

Helen's Story: There is still so much love

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My Dad's name was Yushu Liu; he was a caring, loving father and Grandpa. He was diagnosed with dementia at the age of 75.

My parents moved from Northern China to Canada in 2002 to help take care of my children. For many years my Dad was very healthy and involved with my kids, sending them to the school bus each morning, gardening, and playing basketball.

In 2013, he suffered a stroke and hit his head that left him hospitalized for 65 days. After he was discharged from the hospital, we noticed he wasn't the same. His mood and behaviour were wrong. For example, he had hallucinations and talked about things that did not make sense, he napped a lot during the day but became restless at night and wanted to leave home, and he became suspicious about things that were not true.

I was shocked and worried about my Dad. I started doing my own research online to find resources that could help my family and I understand what might be happening. I didn't find much information available in Chinese, and neither of my parents spoke English. After a long-wait, my family and I met with a geriatrician. A CT scan of my Dad's head showed he had developed Vascular dementia.

Vascular dementia occurs when there is poor blood flow in the brain, which can lead to death of brain cells, and strokes.

“At that point, I had no idea how dementia would impact our lives. I didn't even know there was a difference between Alzheimer's disease and dementia.”

When the geriatrician told us the dementia diagnosis, I said: "It can't be! He has no memory problems!". The doctor explained that Vascular dementia is different from other types of dementia, and there are different ways someone can develop dementia. At first I was in denial because he had been so healthy - it was challenging to accept until the doctor showed us the scan and pointed out all the black holes in the image. From there I started to accept the diagnosis and said to my Mom: "let's prepare for a long journey ahead of us."



Stigma about Dementia

The word dementia was not in our vocabulary before my Dad was diagnosed. In the Chinese culture, there is a stigma against the word "dementia". People believe it means "stupid" and "foolish", so people don't talk about it because it's like a curse. We never discussed dementia in my family.

"Stigma can lead to lack of knowledge and willingness for people to talk about their experiences with dementia."

And that's what happened in my family. I didn't want to share the diagnosis with people around us because I didn't feel there was anything good to share, and it was already so hard to face and accept.

Sharing my Story in Hopes of Helping Others

“I want to share my story now because I look back and see all the things I would have done differently and I wish I could have learned from others. Hearing from someone who has experienced dementia first-hand can be easier to connect to, than hearing it from a medical professional.”

My Dad lived at home for 8 years while having dementia. My parents lived in their own apartment and not many people in the neighbourhood spoke Chinese. For our family and especially for my Mom, there were no resources in Chinese about dementia. I had to translate for her, and because I was still working I wasn't available all the time to do that for her. It was a struggle.

I had a good job for an organization I loved for 19 years, but I left because taking care of my parents was my priority. My Dad's dementia was progressing, and my mom was having trouble caring for him. In our culture, we think care should be provided at home. There is an expectation to take care of your parents - it's not a choice.

While he was living at home and on the waitlist for long-term care, there were some frightening experiences. My Dad would often try to leave the apartment on his own, wanting to go for a walk, or thinking he needed to go to work even though he was retired. Once, he even left the apartment on a very cold night in January. He wasn't able to get out of the building and was found by a neighbour, but my Mom and I were so scared and worried.

Eventually, he moved to a long-term care home called The Yee Hong Centre for Geriatric Care. They provide culturally-appropriate care and services, which was really helpful for my Dad. He lived there for 3 years.

At first the separation was very hard, until I realized that I could still love my Dad the same amount, while sharing the role of caregiver with people who have professional training and more resources.

“Even if you need help to share the load of caring, you can still show love. That is my advice to others who are struggling with this decision. I really believe I made the right decision, because the last few years with my Dad turned out to be a really wonderful, beautiful journey together.”

Even when he had dementia, he remembered me. For example, my Dad was a mechanic, so he always had pockets in his shirts and he would keep little candies in his pockets to give to me. When he had dementia, he would still look for treats in his pockets to give to me. And he still cared about his family a lot. He would always ask me who was taking the kids to the school bus, even though my kids were in university by then.

Caregiving can be Challenging and Beautiful

Looking back, I wish I had a better understanding of what to expect as a caregiver, and did more planning in advance. Even with a tremendous amount of love, you may have a shortage of skills, time, experience, and resources to support someone living with dementia by yourself.

You have to ask: Is this sustainable? Is the person living with dementia getting the support they need? Have you planned ahead for the unexpected?

“I have no regrets. It was a very beautiful time, with challenges, but still a beautiful time. I had an opportunity to pay back the love that he gave me, but also this strengthened my appreciation of life and what is really important, and how you can have empathy and unconditional love for someone.”

“I wish someone had said to me: “Plan ahead! You can’t do it all on your own.” It turned out that lots of community services and support from family members were needed to care for my Dad.”

Dementia develops at a different pace for everyone, but it will progress. Even though you can’t see it, it is a health issue - and like any other condition, professionals can help you manage some symptoms.

Good Moments

Toward the very end, he didn’t talk much but he still smiled. You could see the gentle love in his eyes. My parents would hold hands a lot, and they would hug. It was such a joy to see them loving each other, and talking about when they were first dating 60 years ago. It was only toward the end they did that. It helped me to understand my parents better. In Chinese culture we never really talk about these kinds of priceless moments.

We would take him in his wheelchair to sit in the sun in the garden, and I’d bring a little radio with Chinese songs on it. We would often play music while we trimmed his nails or while he was eating. It was a very peaceful, beautiful experience.

“Dementia can be beautiful. Even though there are challenges you have to deal with, there are good moments where there is still so much love.”



To find resources about dementia for the Chinese community, visit:

www.forwardwithdementia.ca.