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SELF-CARE

The friends and family members who care for vestibular patients need care too.

ARTICLE

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5018 NE 15th Ave.
Portland, OR 97211
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info@vestibular.org
vestibular.org

Caring for the Carer

By Rachel Bilgrei, PsyD

Your loved one's well-being hangs in the balance...literally and figuratively. His/her lifeline, her buoy, is you. That is a lot of responsibility to bear, a lot of weight on your shoulders. How do you stay afloat? How do you stay strong and endure?

"Carers" - anyone who cares for a friend or family member with a chronic illness - need care too. Whether it is a vestibular disorder or any other health condition, there are plentiful resources available to support the patient in his/her experience. And far too often, the carer is overlooked, despite playing a vital and extremely difficult role in your loved one's recovery.

The road to recovery is a windy one, marked by unpredictability and instability. The changes to adjust to, the demands to be met, can be daunting. And unfortunately, your feelings, your frustrations get short shrift. So let this article serve as recognition of all that you do, all that you are or have become, and validation of the sacrifices you have made. Hopefully, it will also provide ideas and support on how to best manage your tireless, constant role as carer. But be forewarned: there is no magic remedy, no easy solution. This process is an arduous one, but it can also be an opportunity for growth and enlightenment, further deepening the bonds of your relationship. And that can be inspiring.

EDUCATE YOURSELF

Whenever and as much as possible, attend medical appointments with your loved ones. Write down questions and concerns and take notes during the appointments. Read up on your loved one's diagnosis from reliable sources (like VeDA). If applicable, attend a few physical therapy sessions. Ask your loved ones questions about his/her experiences. During this time of feeling powerless, knowledge can be your power. Armed with information, you can make some of the unknown, known.



ENGAGE IN SELF-CARE WITHOUT GUILT

This is not being selfish. It is being smart. Far too often, carers are so involved in taking care of the patient they often forget or don't have time to care for themselves. You will be of no good to yourself or your loved one if you don't attend to your own physical health and emotional well-being. First there are the basics: eating healthy and getting enough sleep. Exercise can be a relieving and energizing outlet for the complexity of feelings you are experiencing.

Then there is recognizing your own limits and heeding them. Think of this as your own "balance awareness." As a carer, balance awareness can mean recognizing and understanding not only your loved one's strengths and limitations but also your own. As your loved one strives to achieve a sense of physical equilibrium, you can be working alongside him/her to achieve your own sense of balance as well. Set boundaries. Protect and nourish your own individuality by maintaining aspects of your own life that do not include your loved one. Continue to engage in the activities and pastimes you enjoy. Carve out time for these activities, as well as for some down time. Ask for additional help when needed.

Be Patient...not only with your loved one, but also with yourself. There is a lot of information to take in, a lot of changes, and a host of uncertainty. You are BOTH scared and overwhelmed. Give yourself time to gather information, time to take care of yourself and time to just BREATHE. Begin a practice of meditation, mindfulness or yoga. Perhaps it is something that you and your loved one can do together. The benefits for both of you will be enormous. The two of you together can work on creating and establishing a mutual sense of balance in your life.

KEEP LINES OF COMMUNICATION OPEN

Ambivalence is in abundance. Of course you love and support your loved one, but feelings of fear, sadness, anger and resentment are naturally going to arise. Make space, both with your loved one, as well as in the context of counseling, support groups, and/or religious affiliations to express your own emotions, even and especially the difficult ones. Create a partnership. Work as a team. Set aside a specific time each week to touch base with each other. Make sure it is a time when you both feel calm and open (i.e. NOT after an argument or a difficult medical appointment or an exhausting



physical therapy session). During this time, share feelings of affection, forgiveness and acceptance. Provide feedback about what has and has not been helpful and productive, and explore ideas to improve upon your current situation. Develop a private language: gestures and/or single words that convey a larger idea to be used in moments when more elaborate expression is difficult. Continue to do the activities you enjoy doing together - with some modification if necessary and perhaps find new activities to discover together.

MOURN LOSSES

The patient is not the only one suffering. You have both experienced the pain of loss...loss of functioning, of activities, of quality of life, of freedom, of your sense of self. Stripped of these things, you may not recognize yourself or the life you once led. Some aspects of your life will stay the same. Others will not. Some losses may be temporary, others permanent. Take the time to acknowledge and process these losses. Thinking about the stages of grief can be helpful because you may well find yourself going through them. They are: denial, anger, bargaining, depression, and acceptance. (Click here for more on Elisabeth Kubler-Ross's stages of grief.)

Yes, your loved one's progress and well-being depends upon your support and presence. Find your balance and it will be easier to help them find theirs.

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