

# DOULAGIVERS CAREGIVER CHECKLIST: Caring for the Caregiver



Doulagivers Institute™

*"When you take care of yourself, you are taking  
care of your loved ones too."*

– Suzanne B. O'Brien RN



## Topics Covered in this Doulagivers Caregiver Checklist:

1. Self-Care is Not Selfish!
2. How are you doing really? (The Daily Self Check-in)
3. Who is *YOUR* Caregiver?
4. Are You a Confident Caregiver? Get the help you need to reduce stress.
5. Make Life Easier and Get the Support You Need With CaringBridge!

**Use this checklist while caring for someone else at the end of life to ensure your own needs are met during this time.**

**Caregiver Syndrome is a silent epidemic and when you are burned out, exhausted, and pushed to your limits you cannot provide the highest quality of care for others.**



# Introduction

Recently, I was watching someone I knew share the journey of her father's end of life. He was a beautiful man and their relationship was obviously special. Being his main caregiver, she was sharing with all her friends the type of care she was providing, and the details of all the sudden, scary and poignant moments along the way. Then she shared that her father had taken his last breath surrounded by family who loved him dearly. Her posts then went silent, and the next time she posted, she shared that right after the funeral home came to take her father's body away, she fainted and ended up in the hospital. After further assessment, it turns out that the daughter had not eaten or even drank much water in many days. She was completely exhausted and dehydrated. I wish that I could say this was an anomaly, but caregivers not taking care of themselves happens all the time.

Family caregivers are often faced with a unique set of challenges as they juggle the demands of work, family and caregiving. From managing complex medical tasks to navigating legal and financial issues, it can be difficult for caregivers to find balance in their lives while providing the best possible care for their loved ones. At the end of life, it is common for a family member to be suddenly thrown into a position where they are fully responsible for the care of their dying loved one. Although hospice services help tremendously with structuring a care plan and receiving the necessary equipment and medications to provide this care, the family is still responsible for the majority of hands-on care. This current system takes a toll on already stressed and grieving individuals and leads to Caregiver Syndrome - a silent epidemic that is taking place in our country and around the world as a direct result of an inadequate elder and end-of-life care system. We can, and we *must* do better.

**Go through this checklist when performing the duties as a caregiver so you know how to support not just your loved one, but also *yourself* during this difficult time.**



# 1. Self-Care is **NOT** Selfish!

First and foremost, please hear this: Self-Care is NOT Selfish! When you take care of you, you ARE taking care of your loved ones, your family, and your friends. It allows you to be the healthiest, most vibrant and present caregiver possible.

Caring for a dying loved one can be an extremely stressful experience. It can be seen as the last act of devotion in a long and loving relationship. End of life should never be done by one person (it cannot be done well by one person alone) - but this is often the reality for millions of people every year.

Many times, you might be so concerned with caring for the needs of your loved one that you don't care for yourself. I see this all the time. Caring for someone with a life-limiting illness can be physically and emotionally draining. Often the primary caregiver for a dying patient is a spouse or an adult child. When the patient and the spouse are both elderly, the spouse may not be in such great shape physically either.

When the primary caregiver is an adult child of an elderly parent, they are in what we call the Sandwich Generation. They're caught in the middle of caring for a dying parent or grandparent and also trying to manage their own families and careers. That's a pretty challenging task. It has big financial implications if someone has to take leave from work or quit their job, or ends up being fired because she (children who are primary caregivers are almost always daughters) misses so much work. That puts a lot of stress on family relations and further compounds the difficulty of caregiving.

Caregivers may have medical issues of their own that mean they too need to get to the doctor, refill prescriptions, and take care of themselves. I see caregivers neglect their own physical health often, and I see them neglect their mental health all of the time. This isn't a recipe for a positive end of life experience.

Caregiver burnout can lead to physical and emotional distress - what we call Caregiver Syndrome - and that can affect how well you can take care of your loved one. I see caregivers struggle with feelings of anxiety, guilt, anger, resentment, and grief. They may feel unappreciated or taken for granted. They sometimes start to feel that life is meaningless and filled with too much suffering. All these feelings are normal. In fact, if you didn't have them sometimes, I would be worried about you. Nobody can be upbeat and energetic all the time when caring for someone who is dying. But you have to make sure you take care of yourself as well.



## 2. How Are You Doing Really? (The Daily Self Check-in)

Every day, stop and ask yourself how you're doing. This is great to do when you first wake up in the morning, as well as at the end of each day. Are you feeling fatigued? Are you sleeping okay? Are you eating enough? Are you feeling useful and needed? Are you getting enough support from other family members/caregivers? Are you getting out of the house now and then? Do you feel trapped by the whole situation?

Think about your emotions. Are you feeling overwhelmed? Are you upset that your loved one has changed from his or her former self? Are you having crying spells? Do you feel edgy and irritable? Are you having trouble concentrating or making decisions? Do you feel lonely? Are money concerns keeping you up at night? Every one of these emotions is perfectly normal and even to be expected. Talking about them in a support group or with your hospice nurse, social worker, or spiritual advisor can be incredibly helpful. Just knowing that your emotions are normal can help you feel a lot better about them.

Also think about your physical health. Are you getting enough sleep? Do you have back pain? Are you eating properly? Are you taking your meds? Are you feeling ill in any way or have any ailments such as headaches or digestive problems? Are you staying hydrated? Are you spending some time outside each day?

Whenever I see a caregiver who's answering these questions negatively, I know the caregiver's stress level is way too high. That's when I suggest the caregiver see his/her own doctor for a checkup. I also strongly recommend getting some relief from the pressures of caregiving. When I was a hospice nurse, I would work with the social worker to try to get more home aides for the patient. We would also try to get other family members to pitch in more. Sometimes the primary caregiver actually fights this, because as a loving spouse he or she sees the care as their sole responsibility. When we talk this through and I point out that harming yourself also harms the loved one, we can then usually come to an agreement about delegating some of the work. Friends, neighbors, and other family members can be asked to pitch in. Even family members who are far away can help by calling regularly, by contributing financially if needed and if possible, and by helping out with paperwork and any other tasks that can be done from a distance.



## 2. How Are You Doing Really? (The Daily Self Check-in) cont...

If there aren't any family members to help, I work with the social worker to use local resources, such as hospice volunteers, to give the caregiver some assistance. We also run support groups for caregivers, which can be helpful for expressing your feelings in a safe environment and receiving tips and advice for coping. These online support groups can allow you as a caregiver to connect with people who understand what you're going through and support you through it.

Devoted as he or she may be—and I have seen many examples of amazing devotion—the primary caregiver needs a break now and then. A few nights of sleeping through, instead of waking up in the middle of the night to take care of the patient, can work wonders for restoring the energy and spirits of a caregiver. Even a couple of hours off to go out to lunch with a friend can be a great morale-booster. I always urge family members to arrange time off for the primary caregiver. That's why I recommend respite care whenever possible. Respite means rest or relief, which is what many caregivers desperately need. Some hospice programs offer respite care - programs that provide temporary, short-term assistance with caring for someone with a life-limiting illness. The programs let the caregivers take some time away from the patient, even if it's just a few hours, to recharge physically and emotionally, knowing that the patient is in capable hands. But caregivers need much more. Sometimes we can arrange for the loved one to spend some time in a residential hospice center so the caregivers have some time with less work and fewer pressures. Medicare and most insurance plans will cover the cost of five days of respite care in a residential setting once every couple of months.

Respite care can be important for the patient, too. Many feel guilty about being so helpless and putting their loved ones through so much trouble. I've had many patients bring up how guilty they feel for what they are putting their loved one through. I once worked with an elderly man whose wife was a devoted caregiver, spending all day with him and staying up most of the night as well. She kept saying to him, "How can you leave me?" Well, it wasn't as if he had a choice in the matter, but it made him feel that he couldn't let go in front of her. The family finally persuaded the wife to let his grandson stay by him one night so she could get some sleep. The patient, knowing he wouldn't be devastating his wife by dying in front of her, died peacefully that night. I have had a number of patients who died peacefully while they were in a residential hospice for respite care. I felt in each case the patient actually was waiting for the opportunity to leave so that the family wouldn't have to watch or forever associate their death with the home.





### 3. Who is *YOUR* Caregiver?

One of the most important things you can have when caring for someone at the end of life is a person that can ***just listen***.

The power of presence is the best medicine we have to give to one another. You are going through so many emotions and to have someone you trust that you can confide in is important. Having a person who can listen without judgment and without an agenda - purely to be a loving supportive presence that can “hold the space” for you - is priceless during this time.

This will allow you to debrief and honor your emotions. It is like an energetic cleanse. You should do this on a regular basis.

If you do not have anyone in your life that can be this person, please join our **Free Family Caregiver Community** on Facebook. There are thousands of beautiful people from all over the world in that community that know exactly what you are going through and are ready to be the person that listens and provides support to you.

Doulagivers Institute™

## FREE Doulagivers Family Caregiver Community

*"A place to connect, support and learn!"*

Join Us Now!



## 4. Are You a Confident Caregiver?

Get the help you need to reduce stress.

One of the main reasons that there is so much stress on the caregiver at the end of life is that they usually do not know the first thing about how to care for someone who is dying - yet that is exactly what we expect them to do in our current end of life care system.

The fact that people usually come on end of life support late in their disease process, that family caregivers lack the proper skills and training to provide high quality care, and that a hospice worker is only in the home an average of one hour per week all contribute to making the end of life a challenging experience.

**It does not need to be this way.**

Request that the hospice nurse come back and reteach the medications in the comfort kit until you are thoroughly confident in administering them. Uncomfortability and anxiety around giving medication is one of the biggest issues in home hospice care that I noticed when working cases. Ask the hospice nurse questions like:

***“What should I expect?”***

***“When should I call you?”***

***“What should I do after they die?”***

These are all normal questions to ask, and when you have answers, you feel more confident and empowered in your caregiving duties and your stress and anxiety will decrease as a result.





## 5. Make Life Easier and Get the Support You Need with *CaringBridge*!

We have heard from many families that have used CaringBridge just how wonderful it is as a resource to stay connected with family and friends during the end of life journey.

You can update all your family and friends in one post instead of multiple calls/emails and texts.

You can also post **YOUR NEEDS!**

People want to help and when we are the primary caregiver for someone at the end of life, it's really important that we let them.

You can use CaringBridge to share tasks and chores and make a "meal train" so that people can take turns preparing and delivering food to you while you are caregiving.

These simple yet powerful things allow those that love you to support you and your family through this difficult time - and that's what we're supposed to be doing in the world!

Access CaringBridge Here:





# Doulagivers Self-Care "Pearls"

- **Ask for help.** We know this can be hard to do, but you cannot and should not do this alone. Don't be afraid to ask for what you need from others. People are good and they want to help you.
- **Give yourself time in nature.** Even a 5 to 15 minute walk outside each day to get fresh air and sunlight can greatly improve your mental and physical well-being.
- **Practice Breathing Techniques.** Sitting quietly and either meditating or taking a few deep breaths can be extremely beneficial to you as a caregiver. When you start to feel overwhelmed, try to practice controlling your breath and slowing things down.
- **Have convenient and quality sources of nutrition in the home.** Drinks like Boost or Ensure (Milk Chocolate is my favorite!) are a good source of protein, vitamins and minerals, and energy to help you perform as a caregiver. Neglecting your biological needs will make caring for someone at the end of life even more challenging.
- **Fill up a large water bottle in the morning and make sure you finish it during the day.** Just like keeping yourself fed, keeping yourself adequately hydrated is imperative to your ability to provide care. Drink at least 2 liters of water daily to meet your needs.
- **Turn off your phone when you can.** Having some time to unplug and calm your mind each day is extremely beneficial. Try to create one or two times a day that you can have your phone off.
- **Move your body!** Even that fifteen minute walk out in nature can work wonders. If you can't get out, do some light stretching for about ten minutes each day to feel better.
- **Listen to your favorite song.** Music has the ability to take us to a different place temporarily. Whatever your favorite music is, try listening to it and really immersing yourself in the moment to boost your mood.
- **Spend time with your pets.** We all know our beloved furry friends provide us with an enormous amount of comfort during difficult times. If you have a pet, take some time to play with them or pet them. This can relieve stress and really lift our spirits.
- **Get a baby monitor.** A baby monitor will give you more peace of mind and allow you to relax knowing that you can spend some time lying down or doing activities you enjoy in another room without neglecting your loved one.



## Additional Resource Links:

Caring for someone who is dying can be an extremely stressful experience, but it doesn't need to be. Below is a list of additional educational and supportive resources to help you in your role as a family caregiver. **You are not alone in this journey.**

- [Free Doulagivers Family Caregiver Community](#)
- [Free Level 1 Family Caregiver Webinar](#)
- [Free Death Talk Q&A](#)
- [Free Life Cafe](#)
- [CaringBridge](#)

In Love & Service,

Suzanne B. O'Brien RN and the entire Doulagivers Team

