

You Are My Sunshine

Therese Henman-Philips

At 88, my Dad became ill and was diagnosed with dementia. Coming from a supportive family network, we rallied to provide the care he needed at home. Myself, my three siblings along with numerous grandchildren stepped in to support Mom as we looked at medical and community supports. The dementia appeared so quickly, struggling we tried to get a process in place to stabilize him. While getting to 88 years is a goal most would hope to achieve, I'd have to say we hoped and expected longer. Looking back, I think we thought he was invincible, that old age had eluded him, thinking his fate would be governed by something other than dementia! Something quick and painless.

After a hospital assessment and treatment for dementia, it became apparent that our goal of having him return home was going to be a challenge. Systems are not perfect. Navigating and getting the information we needed at the time we needed it, was not always possible. Having said that, as a family, we did the best we could with what we knew.

In the early months of his disease, we were introduced to many compassionate medical professionals and while they couldn't accurately predict his trajectory, I distinctly remember one doctor saying our job was to, "just love him". That resonated. So, as a family, we set out to make his experience as positive as it could be while we awaited placement in long term care. We set up a very committed family system ensuring as much as possible that he was a continued and valued part of the family while also making sure his needs in hospital were adequately addressed. Personally, there were costs, but not one regret.

While we all knew his death was a possibility, we were still not prepared to lose him, and the information given to us at times contradicted this eventuality. I don't think anyone, if I recall, used the word palliative or frailty to describe his medical condition in the way I understand these words now. For me, palliative care was something reserved for those in the final stages of cancer. The fact was that Dad

was palliative. I don't think I understood that at the time. I know that now. Palliative is about the living and the process leading to up to death. Frailty was his disease. Dad was moving through the stages of frailty towards the end of his life.

While Dad had addressed his advanced care directives from a legal sense many years before, we never really spoke about them at an emotional level. While I have no regrets about what we did as a family in the circumstances we were presented with, we never really had that conversation with him while he was an active agent of his own destiny. I don't know how he felt about the choices we made on his behalf. I can only hope he trusted us to do the best we could.



Dad was in hospital for fifteen months; he never did see long term care. His end of life came quickly and by way of pneumonia and a fall that robbed him of that physical strength we had always seen. It was at this time that I remember first hearing the word palliative. There is a reality attached to the word palliative, the decisions and needed support that comes with that understanding.

We had requested to bring Dad home to die on a Thursday but his deterioration over a weekend didn't allow for this planning. Dad died that Monday. The room in which he died however didn't matter. It was just a room. What mattered was that everyone who was significant was there in some form. Despite the event, his death, his end of life, it was a time marked by togetherness, sharing of memories, joy, faith, prayer and song. He was not alone. That mattered. That is what I remember most despite any decisions that I replay in my mind from the months and days preceding it. That is where I gain my comfort.

As we travel through our world's current circumstances, I have so much empathy for those who are unable to be with their loved one at the end of life. It truly was a gift to be with him on his journey. As a man of great faith, on his journey home.