

# Shireen's Story: Finding happiness where we are

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**“In 1971, my Mum and Dad moved to Canada from Guyana in search of a better life for their family and four children. At the age of 80, my Mum was diagnosed with dementia, and I, her eldest daughter, am her caregiver.**

**My name is Shireen and I want to tell you our story.”**



For many years prior to the diagnosis, there were intermittent changes in Mum's behaviour that were overlooked due to the stigma attached to dementia.

We noticed that Mum had difficulty making routine decisions, such as choosing produce or bread products when grocery shopping.

I recall conversations with Dad when Mum was in her early 70s about how long he waited for her to come out of a store. He is very patient and because she had always enjoyed shopping, he considered it "normal". But over time, other everyday routines such as washroom visits, bath time, choosing clothing or jewellery, and making meals took longer.

Mums language became very "scripted" in that she uses the same, general phrases in her conversations, most notably on the phone (i.e. How is the family? Give my love to everyone). If Mum answered when I called, she was quick to get Dad to pick up the second handset. She also began making excuses for not wanting to meet friends for coffee, saying the conversations were a "waste of time". She may have been afraid to admit that it was hard to keep up with the conversations because this might mean there was something "wrong" with her. She took pride in her health and any "sickness" in our culture is seen as a weakness and becomes hidden.

**Shireen recently sat down with her parents to talk about their experience with dementia, in an effort to help others in the South Asian community. Read their conversation below:**

## Living with Dementia

**Shireen:** How do you feel about having dementia?

**Mum:** "It means I forget things. The important things that I forget are my kid's birthdays and things like that. I have to write them down."

## Staying Healthy

**Shireen:** What are some things that you do to keep you healthy?

**Mum:** "I get up every morning and do my exercises, I do stretching, and I go on a walk. And every afternoon my husband and I go for a walk."

**Shireen:** What helps you get through your daily routine?

**Mum:** "My kids, and my husband. I'm happy where I am. And the day program I go to two days a week - I like going and the people are very nice to me."

## Connecting with Family and Friends

**Shireen:** How do you feel when people visit?

**Mum:** “When people visit, I have to concentrate when they talk, but I enjoy company.”

**Shireen:** Do you keep in touch with family on the phone?

**Mum:** “Yes, I can talk to my family on the phone. I just have to concentrate on what they're saying to me. But I don't like too many phone calls, I don't want people to call all the time.”

**Shireen's Mum explained that she doesn't want to discuss her diagnosis of dementia with others, saying: “Next thing you know, people will think you're going crazy!”**

## Stigma

**Shireen:** How is dementia viewed in our culture?

**Dad:** “There is a lack of knowledge, they don't know what [dementia] is. I find that if someone is different or acts out of the ordinary, people assume that's the way it's supposed to be, or they may make a joke of that. So a lot of people would be ashamed to admit they have dementia, because it would make them different.”

**“Because of Mum's love for people and life in general, she is successfully living with dementia and I plan to continue to advocate for her, persons living with dementia and their caregivers in my community.”**

To find resources about dementia for the South Asian community, visit [www.forwardwithdementia.ca](http://www.forwardwithdementia.ca).