Thanks very much for giving me the opportunity to talk about my father, Paddy Kelly.

Let me tell you a wee bit about him. My daddy was born in 1937, and he was 85 when he passed away. He was one good-looking guy. He met and married Mum in 1962. She died in 1979, and he raised seven daughters single-handedly, which is some going, let me tell you. He spent his whole life surrounded by women. He went to the Derry dances in his youth, and he loved to jive. He played snooker, and his nickname was "Cautious Kelly", because he could make a snooker match last for ever. He was in Derry when Dana won the Eurovision Song Contest. He met Bill Clinton in 1995 when he visited Derry, and he wrote a poem about him that was published in the local papers. He loved his garden: roses were his favourite. He was a DIY fanatic and lived by the motto, "If it moves and it shouldn't, use duct tape. If it should move and it doesn't, use WD-40". He believed that Sudocrem was an all-round cure for everything. He was a great storyteller. He loved a good laugh. He dressed up at Halloween, Christmas and for parties. He had an encyclopaedic memory, and he was always up to date with current affairs. He was grumpy sometimes, but who is not? He was our dad, and we loved him. In his last days, he was in extreme pain, and he asked to die. Every pain, scream and tear that was shed tore through our hearts and souls, and we will never forget that. We and the GP promised him that he would not be in pain. We failed him, and the system failed us.

Let me tell you a wee bit about that journey. In 1948, the NHS was created by Aneurin Bevan to meet the needs of everyone, free at the point of delivery and on the basis of clinical need and not the ability to pay. Winston Churchill coined the phrase "from the cradle to the grave". We all put our trust in the NHS's systems and believe that, when our time comes, we will be cared for and have a pain-free and dignified death. When I started to train as a nurse, which was a wee while back now, the one thing that struck me over the years was that we had a duty to provide care to all our patients and to aid their recovery. When that was no longer possible, we had a duty to assist them towards a dignified and pain-free death. That was something that I worked towards my whole life.

In Northern Ireland, dying and death are taboo subjects. None of us wants to think about our mortality, fragility and inevitable death. However, none of us can escape it. Therefore, the first experience that many of us have of palliative and end-of-life care is when we are at the centre of it, and it is often found lacking and not what we expect. Even as a healthcare professional, my understanding of palliative and end-of-life care was lacking. I thought that they were one and the same, but they are not.

My understanding now is that palliative care is there to provide care to the patient whose condition is no longer treatable. It aims to treat the symptoms and to provide support for family and friends whilst they come to terms with the realisation of the patient's condition. It also allows the patient to live their life to the fullest, taking into account the restrictions that they have and providing them with physical, spiritual and emotional support.

End-of-life care is just that: providing care and support for the patient and their family as the end draws close. That includes the provision of physical care, such as washing, feeding and administering medication. Most important, it also includes pain management, which can be a fine balance between controlling pain and allowing the patient to spend their last days with their loved ones in a meaningful manner. We understood that only when my daddy was in the middle of it.

Dad had been ill for many years with various health conditions. He had heart failure following a heart attack 20 years previously. In the last years of his life, his condition slowly deteriorated. He lost weight, he had poor appetite, his mobility decreased and he experienced what he thought were side effects from his medication. With hindsight, however, I realise that he was displaying all the symptoms of chronic heart failure, and his medication became less and less effective. Through all that, his mind remained very sharp, and he held out hope that the medication could eventually be changed to control the symptoms, because he wanted to live till he was 100.

In May 2022, he was hospitalised again with distressing symptoms of vertigo and breathlessness. Following investigation, his consultant explained to my dad that he could do nothing else to control his symptoms and that he was moving towards the end of his life. We all wanted Dad to come home, so he was sent home. Unfortunately, that happened to be the weekend of the Queen's jubilee, which was a long bank holiday weekend. Everybody who has talked to you today has talked about the lack of cover at weekends, and we experienced exactly the same thing. That weekend, due to the exceptional circumstances, no Marie Curie nurse was available.

That night, Dad was again in acute pain. The on-call GP said that he would come to the house to administer pain relief. As Dad was in acute pain and we had been told that the GP would come out, we assumed that that would happen as soon as possible. The GP arrived two hours later, after another phone call from us. He was carrying out home visits for other patients as well as looking after palliative and end-of-life patients. His call sheet noted that Dad's call was urgent, and "2 hours" was written in the comments box beside Dad's name. Although it was an urgent call, the GP was given a two-hour window in which to see him. We were not aware of that. All that time, Dad was in acute pain.

The nurses who cared for Dad in his final days were caring and compassionate, but it was very evident that they were stressed because they could not deliver the care that they knew that he needed. The palliative and end-of-life care strategy Living Matters, Dying Matters talks about a "holistic approach" to individualised care, but that is impossible to deliver when you have to travel up to 30 miles between patients to deliver basic care. There is little time to give emotional support to the patient and their family when your next patient is waiting for you and is possibly in pain.

On Sunday 5 June, it was finally decided that Dad needed to have a syringe driver for pain relief. The drugs protocol stated that the patient had to receive morphine three times in 24 hours before a syringe driver would be considered. Whilst I understand the reasons for protocols, that protocol was rigid and was not flexible to the needs of the patient, who was our dad. It was obvious from early on that he would require a syringe driver at some stage; however, not all the drugs that were required were in the house. On the very day that Dad died, therefore, we were away — again, for two hours — to get his medication. His syringe driver was erected at 1.00 pm, and he died at 3.15 pm that same day.

None of the services or, indeed, staff started with the intention of causing obstructions or delays, but the system has been set up in such a way that means that they are inevitable. None of the staff members or services that we encountered, although professional, kind and compassionate, realised how their role was key in delivering the care that my dad needed. There was no real sense of there being a joined-up approach. They were just different cogs, all doing their thing but not really engaging.

There are national strategies for maternity care, cancer care and mental health. Most of us will never have to access them. However, the one service that we will all be exposed to in one way or another is palliative or end-of-life care, which does not have a current strategy. A strategy was put in place and reviewed, but it needs to be reviewed again. To ensure that services are delivered when and where they are needed, strategies need to be live. They need to be reviewed regularly to ensure that they are still relevant. There is a great urgency for a new strategy for palliative and end-of-life care, considering the post-COVID world, where new challenges and gaps in the current services have been identified. The strategy still needs to be created with input from service users to ensure that it delivers where the patient needs it. Its focus needs to be on working together for a common purpose.

We, as a family, made some suggestions, and some came from my background in nursing. Those include the fact that change does not have to be big and that small changes can have a huge impact. Nursing staff should have direct contact with GPs. The palliative care nursing staff had to ring a centralised number, wait for the GP to get that message and the GP would then ring them back. There should be a direct line. We have done some work with the Western Health and Social Care Trust, and I know that direct line contacts are now available for the nursing staff. It cuts out a part of the process that does not need to be there.

Another suggestion is nurse prescribing. Why can nurses not prescribe certain medications? They can prescribe them in hospital situations, so why can they not do that out in the community? The nurses have the same qualifications and are experienced, so why can they not do that? I know that there are protocols etc for that, but it needs to be pushed forward quickly.

While there is a prescription delivery service, there is nothing for urgent prescriptions. You could wait for a day, two days or whatever. I will mention electronic prescribing. We all use laptops and PCs — I can see them in the room — so why can we not do electronic prescribing? What is all the paper about? You have to collect a prescription and take it here, there and everywhere.

There should be a telephone tree or an online medication stock-availability system. We went to various pharmacies on one day alone to try to get the prescriptions that my daddy needed. Nobody had everything that he needed. Once I had taken a prescription to one pharmacy, they would not let me take that prescription to another. Nobody ever offered to phone to check whether Boots had it. Nobody did that. We had to run around half of the town while Dad was in pain. What about a telephone directory? In other words, somebody could say, "I will ring that pharmacy, so you can go there directly." There should be a central fully stocked pharmacy that is open 24/7, possibly located in a healthcare facility, for those urgent medications.

We support adequate staffing that is based on workload and clinical priorities. An older population means that more and more people require palliative or end-of-life care. There should be robust and flexible drug protocols. As I said, Dad had to have morphine three times in 24 hours before they would even consider a syringe driver. In that time, he had lots of breakthrough pain. You need to be flexible, because there are different circumstances.

We need to raise awareness in the public of palliative and end-of-life care and of how they can be part of it. As a family, we did not realise that you can be in palliative care from the day and hour that you are diagnosed with a condition. It is there to provide you with support to live your life as you are. It is not end-of-life care, but the public do not know that. We as a family did not know it, and I know that the public do not know it. Palliative care can be instigated at any stage.

Given what I have told you about Dad being in pain in his last hours, I ask you to try to imagine that he was your loved one and to please not let anybody else suffer unnecessarily.