

Irfan Mandozai

■ Cite as: *CMAJ* 2020 November 16;192:E1473.
doi: 10.1503/cmaj.202441

Photos by Seema Marwaha



My mom, Abida, is 87. She has diabetes, heart disease and kidney disease. She lives in a long-term care facility and gets dialysis 3 times a week. But she has a good quality of life and enjoys the time she spends with her grandkids.

During the [early pandemic] lockdown she was admitted to the hospital for delirium. No visitors were allowed, so all my conversations about my mom's care were over the phone. She was having trouble swallowing, and there was no safe way to feed her; her doctor said she was imminently dying and recommended transferring her to palliative care. I agreed. This change in status meant I could finally come and visit her.

My mom was awake. She kept asking me in Urdu why they weren't feeding her. She clearly told me, "I can swallow." I asked the nurse if I could give her some applesauce. I had to agree that I would take full responsibility if something happened to be allowed to try. But she did not cough or choke. So they brought her puréed meals. There were probably cultural and language barriers that led to her not being fed for her safety. But it could have ended up killing her.

Her dialysis had been stopped, but she was not dying. I had to advocate to get her put back on. Ironically, my visiting privileges were revoked because now she was not dying. It felt like a punishment.

You can't look at the individual as just a problem to solve. I would get the usual daily call from the doctors talking about Mom's blood pressure or blood counts. Medical information

like that is meaningless to me. Every day, my question back would be: "How is she doing? As a person?" But I do not think they assess that.

Ironically, my visiting privileges were revoked because now she was not dying. It felt like a punishment.

