

Title slide: In recent years the rate of caregiver distress has doubled

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Mentally, I'm still not healed. Bills wounds have healed but I don't think I have.

Before I became a caregiver for Bill, our social life was pretty big, we were very spontaneous, we travelled a lot – all over the world. But once Bill started to have his surgeries our world got a lot smaller. We stayed in the condo, we didn't see as many people. We didn't have our grandchildren over for sleepovers which was a really big deal for me.

Title slide: 97% of patients receiving home care over a long period rely on unpaid caregivers

It was so busy during the day between wound care and grocery shopping, getting him out to doctor's appointments which were pretty much every day.

I did feel about three or four years into the series of operations that something was wrong, I really wasn't coping as well as I had at the beginning.

Title slide: Nearly half of spouses providing home care reported experiencing distress

I think back to the time when he was first discharged from the hospital and he was on crutches and he's 6ft10 and I'm 5ft1 and why didn't anyone think to say how are they going to manage when they get home? Because he has to keep his foot up all the time - so how is he going to bath? How is he going to get in and out of a car? He's such a big guy as it is.

It was all about Bill's health – I was just focused on him and it just got to be too much and with the rollercoaster with the number of operations that he had, I just started withdrawing.

Title slide: As the population of Ontario ages, it will be important to focus on the needs of unpaid caregivers as much as the patients they look after.

It was such an exhausting time, where I felt invisible and isolated.

Ask a caregiver if they are going to be able to help out at home. Are they going to be able to take care of this person and if not what can you do? Or what can you not do? Because so many people are working, thank goodness we are both retired. I don't know what I would have done – I probably would have had to quit my job because it was so labour intensive taking care of him.

I think too, trying to watch everybody, I can't imagine what it's like going through the health care system without an advocate.

Reach out and talk to people, close friends, family, rely on them, you need to ask for help.

The patient and the caregiver need to be addressed as a whole, because the patient can't get well, if the caregiver is not well.