

# Caregivers Voices: For Community Awareness

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May is Caregiver Awareness Month. I asked Caregivers what they would like their communities to be aware of when it comes to the caregiving journey.

"It is after the fact now and I would not have given up that journey for love or money. In the throes of it all there were many days I wanted to give it up. Caregiving is isolating and your world can become very small. Little moments become precious amongst the mountain of moments of fear, grief, frustration and feeling like no one else cares, not even the professionals."

"I never expected this to happen. There have been a variety of serious medical conditions, but we never had to deal with a diagnosis like this one. It has been a big learning curve, and I have had some difficulty in asking for help. I am a very private, introverted person, and this requires me to reach out, and ask for help. I often feel inadequate, and don't think I am doing a good job. I wish I had more help, someone to really understand this, and what the future looks like. If I look at them and really think about how they used to be, it is so heartbreaking, so I don't do that. I have to take it one day or even one hour at a time. I think most of us are just trying our best to cope."

"You need to consider self-preservation when caregiving as you can quickly burn out, you need to consider yourself and your own self-care."

"Caregiving is a huge but necessary commitment on the part of the caregiver when dealing with dementia. It is important for me to arm myself with knowledge of the disease with which our loved one has been diagnosed with, as there are many different forms of dementia. As a caregiver one cannot fix the problem, therefore one must stay on the outside of the problem so you can be a good caregiver, not easy but necessary to maintain your mental health. Always seek self-care either through support groups where there are common

thoughts or privately for personal care."

"Please do not say it is a really good thing you are doing, pat me on the back and say, let me know if I can help, unless you mean it!"

"I don't need others' advice, sometimes I just need you to put your hand on my shoulder and listen whether I am crying or venting"

"Ask me how I am doing versus asking how my person is doing, means a lot"

"Please do not ask me to do things. I have a hard time saying no and I am already overwhelmed"

"I am sleep deprived and deal with compound stress please be gentle and understanding with me."

"Do not ignore me like I do not matter, am not essential or don't know my people better than anyone."

"Bring a meal, rake my leaves, visit, take them for a drive don't say let me know if I can help, I already have too many things to think about to figure out how you could help. Please, if you see something that could help do it. If I do not seem grateful at first remember it is hard to receive until you get practiced at it."

"Thank you to all the neighbours, businesses, health professionals who do all they can to make it easier. Making things easier in this day and age does not seem to be the norm. I know your efforts have extended my life as a caregiver"

I would like to thank all the caregivers who shared their thoughts. I hope Caregivers NS makes caregivers feel appreciated, heard and contributes to making something feel a bit easier.

