved one requires more and more assistance cognitively, emotionally and physically. If you are someone who has always prided herself in being self-sufficient, you will have to shift your attitude. Getting the help you and your loved one need is a sign of psychological strength. There are many who are there to help you: geriatricians, neurologists, geriatric care managers, nurses, home health agencies, other family members, physical therapists, psychotherapists, financial planners, volunteers, etc.

9. Get enough sleep, eat well and exercise.

As important as your emotional health is keeping your body strong and healthy. With the stress from dementia caregiving, one may be tempted to eat not enough or too much, or stop exercising altogether. Worries about your loved one wandering or accumulated nervous fatigue from a long day of care may dampen one's ability to sleep. Associated with these lifestyle changes are recent statistics from the Alzheimer's Association showing that caregivers are at a substantial increased risk for hypertension and cardiovascular disease. You need to remember that your physical health comes first. Make it a point of having only healthy foods in the home and of walking as much as possible.

10. Validate the person's reality.

The person's experience of the world and their relation to it has changed, and there is nothing he or she can do about it. You, on the other hand, have it in you to make some adjustments. Not doing so will only cause more suffering for your loved one and more trouble for you, since your loved one will have to act out his or her suffering in one way or another. Yes, you may be attached to the idea of your loved one as your husband, but if he insists on calling you his daughter, go with the flow and remember that for him, you have fallen into the more general "love" category. The fine distinctions we usually make between various roles no longer apply.

11. Still see the person as a whole person, and behave accordingly.

Beware of falling into the trap of positioning the person as incompetent, as a child or someone who is no longer there. Holding these ideas will act as a self-fulfilling prophecy and influence your behavior in such a way as to cause the person to behave more and more as if there is no one there. Rather, operate from the premise that the person is still very much there, no matter what it may look like from the outside. Do not expect anything and welcome the surprises when they come, as they often times do with persons with dementia. A smile, a word, a sentence, singing an old song, dancing -- you never know.

12. Meet the person's five universal emotional needs.

Regardless of their cognitive, emotional, physical state, human beings all have five universal emotional needs: 1.) to be needed and useful, 2.) to have the opportunity to care, 3.) to love and be loved, 4.) to have self-esteem boosted, 5.) to have the power to choose. When caring for your loved one, make sure that each of these needs is being met. Failure to do so will negatively impact his or her well-being and will lead to either shutting down or agitation. For someone who no longer speaks or moves, honoring that person's need to be needed may mean telling them how sitting next to them brings you a sense of peace.

13. View the person's difficult behaviors as expressions of unmet needs.

Adopt the point of view that any behaviors, particularly difficult ones, are the person's attempt to communicate distress, using the limited means of communication at their disposal. They are not being difficult, they are simply telling you that something needs to be attended to urgently. Too much noise or not enough, a brief that needs to be changed, being thirsty, not being "seen" for the person they are, pain somewhere in the body, temperature that's too hot or too cold, a sense of personal space that's being invaded, words that don't come out as intended ... so many possible reasons to get upset that may not be obvious to you. You need to become a detective and figure things out. But before you do, take your loved one's distress seriously, not personally.

And remember, this is not just for you alone to practice. Instead, get the whole care team to join you, and together become more mindful and understanding. It will be good for you, and it will be good for your loved one.