Vulnerable populations

Coda | Patient portraits

a series by Seema Marwaha

Lorna and Eleanor MacDonald

■ Cite as: *CMAJ* 2022 March 7;194:E349. doi: 10.1503/cmaj.220233



Eleanor's 2-year hospital discharge anniversary at their home.

am my mother's only living child. Her care and well-being are my responsibility. I wish that the health care system partnered better with caregivers like myself.

Mom has dementia and has had 2 strokes. She was living with me until her second stroke and then moved to a retirement home when unfortunately she fell while going to the bathroom and broke her hip. She came through the surgery but was in hospital for a long, complicated 8-month hospital stay.

When planning for her discharge, it was very important to me that I could continue to visit her every day. Without many options, I applied for placement in long-term care for my mother. I felt constant pressure from hospital administrators to find a place as quickly as possible. But I also needed to continue to work and look after both our emotional needs.

Eventually, a place opened up nearby in an older building with curtains as partitions and little privacy that was scheduled for demolition. I saw several older women in wheelchairs, many much sicker than Mom, sitting in front of a desk waiting for their medications from a single, overworked employee. I felt under immense pressure to take this spot despite feeling it was not the right place for Mom. I expressed this to her physician but realized that my options were exhausted. The stress and distress were terrible. I felt I was failing my mother.

As I prepared to accompany Mom to the facility, I learned that her physician had taken my concerns into consideration and cancelled the transfer. She was moved to a palliative care unit

instead. I was so grateful her physician had stepped in when I felt helpless. Mom improved to the point that I started to explore the possibility of her coming home with me. I advocated fiercely for maximum supports, and she was discharged to live with me more than 2 years ago, with a prognosis of 4–6 months. We just passed her 96th birthday. Taking Mom home was the best decision for us.

I provide a lot of Mom's care. I do the evening change and medications, procure all supplies, prepare her meals and do all of her weekend care. I've modified my work schedule, and a caregiver comes during my work hours. Taking a loved one home is not for everyone, but it has allowed me to give Mom

the dignity she deserves and to reframe dying into living. The system does not provide consistent care for her, but I do.

Content licence: This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC-ND 4.0) licence, which permits use, distribution and reproduction in any medium, provided that the original publication is properly cited, the use is noncommercial (i.e., research or educational use), and no modifications or adaptations are made. See: https://creativecommons.org/licenses/by-nc-nd/4.0/



Eleanor MacDonald just recently celebrated her 96th birthday.