

What to Expect as a New Caregiver

Finding yourself in the role of a new caregiver can be devastating, unnerving, and distressing. There is no real way to prepare for a loved one receiving a frightening diagnosis such as a terminal illness or a debilitating disease like dementia. A new caregiver often finds his or herself making major life decisions without a road map containing all of the right answers. While every situation warrants developing its own specific plan, there are several things all new caregivers should consider in order to navigate their own individual road maps.

Take a deep breath.

As a new caregiver, this is something you are going to inevitably hear frequently no matter how many times you habitually and automatically nod along in an attempt to quiet your friends and family. Pausing to take a deep breath can actually help you clearly organize your thoughts and manage what you need to do successfully. According to Psychology Today, abundant levels of stress initiate our instinctual “Fight or Flight” response, which is a defense mechanism we have developed to react to fear. This response increases our body’s adrenaline and blood flow, and while this response is helpful in an instance of reacting to danger, it is not so helpful when it is constantly triggered due to being in an ongoing state of stress. Entering the role of a new caregiver is often unexpected, and caregivers usually have spouses, children, grandchildren, jobs, their own health complications, and other various obligations to balance while navigating becoming a new caregiver. While it may not seem productive on the surface to focus on something as basic and automatic as breathing, ensuring the body and brain are receiving enough oxygen will slow an elevated heart rate and will activate relaxation responses that will relieve some of the apprehension and anxiety. Focusing on breathing for ninety seconds at the beginning of the day or prior to making a stressful caregiving decision helps properly organize exactly what you are going to do, and can help you avoid entering a situation feeling shaky and unsure. Relaxing the body through various breathing techniques, stretching, and meditating can also benefit poor sleeping patterns and an unhealthy appetite. While these tasks may seem of minimal importance in comparison to all of the other daily life stressors, there are direct correlations between eating and sleeping habits and both short and long lasting health effects.

Recognize what you are feeling.

As a new caregiver, you may not be used to processing a daily rollercoaster of emotions. Caregiving can often be a thankless job, and juggling the task on top of everything else with little gratitude or support can leave caregivers feeling helpless, frustrated, afraid, angry, and isolated. Caregivers often express feeling guilty about experiencing these emotions, and will try to ignore what they are feeling. Guilt is not only counterproductive in that it will consume your much needed energy, but is not going to help process and manage these emotions. Experiencing a variety of emotions is normal, and recognizing what you are feeling is the first step in addressing feelings that may weigh you down and lead to feeling depressed and anxious.

You are not alone!

Caregivers will often seem embarrassed that they are experiencing various emotions or if they are not sure what to do. Caregiver support groups offer a sense of unity, and many caregivers find that sharing these experiences with others who truly understand can help these feelings subside to an extent. Support groups offer problem solving skills and strategies that can teach survival tips, and it can be helpful to have a fresh set of experienced eyes to look at your problem with you. “Venting” about your stress and focusing on yourself can be refreshing, and support groups are compiled of people who are there for the purpose of listening and contributing. While support groups take place at various times of the day, there are also online support resources for those that may not be able to easily get out. You have access to live chat and discussion boards, blogs about others’ experiences, tools and applications, coping strategies, activity ideas, and numerous other resources all easily accessible online. It is also important to remember to ask others for help. Sometimes family members or friends will want to offer help, but will not know where to start. Caregivers are often surprised at the help they receive after directly asking for it. If you are feeling burnt-out and overwhelmed in managing your emotions, professional therapy is also a very positive option.

Check, double check, and then triple check that all resources are being explored.

After collaborating with a new caregiver, more often than not I will hear the response “I had no idea something like that existed”. This will apply to various available programs, benefits, funds, or options that you may not be aware that you or your loved ones are eligible for. Collaborating with your loved one’s physicians, hospital social workers, town hall, council on aging, and local community agencies such as Aging Service Access Points can help lead you in the right direction. New programs are continuously being developed and the criteria and eligibility for these programs can change, so it is imperative to continue to reach out and ask questions.

Make sure you understand as much as you can.

If your loved one has received a new diagnosis, it is important to develop realistic expectations about the disease. While researching the disease may be difficult, understanding the expected trajectory of the disease and what it will mean in the future for your loved one will help you care for him or her in the best way that you can. Many diseases have organizations that offer educational workshops, reading material, information, and resources to help you understand the best way that you can help the person. Forming a list of questions for your loved one’s primary physician and specialist doctors can also help you gain an understanding of exactly what is going on. It is also essential to understand upfront what it is that you are committing to. It is necessary to have an honest conversation with your loved one, your family and other support systems, and yourself, about what is realistic for you to manage and what you are going to need help with. There are resources available online for having difficult conversations with your loved one and

for facilitating family meetings to get everyone on the same page. Please refer to the New Caregiver Checklist to get you started.

Remember why you are doing this.

While caring for someone you love is challenging and requires incredible strength and resilience, it is important to remember that you are offering this person your care for a reason. You are giving them a gift that they will never be able to thank you for by giving them care at a level no one else can, and are providing support for someone when they need it the most. Your loved one isn't the only person whose life you are making a difference in, as you will develop listening and time management skills, and will probably develop a new level of patience and compassion. Spending time caring for someone offers the chance to create precious memories with your loved one that you will cherish long after they are gone, and you will likely learn a lot about your own strength during this rewarding yet difficult process.

“To the world you may be one person, but to one person you may be the world”. – Dr. Seuss

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