

A message from Wendy

Briefly describe your caregiver experience.

Hi, my name is Wendy. I retired in 2013. I was planning to enjoy retirement by doing some fun things I could not do while I was working and spend more time with aging parents. Dad was 93 and suffered from kidney disease. My father-in-law was 88, had COPD, liver issues and some mobility challenges. My mother-in-law, also 88, had dementia. I did not learn much about their illnesses when I was working. I thought if they took their medications as directed by doctors, they would be ok.

My husband was the only child and was still working. So, taking care of my in-laws was naturally my responsibility. We moved them in to live with us after my retirement. Only then I started to learn about dementia's impact on my mother-in-law. She often forgot her medications and could not cook meals anymore. They ate at the food court below at their apartment complex or just had simple sandwiches. My father-in-law did not know how to take care of her and was not willing to ask for help. At the same time, my father's kidney problem was severe, and he had to start dialysis 3 times a week. Suddenly, I was drowning in care giving duties and did not know what to do most of the time. I learned my way through mistakes. Guilt and frustration were hitting me all the time. My own health was at risk because of it.

Is there anything you wish others to know about your caregiver experience?

For Chinese, I think the language barriers was a challenge for me. My in-laws were ok in simple conversational English; however, when it came to medical problems, we had to be there for each doctor's appointment and medical tests. When they were in hospital, the stress doubled. Record keeping and communication with different professionals were our duties. Looking back, I would not have survived if I was still working or did not get lots of help from family, friends, and healthcare professionals. I know in our culture we don't want to bother other people with our problems. However, people around you are often happy to help. You don't have to do this alone. Please do not hesitate to ask for help or accept the helping hands from family and friends.

Is there anything specific about your caregiver experience that may be influenced or affected by your cultural norms or traditions?

Our cultural has a high sense of pride. My in-laws would not let me know their struggle until I was seeing it with my own eyes. While my mother-in-law's symptom got worse and was hitting my father-in-law, I was not allowed to tell the doctor about these incidents. Sending parents to long term care is frowned upon in our culture. We did not even consider it until my health was at risk. With the help of the social worker, we began the application to LTC. Although we did not end up in LTC at the end, it was helpful to know there were other safe options if I truly could not do it. My advice is to start planning earlier because these processes take time.

Why participate in this survey?

Ontario's government has been working on ways to improve our current healthcare systems. Dr. Parry's program aims at gaining a deeper understanding of various cultural related difficulties that we are experiencing. One of the areas is Chinese culture. We hope to gain more insight to caregiver's needs and make appropriate suggestions to improve the healthcare systems. If you qualify for the study, please take the time to fill in the survey to help us find ways to create a culturally appropriate healthcare environment in the future.