



Linda – Caregiver for her father

My name is Linda Smyrski and my parents are Marion and Ernie in their eighties. My dad died in August of this past year. He was diagnosed in April with lung cancer and at the time of the diagnosis he already has metastases to his spine. My dad was primary caregiver for my mum, who is still living, and she has moderate dementia. So now I'm her primary caregiver. I'm a nurse by background. Going through all this I'm a daughter first.

End of life conversations

We were able to get his affairs in order with him entirely engaged which was probably our greatest blessing because you just ... that that pressure is on your shoulders to not spend your entire time just grieving and bawling and though that's entirely what I felt like doing the whole time. He was worried about my mum. So every day I would just make sure that whatever concerns he had about my mum, took them home. And we were starting to get some things in to into order, so I'd report back that day saying today we took care of this, we took care of this. You know, in hindsight I just wish we'd had this conversation so much earlier and then you could just not be thinking about it and things would be in place. Like talking to your dad about whether he wanted to be buried or cremated. You know when you haven't talked about end of life before is very hard. Talking to your mum who has dementia about what she'll need as support once my dad's gone was like something that I never want to do again. I never will have to, but — you know it was just...timing ... timing I think could be improved in some of these situations. So what we're taking away from this is my husband and I have had these conversations to set things up. We've talked to our kids because we never want them to go through what we went through.

Peace of mind

As time went on I could tell my dad wanted to start taking more control of how he was going to die. And I was so happy with that because we were talking about how he was taking his sedation, how he was taking his pain medication, and he was reluctant to take any, I think he wanted to stay in the moment, which he did for most of the time. But near the end you could tell the pain was quite bad. And I remember the night, the last I saw him, he was starting to get medication fairly frequently and we were all around and we talked again, we did our usual check-in where's this at, where's that at... probably what was the most ... now that he knew that my mom was taken care of. She'd been assessed. He knew that she was safe at home, knew that, you know, the funeral home was set up, everything, where his ashes were going. His next concern was the cottage because we were in the flood zone and all during this time we were trying to save our family cottage. And he looked over at my husband and said, you know, 'Is the cottage still standing?' And we said yes. He says, 'You do whatever you can to keep it.' And he just um... one more thing to check off my list. Our goal was to make sure Dad didn't suffer and he stayed in charge as long as he could and in a place that he wanted to be, in a state that he wanted to be, you know, as long as he could.

Caregiving

If I had to think about anything and I think there's room for improvement for how I could have got some more

assistance with my mum. I found that really hard because I wanted to meet my dad's needs, making sure she was being taken care of, and I found being the caregiver for both of them at the same time with everything else that was going on like quite, quite stressful. And I felt like I wasn't giving my mum all she deserved because she was going through this with me. And I wanted to be the daughter for her going through this, but I had to be the daughter for my dad, too. And I was at some times you're picking, you know, teams. Which team, which one is going to be easier to be on today, or who has highest priority so... that I have some thoughts on how, you know, that might be improved.

How did you cope?

Some days I would say not very well. I had a fair amount of meltdowns. I am very lucky that I have family that support me a lot and were there for me as well as for my dad. But there were some days that there were just too many things on my plate and my dad knew that. He ... yet...you know he wanted me to be there a lot. He was scared — scared, scared, scared. And I...other than being there physically for him I don't know...what more I could have done for that. But he was scared. So I spent nights with him and then would go to work and go back during the day. And work knew what I was going through. They did work hard for me to give me some flexibility but I never felt like I could just walk away entirely. I would have taken that time off. It would have meant the world of difference. I could have been there for me and for everybody else and done a way better job of just taking care of everybody. Because work is work and it shouldn't be a high priority when you're going through this. It shouldn't be a high priority any time. It's work. At the end of the day that's another thing as a take away. Work is work. But you know you need it. Put a meal on the table.

Battle fatigue

Life is never simple. I'm still exhausted and I think I, I'll just have to keep taking the time for myself. When I've been to my physician they say it's battle fatigue. This last year for you is battle fatigue. Taking care of your dad the same time knowing the cottage...you know, you could have lost the family cottage, now being the primary caregiver for my mum, having a family that you're still taking care of, having a job, it's just all of that and more. I'm waiting for when I wake up one morning and go, 'Oh! whew.' So I think it's just how you cope. So developing some coping strategies for how you manage each one of those pieces is really important. How can you do that before something like this happens. Recognizing when you are under some stress I think and just dealing with it because if you just ignore it when something really bad comes along it's only going to get increased and increased. I did make it all the way through and now I think I'm fatigued. I think I put so much energy into making sure I was 'up' all the time and always ready to give my dad the black and the white that at the end of the day I'm a little empty. And that surprises me because I thought I was pretty strong.

Taking time

I took four or five days in the summer where I physically had to leave. I went to visit my sister in Ontario and I told my dad that I just needed to take a couple of days off. And I came back, I felt guilty for the first few days I was away but I was burnt out. When I came back it was a good thing I had taken that time because then, within couple of days, my dad died. But I don't think you realize just the burden that you are carrying when you're caring for that person. And then everything else that's going on, well how hard that is on you. And so I would tell people, just remember to take care of yourself. Keep your own reserves as high as you can and don't feel selfish about doing that. So back off some of the things, if people feel like you're obligated to do, you're going to make a whole new list of what you're obligated to do. I should have taken time to take care of myself too. I mean that was an extra burden but you just — you do it when you see someone going through that. But if I had to give anyone advice — take care of yourself too because then you'll be able do a better job of taking care of everybody else around you and they'll understand.