

# My Father's Dying

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The monarch butterflies so abundant around the small pond are slowly disappearing. Tomatoes from the vine that curled its way up the drainage spout are now lined up on the kitchen windowsill to capture the sun's rays. Summer draws to an end as my father's life also draws to a close.

As part of my narrative, I have included, in italics, entries from my journal from this time.

## MARCH 17, 7:55 PM

*I am sitting next to Dad on a wooden chair as he lies sleeping in the hospice bed in the local private hospital. His wasted body is barely visible under the sheets. His arms rest on his chest as he lies on his back in exactly the same position I lie in each night. It's somehow familiar and comforting. Every so often his breathing becomes erratic, and he pants with the exertion of keeping his body in this world. And then he is silent. I hold my own breath, waiting for the familiar sound of his breathing, alternating between wanting that breath to be his last and fearing it may be. I am anxious that my father not die alone in this small room and anxious he will die with just me here.*

During the past few years, we have watched Dad slowly disintegrate. The losses were gradual but steady and devastating in their completeness. Major heart surgery offered him the possibility of a better quality of life, yet it never came to pass. The lethargy that had plagued him before the surgery remained. He became increasingly dependent on Mum for everything as he lost the ability to make a decision, give an opinion, help around the house, and care for himself. Slowly Mum's caring role became just the way it was: She became stronger through necessity as he became inescapably weaker through poor health. Yet through it all, he never complained.

Admission into hospital after a fall and then into hospice several days later announced the beginning of another end.

*It seems now that death is waiting close by in the wings.*

## MARCH 18, 8:12 PM

*Tonight I sit in the dim glow of the night light and reflect on this man; my father for 51 years. His contribution to my life has been immense. When I took classes at the university in my late teens we had many heated discussions. Years later I realized he was encouraging me to think critically and defend my views on contentious issues. During the past decade the discussions we had concerned my research focus on legal assisted dying in New Zealand. He strongly disagreed with my position that it ought to be a choice at the end of life. A deep Christian faith sustained him throughout his life, and he believed hastening death wasn't a choice we had authority over.*

*Now, as he lies in bed withered and almost unrecognizable as my dad, I rail at his God. "Take my father," I implore. "He deserves to go home. If you really do exist and are loving, prove it!"*

*I hold my dad's hand, so parched and thin that deep hollows carve into the skin between his thumb and fingers. These hands that held my mother in loving embrace, and wrapped around his children in welcome and farewell, now grasp repeatedly and unconsciously at the sheets.*

Vulnerability speaks clearly of confusion, frailty, wearing incontinence pads, having whatever meal is served up during the day no matter how carefully prepared, and being woken and put to bed when routine dictates. It also speaks deeply of the kindness and gentleness of compassionate nursing care, a glass of cold lemonade or a bowl of vanilla ice cream, a joke to lighten the load, and being wheeled outside to enjoy the warming sun of a dying summer.

## MARCH 20, 4:45 PM

*My father's blue eyes are milky and sticky, unable to focus, and now devoid of recognition. I comfort myself that my voice, reminiscing on the past, may ease any distress when he can no longer recognize who I am, but I know he is almost gone to this world. Perhaps he hears nothing.*

Dad's good clothes hang in the bedroom at home, his trousers dry-cleaned, shirt ironed, and shoes polished. Final loving acts that speak deeply of a wife's devotion, respect, dignity, and love.

Dad has stopped being able to suck on a straw.

His funeral is prepared, the death notices written, groceries brought to make food for the morning and afternoon tea to be served during the open home when Dad comes home for the final time. My brother and sister arrive, and we spend Sunday morning out walking along the riverbank. Dad's inability to suck seems another final step on this journey we are all on. We wonder aloud at what Dad might think of the situation if he were to witness himself lying in bed. He never spoke about dying or what he wanted. I cannot comfort myself that we had a conversation that clarified what was important to him at the end of life so that we would know what to do, so that we wouldn't question every decision that needed to be made. Dad never discussed his health even when it became clear that he was not improving. Always a very private and proud man, Dad walked the final journey on his own.

We talk with Mum and call the hospice nurse to arrange a meeting. In a small room off the corridor we sit and discuss what stopping all fluids—unless he asks for them—will mean. I know the enormity of what we are asking: No fluids for more than a couple of days in his condition, in this heat, will almost certainly mean he will die by dehydration. If he dies within a few hours

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or a day, death will be the end result of his condition. I know that as Dad moves closer toward death, giving him fluids orally can be problematic if they pool in his throat, causing choking and possibly setting up an infection site, aspiration, and possible pneumonia. Intravenous fluids are futile given that he is dying. The clinical reason for acting to withhold fluids and the family's decision are similar—to not prolong his dying, to act beneficently and humanely, and to allow Dad to die with some measure of dignity. Yet I grapple with the implications of withholding fluids and cannot escape the thought that in making this decision we are complicit in hastening his death.

### MARCH 22, 8:30 PM

Around 4 pm Dad's breathing became much more labored. He is now deeply unconscious. His chest heaves with the exertion of breathing. When I swab his mouth to keep it clean and moist, there is no sucking response at all.

*Isit and hold his hand, talking to him quietly of memories we shared: Heading to the beach for a BBQ after work, camping holidays at the lake, taking the dog for a walk along the beach in winter, cooking sausages on a fire, car trips into the city each weekday morning; good memories of a happy, loving childhood.*

*I have a vision of my Nana and Pop preparing to welcome Dad home. While we are saying farewell, they are rejoicing that they will see their son again. "You can go, Dad," I tell him. "Don't worry about Mum, we'll look after her."*

Dad died at 12:15 am on Tuesday, March 23. My fear that he would die alone did not happen. My fear that he would die when I was with him seemed to dissipate as I sat with him and his breathing slowly quietened and then stopped. It was quiet and peaceful and final. I was able to say goodbye and it felt right.

Since my father died, the questions I asked myself remain unanswered: By deciding to withhold fluids, were we complicit in hastening his death? Did we make the right decision? The answers are impossible to know beyond a shadow of a doubt. It is probable, given his physical deterioration during the preceding days, that he died of the underlying condition. But perhaps those 24 hours without fluids contributed to him dying sooner rather than later. I have come to realize that whether or not we

hastened his death is irrelevant because the reason we chose to withhold fluids was acknowledgment that he was actively dying and it was time to let him go. Continuing to hydrate him may have prolonged the dying process and seemed an indignity to the way my father had lived his life.

### EPILOGUE

Two years after my father's death, I look back on the weeks we had together before he died with a deep sense of comfort and stillness. My father died in the way he wanted—privately, quietly, dignified, and on his terms. Although he never made his wishes clear about his medical preference regarding treatment, I believe that the values he held, combined with the way he led his life, were consistent with him agreeing with the family's decision to withhold fluids. He would have wanted to spare my mother having to endure a slow dying process. He was also a very private man who had no choice but to accept the care of others. Although he was gracious in this, he was not comfortable with it.

But if he were alive today, perhaps he would be troubled by the recent events that have set in place a governmental process to discuss the legalization of assisted dying in New Zealand.<sup>1</sup> Perhaps we would sit down together over a glass of wine, and he would question my support of the bill. We'd banter back and forth. I'd tell him that if he were dying, I'd respect his wishes about what he wanted. I'd hope he'd respect mine. ❖

### Disclosure Statement

*Dr Malpas is a member of the End-of-Life Choice, Society of New Zealand, Inc (Waikanae, New Zealand). The author(s) have no other conflicts of interest to disclose.*

### How to Cite this Article

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1. New Zealand Parliament. End of Life Choice bill. Bill no. 269-1 [Internet]. Wellington, New Zealand: New Zealand Parliament; 2017 Jun 8 [cited 2018 Apr 5]. Available from: [www.parliament.nz/en/pb/bills-and-laws/bills-proposed-laws/document/BILL\\_74307/end-of-life-choice-bill](http://www.parliament.nz/en/pb/bills-and-laws/bills-proposed-laws/document/BILL_74307/end-of-life-choice-bill).