My mum and dad, Jim and Clare McVeigh, died within six months of each other in 2020, during the first eight months of the pandemic. Their combined age was 180, and they were in the sixty-fifth year of their marriage. The last five years of their lives were marked by deteriorating health problems. Both had multiple challenges, and both experienced an accelerated entry into end-of-life care. Our relationships with them had changed from being cared for to being the carer.

Following a couple of ED attendances and out-of-hours paramedic visits in early March 2020, Daddy reluctantly realised that he needed to accept palliative care. Daddy was not prescribed palliative care, nor was he moved into palliative care, but we had a chat with him, and he accepted that. Despite his wishes and everyone's efforts to have him at home, he spent the last six weeks of life as a hospice inpatient at Somerton Road. He made a bit of a recovery two weeks in, but, again, despite everyone's best efforts, he was unable to return to the care of the amazing district and community specialist palliative care nurses, because essential social care could not be joined up before he started to decline further. Daddy was blessed with a peaceful passing and, unlike many others at the time, with his children supporting his care.

Daddy died with various bits and pieces of tubes; he had a laryngectomy. We were able to go into the Northern Ireland Hospice to provide care for him. The Children's Hospice could look after trachies, but the adult care people were different. We were in a privileged position. My two sisters and I had a 24- hour rota. We were there, and they were there at the end. Daddy's end-of-life story was published in the 'Belfast Telegraph' and the 'Sunday Life' in November 2022, so, if you are interested, you can find out a bit more about his history there.

As a result of that, I was invited to be our voice in the development of the Belfast community palliative care hub, where our representation has been very much appreciated and listened to. I am so pleased that the hub has had its soft launch; it has not had its big formal launch yet. It is absolutely wonderful.

The hub brings together Marie Curie, the Northern Ireland Hospice and the Belfast Trust to attempt to make the best possible palliative care available for people in Belfast.

In our palliative and older care forums, I am very conscious of those who do not have family carers and who struggle and often die alone. Inequity in access to and delivery of care, especially social care, is a challenge that very many people face. My mum's final days were very difficult for her and my siblings. Mum died from a broken heart, being isolated and unable to be with Daddy through his last weeks — the power of lockdown. From June 2020, Mum received amazing care from the Belfast Hospital at Home team, which is incredible, as you mentioned. She received amazing care from that team a couple of times. However, in late September 2020, she was referred by the team via ED for inpatient treatment for heart failure and kidney concerns. Classically, she was released on a Friday evening. Mum's condition deteriorated badly over the weekend, and she was readmitted to the ED on Monday morning and sent home that evening with no change in treatment. Mum appeared to move very quickly and abruptly from active treatment to apparent "Do not treat" status. It is very painful for me, because I took a couple of weeks' respite with my husband, who had been seriously ill the year before as well, and I was not there during that. At that stage, her GP apologised, and the palliative pathway followed. Unlike Dad, however, Mum died at home — the home that they shared for those 65 years — with good community, social and palliative care.

I feel that, with both Mum and Dad, poor communication and understanding of their final transition to the last days of life meant that there was undue anxiety for both them and us. I am a staunch proponent of advanced care planning. I appreciate that that is a difficult conversation, but, when properly communicated, it will mean that folks can have their decisions about ending treatment supported, a peaceful, natural death realised and crises avoided. While Dad was safe and well cared for in the hospice, initially, it was unable to accommodate him, with demand very much outweighing supply, as we heard. We were also aware of the cost of providing that care, which is paid for through voluntary donations. I reckoned that his six weeks cost about £30,000. At that time, we were in lockdown, so there were no donations. We raised £4,000 in a run/cycle challenge that even my mum participated in on her Zimmer frame. However, that sum would not make a big dent in the need. While most would like to leave this world in the comfort of their own home, that is not always an option due to complexities such as those in my dad's case. Why is access to inpatient end-of-life care a lottery? The care is in short supply, there is an inequity and it depends, as someone said to me, on cake sales.

I am grateful to have been given this opportunity to briefly share the end-of-life care experience of two amazing people. I would have loved to ensure that it was better. However, theirs was better than that of many. A lot has been learnt from my life experience, but, in a nutshell, I would like to see more equitable access to inpatient end-of-life care that is not dependent on voluntary funding. There should be a joined-up provision of services between health and social care providers, including our charitably funded hospice services. There should be no gaps, duplication or confusion. There should be early, prompt diagnosis and an awareness of the fact that life is ending and of end-of-life needs. There should be clear identification of the key worker. Alan mentioned that his key worker gave him access to their phone number, but my siblings in Australia phoned me to ask who was managing the patient. We had a long list of people to contact but did not know who the key worker was. Finally, there should be an adoption of advanced care planning to ensure that everyone can inform people of their wishes in a timely manner and smoothly transfer into the end stage of life.