

SAYING *Goodbye*

Text by Margaret E Perry

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In July 2018, I experienced my first “real” death where I finally had to face life’s only certainty. Until then, the subject of dying had always been a taboo for me and best avoided at all costs. My beliefs around death were formed from watching television; seeing people drop dead from heart attacks and old ladies move seamlessly from their beds to their coffins in one swift scene change.

No doubt some people do die sudden and dramatic deaths, but that wasn’t what I witnessed in my father’s final days. Dying was a journey that began long before he took his last breath, and so too was my goodbye.

My father retired at 65 years old and two years later he was diagnosed with Parkinson’s. At the start, it had little impact on his life. He took a couple of pills a day and kept busy. He was a volunteer secretary of the local Parkinson’s UK branch, played the piano, was the main driver, mowed the lawn when nagged, and every year, he and my mum flew to Singapore to visit me and my family.

Preparing for the end

I had heard of Parkinson’s and knew there was no cure, so I read up on the

disease and pondered dad’s future. It felt like we were staring into the headlights of a distant oncoming train that would eventually shatter my father’s life. The clock had started to tick and I needed to make the most of the good years he had left. Living overseas, I wasn’t able to visit every weekend so I made a conscious effort to spend more quality time with him and my mum when I saw them. Every time they came to Singapore, my father and I attended a concert by the Singapore Symphony Orchestra and we went to midnight mass together when we were together for Christmas.

Dad had always been averse to being “poked around” by doctors, yet treatments such as feeding tubes were a future possibility as the disease often affects swallowing in the advanced stages. At that time, I was working in the communications department of a public hospital in Singapore that was actively promoting advance care planning for patients and their caregivers.

Not knowing what the future held for my father, I decided to document his care wishes while he was still healthy. I downloaded the advance care planning forms and brought them with me to the UK during a visit to my parents’ home. My mother could see the need but didn’t

want to take part in the conversation, so she left my father and me to it. I was nervous and a little awkward at the start, but my father's pragmatism and desire to have his wishes respected allowed us to talk openly. It helped that he was still active and relatively well, so some of the questions were hypothetical, beginning with "if you..."; rather than "now that you...". The conclusion was that he would only agree to tubes being poked in his body if it meant that he could continue to be independent and contribute to the family and society.

Very slowly, the disease started to rob my father of his abilities and sense of self. He lost his appetite when he could no longer smell, his striding walk became a halting shuffle, his quick wit slowed as he struggled to keep up with conversations and, for the first time in his life, he lacked confidence as he started to fall. My mother began to do his "jobs" such as driving, which was usually to visit friends nearby or to a cafe for a cup of tea and a piece of cake.

Earlier in 2018, my dad shared with an old friend that he felt he was "running on empty". The effort of thinking through even the simplest of movements was physically and mentally draining. His falls became more frequent and eventually landed him in his local hospital in Hull, East Yorkshire, at the end of May. Fortunately, he didn't suffer any broken bones, but his low blood pressure needed to be sorted out before he could go home.

Turning his face to the wall

This was his second hospital admission in six months, but my mum noticed his attitude was very different this time. Previously he had been desperate to go home, whereas this time he didn't mention it. He seemed more withdrawn and ate very little. My mum has never been one to bother people, so when she said it might be good if I visited, I booked my flight to the UK and took a week's leave.

I hoped for the best but prepared for the worst. When my children asked if Grandpa would get better, I said I hoped so, but his body and soul were

very tired from fighting Parkinson's so he might not have the strength to continue. The truth hurt and all I could do was to wipe away their tears and hug them. They wrote letters for me to bring along, each showing their love for him in their own way. My son knew his Grandpa didn't like being in hospital, so his included jokes to cheer him up. It worked, because when I read the letter to my father, he laughed. My daughter's letter was more poignant and made him tear.

When I first saw him in his hospital bed, I started to have hope that he would recover. He seemed pleased to see me; we talked and when I showed him a photo from his school days he was able to name several of the boys whom he hadn't seen for more than 60 years. But he also had hallucinations that made him very anxious, such as when he believed that my daughter's life was in danger. When I tried to brush it off, he became angry and demanded that I leave immediately to sort it out. I left his bedside, upset that he didn't want me there and bought a cup of tea from the canteen. I sat in the tiny garden at the front of the hospital, sent a message to my husband back in Singapore to double check that all was fine at home, and gradually calmed down. When I went back up to the ward, I presumed that my father would have forgotten about it but he was still concerned and demanded to know how my daughter was. I held his hand, looked him in the eye and said I had checked and she was definitely safe, at home and tucked into bed. After repeating it several times, he looked relieved and more settled.

Other times, my father's mind was crystal clear and he was determined to be in control of his care. He was painfully thin from eating only mouthfuls of food and the consultant suggested putting in a temporary feeding tube to build him up. His answer was a resolute "no". She spent an hour with him, discussing his care wishes and options, but he didn't waver once. The doctor, my mother, brother and I respected his decision, but accepting it was a little harder because we knew there would

be only one outcome. It felt wrong and unfilial to "allow" my father to make a decision that wouldn't prolong his life. I questioned whether I should have tried to persuade him to have the tube feed. Yet his decision was consistent with the advance care wishes he had expressed several years ago when he had been well. Who was I to override his wishes when his Parkinson's was getting worse and a tube feed wouldn't enable him to lead an independent life?

My father also refused to take his medication. He became expert at tucking his pills near his gums, then spitting them out when no one was looking. After a while, he simply clamped his mouth shut whenever someone tried to give him his pills. He was starting to get weaker, and three days after I had arrived, the doctor asked us to meet her for a family discussion. She shared what we already knew – that my father's time was limited. She said it was impossible to say how long he had left, but we should start thinking about where he would want to spend his final days.

Our priority was for dad to be as comfortable as possible. We considered bringing him home, but he was so frail and thin that we were worried he would suffer from pressure sores because of our caring inexperience. We also wanted to make sure he could receive treatment to relieve any symptoms should the need arise, so we opted for the local hospice. His doctor started making the arrangements, but when we arrived the following morning, we felt it was too late to move him. His condition had deteriorated overnight, and the last thing we wanted was for dad to pass away in the back of an ambulance.

Dying with dignity

The staff moved him from a four-bedded bay to a single room, with a sweeping view that stretched for miles. The nurses told us we were welcome to visit anytime, and they provided a camp bed for my brother and his wife to sleep on, as they volunteered to stay with him at night. The staff said their job was to keep my father, and us, as comfortable as possible, so if we wanted anything or

had any concerns, we should just ask. It was a Tuesday, and looking at him with my untrained eye, I thought he wouldn't live for more than a day.

There were no beeping monitors or blood tests. The only medical care given was tenderness, respect and the touch of experienced hands checking his pulse and the temperature of his hands and feet. The nurses turned him regularly to prevent pressure sores and took care of his personal hygiene needs, keeping him clean shaven to ensure he looked his best despite his gaunt appearance. They taught us how to keep his mouth clean and moist using sponges on sticks, dipped in water or fruit juice. The palliative care team visited him every day to check on his condition and wrote a prescription so the nurses could give him medication to make him comfortable, if necessary.

My father lay in bed, staring straight ahead, but he was still able to hear. We talked to him about things that were happening and asked him if he was in any pain or discomfort. He held one of our fingers and answered with a squeeze for yes and no response for a no. The nurses put him on a low-dose morphine pump, enough to ease his discomfort while still able to hear what we said.

Over the days, his cheeks became more sunken and his mouth remained open all the time. But his breathing remained regular and the nurses were surprised he was "holding his own". By Thursday I was in a dilemma – should I fly back to Singapore the next day on my booked flight or stay with him until he passed on? I had heard nurses say before that the dying often choose who they want with them when they go. Sometimes they wait until a loved one leaves the room to spare them from seeing their last breath. I spoke to my mother and brother, and with their blessing I decided to leave it in my father's hands. Before I went back to my parents' house on Thursday night, I told him I was going to catch the train at 11 am the following morning. I would see him in the morning before I left, or anytime in the night should things take a turn for the worse.

Dad survived the night and Friday morning I said my last goodbye, knowing I would never see him again. I thanked him for loving me and my family, for sharing with us his love of music and for teaching me to speak up when I felt that something was wrong. For the first time in my life, I told him I loved him and would miss him, before giving him a last kiss on the cheek and leaving the room in floods of tears.

The sense of loss was staggering. On the journey back to Singapore, I numbed the pain watching mindless movies, unable to accept reality. I checked in with my mum and brother as soon as I landed in Singapore and continued to message them throughout the night.

He passed away mid-morning the following day, with my mother and brother at his side. The nurse had warned them that his breathing had changed and they said their final goodbyes. My mum said he then gave one small gasp and slipped peacefully away. It was Father's Day and I was with my family when the call came. I was able to break the news to my children and my husband was there to comfort all of us.

A father until the end

The funeral was held two weeks later, in the first week of the school term. Education is important, especially for my son whose Primary School Leaving Examination was just months away, but sometimes family must come first. My husband and I took the children out of school for a week to attend the funeral so they could say their goodbyes, grieve with the family and learn more about their Grandpa from people who had known him at different stages of his life.

I've always hated funerals and was dreading my father's send-off. I cried, but unlike my usual uncontrollable sobs at previous funerals. Instead, I felt a sense of calm sadness but also pride in listening to the moving eulogy and address read by my brother and one of my father's oldest friends. They shared his achievements and his unique qualities, both the good and the

bad. There was a raw honesty to the service – a quality my father held dear throughout his life. He was an Anglican priest and the service was held in a church, but the passage his sister read came from Homer's *The Iliad*, a tribute to the years he spent in his youth studying ancient classical literature and his love of language:

*Then Zeus that gatherer of the clouds spoke to Apollo
Go, dear Phoebus, and take Sarpedon
out of the range of the darts,
and cleanse the black blood from him,
and thereafter bear him far away,
and bathe him in the streams of the river,
and anoint him with ambrosia.
And clothe him in garments that
wax not old, and send him to be
wafted by fleet convoy,
by the twin brethren Sleep and
Death, that quickly will set him in
the rich land of wide Lykia.
[There will his kinsmen and
clansmen give him burial, with
barrow and pillar, for such is the due
of the dead].
– The Iliad Bk 16. ll.666-673.*

The days following the funeral have been a time of reflection. Remembering the times I spent with my father brings me happiness and pain, as I know I can no longer see him or ask him for his advice. I hold the life lessons he taught me dearly, and I hope that one day I will be able to accept his greatest and his last: to acknowledge my mortality, be at peace with myself and my loved ones, and when the time comes, to meet death with courage, grace and humility. ♦

Requiescat in pace
D.W. PERRY
1942 – 2018