

The Many Hats of a Caregiver **By: Shelby Downer, Client Support Coordinator**

In facilitating support groups for caregivers, I often hear participants speak about the many different “hats” they wear as a spouse, daughter, son, or close relative of a person with dementia.

The wearing of many hats in caring for someone with dementia often results from the role changes associated with the onset and progression of the disease. As we know, living with Alzheimer’s disease or some other form of a dementia involves the loss or changes in abilities for the person with dementia. As these changes occur, the number of “hats” worn by the primary caregiver can accumulate. Going through role changes may lead to increased levels of stress for a caregiver, especially if the new role is one that the caregiver is not accustomed to. Perhaps the person with dementia took on the main role of overseeing finances, household chores, cooking, repairs, gardening, or served as the primary driver. In the early stages of the disease, the person with dementia may still uphold many of these roles with some additional assistance or guidance. As dementia progresses, the caregiver may also take on unforeseen roles such as administering medications, ensuring safety, providing reminders and cues for daily activities, or assisting with dressing and personal care. If you are caring for someone with dementia, an important question to ask yourself is:

What different hats do I wear in caring for my loved one? What new “hats” have I accumulated as my role has changed or evolved? Take a moment to think of or jot down the different hats you wear and how your role has evolved with the progression of dementia.

The wearing of many hats as a caregiver does not come without an impact. Common outcomes shared by caregivers include feelings of stress or burnout, emotional and physical fatigue, lifestyle changes, loss of freedom, and running on “autopilot” from one day to the next. Self-care and caregiving can sometimes feel like a paradox, but it is important to establish a balance as best you can. Some strategies to consider or questions to ask when addressing caregiver stress related to role changes include:

Can someone else wear a “hat”? Do not be afraid to ask for help, or to accept help from others. Lighten your load by giving one of your “hats” to someone else who is able to help, even if just for a day or a couple of hours. Inquire about community agencies that may be able to assist with various roles.

Plan ahead. Caregivers can often suffer from “decision fatigue” from taking on a number of different responsibilities and the subsequent decisions associated with these responsibilities. When it comes to Advanced Care Planning, make your

decisions early on with the help of the person with dementia and other close family members.

Am I taking on new responsibilities too soon? When supporting someone who has dementia, it is important to respect their autonomy and the activities that are most meaningful to them while ensuring safety. Someone in the early stages of dementia can often still do many of the tasks they enjoy and may only need minimal assistance or guidance. I sometimes hear from clients with early stage dementia that they still want to do their regular routines and responsibilities but just need more time to process the information or steps needed to complete the task. Give them this time, even if the urge to take over the task altogether might be faster or more efficient.

Laugh. Whether it is most appropriate in the moment, or when recalling an event that happened earlier, laughter helps to lighten any moment of stress, whether you feel like laughing or not – try laughing!

Many other caregivers are wearing similar “hats” too. Understand that you are not alone. Connect with others going through a similar experience. Alzheimer Society programs and services provide opportunities for you to both learn about dementia and connect with others who are going through a similar experience.

“The only thing that is constant is change.”

— Heraclitus

Reference:

By Us For Us Guide (2013). *Role, Health, & Well-Being: An inspirational guide for partners in care of people living with memory loss*. Murray Alzheimer Research and Education Program, University of Waterloo.