

# Caring For A Loved One With Dementia

*a practical*  
**guide**  
*for family*  
**caregivers**  
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## Stressors and Challenges of Caregiving



## Introduction

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**You may have heard that caregiving is among the most stressful jobs there is.** Before diving into the material, it is important for us to take a few minutes to spend some time on the actual word “Caregiver.” Did you ever think this would be something you identified with? How do you feel about being called a caregiver? Often times, when working with family caregivers this is one of the first things we address: getting comfortable with the idea that you are a caregiver. Easier said than done, right?

**Most people do not see themselves as a caregiver.** Often, family members associate caregivers with in-home caregivers or professionals that care for older adults in a facility. It can be difficult for you to see yourself and identify with this role, but it will be important to work towards acceptance. And the more able you are to accept this, the better you can equip yourself for the challenges of being a caregiver, and the better care you can provide to your loved one.



## What is contributing to my stress as a caregiver?

At this moment in time you may have many thoughts going through your head. For example, “I am so stressed I can’t even slow down to think about the things that are stressing me out,” or “I’ve been stressed before and this is no different.” Whatever thoughts may be crossing your mind, it is important to stop and take a few moments to take an inventory.

## How do I know that I’m stressed?

As a caregiver, the last thing you are thinking about is yourself. Your first responsibility of the day needs to be checking in with yourself.

Want to be the best caregiver version of yourself? This will help to achieve that. Let’s imagine you have just boarded a flight to Barbados and the flight attendants are reviewing the safety information for the flight. They have just gotten to the part where they describe the oxygen mask. The instruction given is: “Put on your oxygen mask first before assisting the person next to you”. Let’s say that again, “Put on your oxygen mask first before assisting the person next to you.”

As a caregiver, you need to take care of your own needs, essentially your “oxygen mask” before helping your loved one with dementia. If this is not done you will not have enough “oxygen” or energy/ability to function and provide your loved one with the care that they need.

So, this is where you are asking yourself the question- how do I know that I am stressed? There are many signs and symptoms that you or people around you may notice. Can you relate to some of the signs and symptoms below?

### What kind of patterns and behaviors do you recognize in yourself?

- Dismissive of behaviors
- Minimizing situations
- Physical signs such as fatigue, tiredness, changes in weight, appearing disheveled
- Irritability/anger, yelling or screaming, catastrophizing situations
- Substance use or abuse
- Monopolizing support groups or focus groups
- Cynical
- Becoming isolative
- No longer caring for myself or my loved one’s care
- Distrustful of experts/professionals helping with care
- Unresponsive behaviors
- Over-responsive behaviors – too controlling
- Paralyzed to make decisions, overwhelmed by the number of choices or options available

## 1. Trying to survive the day to day changes

You are in the trenches and unable to look outside of the tasks set before you day in and day out. The fluctuation of your loved one's abilities is stressful.

*Diana has significant fluctuations during the day. She can be laughing and dancing one moment and then her expression changes and she is worried and is paranoid the next moment. Through time, her daughter has figured out that often times her steep decline and fluctuation alerted her when she was hungry and needed a snack.*

### What to do?

As the example above suggests, it is really important to find out why your loved one reacts the way they do, and to cope with the fluctuation of their moods.

- Ask a friend or family member to come spend a day with your loved one and take a break
- Attend a support group to learn about how other caregivers manage day to day stress
- Experiment with your loved one what works best in each situation
- Consult with your doctor
- Consider using Adult Day Care services

## 2. Having to compensate for tasks that you have never done before

Often caregivers take on tasks that their loved ones previously took care of. This is stressful simply because there is more to do, but may also require doing tasks that are outside the comfort zone of the caregiver, such as cooking, cleaning, managing finances, repairing automobiles, etc. On top of the already stressful situation of being a caregiver, there may be a learning curve to learn these new tasks, schedule and complete them.

*Molly took on caring for her husband as his Alzheimer's disease progressed. Molly shared that one of the most difficult things for her to adjust to was the finances (i.e., managing accounts, paying bills, and filing taxes). Additionally, Molly shared that she had never filled a car with gas as this was always something her husband had done. She expressed feeling overwhelmed by the complex and simple tasks like this.*

### What to do?

#### 1. Be realistic.

You are one person with two hands, so there is a strong possibility that you will not finish everything you need to do everyday. Accept this and create a realistic plan about what can be accomplished in a day, a week, a month, and a year.

#### 2. Ask for help!

You don't need to do it alone, and often times there are people in your life that want to help, but don't know what you need. Ask and be specific.

### 3. Use a Resource or Hire out.

You may already have resources that will help you with certain aspects of managing new tasks. If you have a financial planner, use that person to assist you in managing accounts. If you don't have an existing resource, consider hiring help to assist you with these new tasks. Sign up for a meal delivery program, pay the neighbor kid to mow the lawn, or hire a housekeeper to assist you with cleaning tasks.

### 4. Put it in perspective.

Learning a lot of new tasks is like starting a new job- usually stressful and a lot to take in! Keep it simple and don't sweat the small stuff. It's okay if your house isn't perfect or you forget to put out the trash cans this week. Like everything in life, do your best and ask for help.

## 3. Lack or change of intimacy level with partner

The disease will change the nature of your intimate relationship with your partner, which may contribute to the stress you experience as a caregiver for your partner. Your loved one may become confused about sexual behaviors, may start wanting sex more frequently, or engage in disinhibited sexual behaviors in public. These types of behaviors are more often seen among patients with frontal temporal dementia. Also, ethical questions such as "Is the person able to consent?" may arise.

*Dolores engaged in inappropriate self-stimulation while at home in the company of others. Her son and daughter-in-law had to shield their young daughters in the home from this behavior when it occurred. They would take Dolores to her room as a space away. This was very stressful for the son and daughter-in-law as caregivers. They struggled with the understanding that this was a behavior of their mother's severe impairment, but had to really find a way to maintain stability in their home and provide Dolores privacy.*

### What to do?

If you start noticing a decrease or increase in your spouse's libido:

- Hold hands
- Put on some music
- Create a safe, loving environment



If your intimacy needs are not being met, try other ways to get close to your partner:

- Dance to your special song
- Give small gifts, or send love notes
- Hug, kiss, hold hands
- Massage your partner's back, feet, hands

At times, your partner will want to have sex, but you will not want to because several factors can put you off (i.e., incontinence, role change, etc.):

- Try to distract and redirect them as much as possible
- If he or she is too persistent, you may ask your doctor to prescribe a special medication
- Sleep in different beds or bedrooms

If your loved one has disinhibited sexual behaviors, such as seeking out relationships with others, making inappropriate comments or sexual gestures.

- Try to distract and redirect them
- Provide them a safe space and privacy when possible

## 4. Role reversal

If you are caring for a parent with dementia, chances are that your roles will change. You will become the parent. It is very common to hear phrases from caregivers like: “My Mom became like my little child.” If you are caring for your spouse or partner, you may also have to take on more of a parenting role.

This role reversal may result in conflicts, mainly because the person you are caring for may not understand why you are behaving as a parent to them. Also, this role reversal may become a problem for you. You may find it difficult to, all of a sudden, have to “parent” your spouse, your mom or your dad. It may feel unnatural, and cause extreme stress, especially in situations where you feel that the loved one doesn’t want to do what is needed.

### Examples:

- A common conflict that arises for caregivers that are spouses is them wanting to continue to consult their loved one with dementia and ask them permission. This is understandable as this is usually a well-established pattern that has been working for 45+ years.

- A mother who has dementia and does not allow children to double check her bills. Bills at times go unpaid and then have to be paid late with a late fee. This person’s children are having difficulty stepping in at this point.



### What to do?

- **Long Term Choices**

Keep your loved one’s best interest and safety in mind. Rather than keep mom at home alone (or with a burnt out caregiver) because she says she “doesn’t want to move into an assisted living”. Consider that she may no longer be able to make the best decisions for herself. Your job as a caregiver isn’t to have your loved one agree with all the decisions you make, but to make the decisions that are in their best interest.

- **Safety**

You are responsible for the safety of your loved one, but also to keep the public safe from harm they may inadvertently cause. If your loved one is unable to find their way while driving, or has had their driver’s license suspended, it is your responsibility to make sure that they do not and cannot access the family car.

Caregivers may disconnect a car battery, hide car keys, or use other methods to make it impossible for cars to be taken out unexpectedly. This will decrease your stress as a caregiver.

The stove is another option to intervene for safety. Your loved one may still wish to cook, but perhaps will forget that something is on the stove top, or to turn off a burner. They may also lack judgment about how long something should be cooked, or how to prepare it. Limiting cooking for safety is a good idea in cases where supervision is not guaranteed. Unplugging the stove, microwave, and oven can limit the access and danger of fire.

- **Financial Interventions**

It is difficult to see someone you love being taken advantage of. While intervening in financial situations may cause stress, tension, and be a difficult intervention, it may be necessary to protect your loved one from being the victim of fraud, or simply forgetfulness. Having a plan in place for Durable Power of Attorney for Health and Financial will help ease this process when it is time. As seen in the example below, it is important to provide the support early on, and help your loved one embrace change in their best interest.

*Marie was diagnosed with Mild Cognitive Impairment. She lived alone for a couple years and was able to manage most tasks. Marie continued to manage her finances, until it was evident that she could no longer make sense of the numbers or pay her bills correctly. When Marie's daughter stepped in to assist (despite the refusal of her mother), she found that Marie had been visiting the bank daily, and making withdrawals from her bank account in cash. Neither Marie, her daughter, or the bank knew what she did with the large sums of cash each day.*

## 5. Disagreements with siblings and other family members

Unfortunately, caring for a loved one may create conflicts and disagreements among siblings, adding an additional layer of stress. Questions like: “Who will be financially responsible for Mom?”, or “Who has the final decision regarding their medications?” At times, one or two siblings end up with all the burden of caring for their loved one when the other siblings do not do as much, which can lead to major conflicts.

Financial conflicts, such as ability or inability to contribute to care, or desire to maintain an inheritance may complicate care decisions. Similar conflicts can arise with individuals who are in their second marriage. The recent history of their relationship with the person with dementia may make it difficult for them to fully invest in their caregiving duties.

*Henry suddenly passed away leaving his wife, Martha, for whom he had been the primary caregiver. This was a second marriage for the two of them and included four children between them. In this specific situation, her children wanted her to stay in her home, and her late husband's children wanted to sell the home. The family utilized a case manager to help sort out financial and health care responsibilities, and put a plan in place for her children to live in the home with her as her primary caregivers, and for her to receive Adult Day Health Care services when they were working during the day. Being that she was not able to live alone, and that her late husband's will entitled her to stay in her home as long as she needed, the case manager helped the family decide that this was the best arrangement for Martha.*

## What to do?

### 1. Use a Case Manager.

Consulting with a case manager is highly recommended. It is their job to find ways to alleviate tensions between members of a family by asking the right questions. Many experienced caregivers say they would recommend it to new caregivers to help navigate sensitive family situations. Often times, one needs a third party, someone who is exterior to the situation, in order to redirect – or even restart – the dialog between family members.

### 2. Lean on the Power of Attorney.

If there is a power of attorney in place, also referred to as a DPOA, it is specified who is responsible for making decisions on the loved one's behalf. Frequently there is one power of attorney for health care, and one for financial matters. If you are a power of attorney in a family that is feuding, remember that your responsibility is to carry out the wishes of your loved one and make decisions in their best interest, not to please the entire family who may not agree with the terms.

### 3. Keep Calm.

Stress is your number one enemy in this situation. Find support, delegate the tasks that can be done by others. Concentrate on your breathing, take yoga classes. Listen to meditation podcasts.



## 6. Missing work

Many caregivers choose or are forced to leave their jobs, reduce their hours, or ask for time off to attend to their caregiving responsibilities. Though it may seem like you are the only one, you would likely be surprised at just how many people in the work force are balancing work and caregiving responsibilities.

*“One day I was talking to my co-worker, and I mentioned to him that my Mom had dementia and that I was her primary caregiver. As it turns out, my co-worker was taking care of his wife with Alzheimer’s.*



*We both found it relieving to have someone to talk to about our situation, with the same struggles and doubts. We then decided to open the conversation, and reached out to the whole company. There were so many of us in the same situation that we opened a caregiver support group. Sometimes, the very simple fact of sharing what one is going through can help so many others.”*

### What to do?

Talk to your employer; tell them exactly the situation you are in. Ask if they can work with you on more flexible hours or other arrangements. Talk to your co-workers, your friends, your neighbors, too. Chances are that some of them are in the same situation as you. You will be amazed by the generosity of a lot of people.



## 5. Loved one requiring 24/7 supervision

There will come a time when you will not be able to leave your loved one home unsupervised because it will become unsafe, or even dangerous. What if they turn on the stove and don't turn it off? What if they cut themselves with a knife? And more importantly, if anything bad happens to them, what if they do not recall that they should be calling for help – call 911? As soon as your loved one is unsafe to stay home alone, it is important that you come up with back up plans to alleviate the burden of being with them 24/7.

### What to do?

- Search for as many resources as you possibly can. Get in contact with organizations such as Alzheimer's Association or the Family Caregiver Resource Center, they provide you with a list of places and professionals.
- Look for the closest Adult Day Health Care center. Your loved one will benefit from a wide range of cognitive and physical activities, as well as socialization, while you will be able to tend to your other duties, go to your own doctor's appointments, and rest.
- Ask for help. There is nothing taboo about caring for a loved one with dementia. Ask family members, friends for help. No one can do it alone, or if they do, they will burn out eventually.



## 6. Advocating

Being a caregiver often times means advocating for your loved one. It might be working with their doctor to get them a referral to see a Neurologist (always recommended in cases of memory loss). It may be negotiating with their insurance company to get coverage for a procedure.

Further, planning for the future, getting legal and financial documents in order, managing medications, and planning for long term care options. For many people, this is a steep learning curve. As you've probably learned, it's not always easy to understand what insurance will or will not cover, or what your options are for medical care.

You will be making decisions on their behalf that are likely to affect both of you, and that can be overwhelming.

*Cora was the primary caregiver for Dave, whose Doctor told them he had dementia. Cora noticed that he was forgetting more and more, but didn't know what to do. She consulted with an Alzheimer's Support Group, who helped her get a referral to a neurologist. After seeing the neurologist, Dave was diagnosed with early onset Alzheimer's disease and started on medications. Cora also worked with the Family Caregiver Resource Center, who helped her get resources to meet with an attorney and put power of attorney documents in place.*

## What to do?

- Use available resources. There are county resources like the Office on Aging that help patients and families work with their insurance company to understand benefits and coverage.
- Talk to your doctor and directly ask for referrals to a neurologist or memory-care specialist.
- Seek out an elder law attorney, or use the Legal aid Society to get the right documents in order that will protect you and your loved one when it's time to make critical decisions.
- Ask the elder law attorney to review Long Term Care policies to see what the benefits are for adult day care, memory care, or any other service that might provide you respite and be able to plan.
- Ask for help, and be specific about how others can help you.



## 7. Feelings of guilt

One of the critical challenges for caregivers is making the best decisions for someone, even though they may not want to do things such as go to the doctor, attend a day care, or move to a new place. Often times, caregivers don't want to force their loved ones to do something, but know that their loved one can no longer make the right decisions for themselves.

There may be feelings of guilt. For example, a caregiver who promised their loved one that they would never put them in a nursing home. It is a common promise, likely made with good intentions that the caregiver would be able to provide the best care as long as possible. Unfortunately, when the caregiver is no longer able to persuade the person to shower, eat, or use the restroom, this promise may not be the best option to keep, both for the patient and the caregiver.

A similar situation exists with utilizing other resources, such as going to the doctor or going to adult day health care. The loved one may resist wanting to do these things, but it is critical for their health, and the caregiver, to fully utilize the opportunity for respite.

Caregivers may feel guilty asking others to help. Your family, friends, and neighbors are likely to respond to specific requests about how you need help. For example, could they come keep John company for two hours on Saturday while you run errands? Reaching out for support will increase your network of helpers when you need a break, and provide more stimulation for your loved one.

In some cultures, there is a spoken or unspoken cultural responsibility to take care of loved one within the home. As a caregiver, you may feel that it is your duty to honor that at any cost, or feel guilty for considering other options to assist with care. It's important to be realistic about what you can manage, and what is truly the best option for your loved one. If you are unable to get your loved one to bathe, eat, or use the toilet, it may be in their best interest to have professional care.

*When Norma's husband Joe was diagnosed with Alzheimer's disease, he told her he never wanted to be put in a nursing home. For years, Norma took care of Joe at their home. As the disease progressed, it became more difficult for her to help him with personal care, bathing, eating, and he became more combative during these situations, sometimes physically assaulting Norma, or falling in the bathtub. Joe began waking up frequently in the middle of the night and on two occasions, tried to open the front door to leave. Norma began attending a support group with other caregivers, and realized that even though she wanted to honor Joe's wishes, she was not able to provide him the care that he needed by herself. She toured multiple memory care facilities that specialize in working with patients like Joe. It was close to their home, and she could visit regularly. After a few days, Joe settled in and is happier and safer.*

## 8. Depression

Depression is a very common symptom among caregivers, and may put you at a much greater risk to get dementia. However, the good news is that depression is very easily treatable. It should never be neglected and always treated, as soon as possible.

A common pattern for caregivers is to neglect their physical health, social life, activities they previously enjoyed, and overall self-care. This will have a negative effect on your mental health, and if left unattended, may become severe and debilitating for a caregiver.

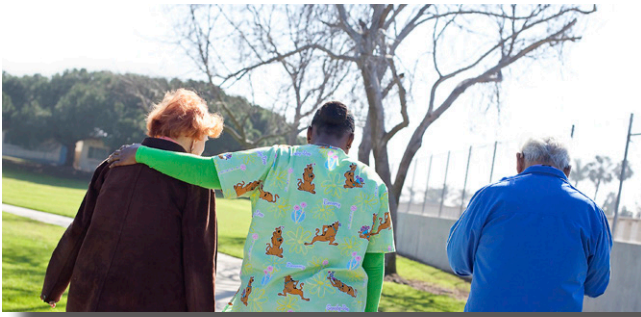
*A Japanese American adult daughter retired early to take care of her mom with dementia and aging father. This caregiver had difficulty remembering things and it took her some time to relax after utilizing Adult Day Health Care services for respite. The center's staff initially had concerns about this person's memory and she voiced similar concerns. However, it turned out that her memory problems were only a result of the impending stress and depression that developed after taking on her caregiver role.*

### What to do?

- Work with a therapist to discuss feelings, stress, and identify triggers that may contribute to depression.
- Consult your doctor to explore if an anti-depressant medication is right for you.
- Talk to a friend or a family member.
- Use respite resources to buy yourself a few hours to do something pleasurable. Take a bike ride, meet a friend for lunch, or go to the library and read.

# Conclusion

The stresses and challenges of being a caregiver are considerable and at times, rewarding. Navigating this journey is best done with help from others and from available resources. Thinking about what you can realistically do - not what you “should” be doing - will help you make decisions that provide the best care for your loved one and for yourself, along the way.



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