Mum deserved a dignified end

**Jackie Stacey’s Mum Kathleen** died of Alzheimer’s, aged 78. Kathleen spent 10 days on a busy hospital ward at the end, to the distress of her family who felt powerless to get her somewhere more peaceful.

"When Mum was first diagnosed with Alzheimer’s, our Dad Dennis took on the role as her full-time carer.

"Over time it got harder for Dad to look after Mum. My sister, brothers and I helped out with everything, and Dad had some carer support, but the pressure of looking after Mum began to take its toll on him as her condition got worse.

"Mum and Dad had lived together in Catford for 34 years, so it was really difficult when we took the decision to find a care home for Mum.

"We all felt guilty about this, but Dad was struggling to cope and in desperate need of respite."

After a happy life, mum deserved to have a peaceful and dignified death. Even now, we feel guilty and wonder if we could have done more for her.

"Dad went to see Mum every day. We took her out for trips and holidays.  Dad was more relaxed, and he could spend more quality time with Mum, without the anxiety of being her main carer.

"It took the pressure off him and could enjoy simple things again, like spending time at his bowls club.

"A few years after her diagnosis, Mum went into hospital with a bout of pneumonia, but she got over it.  The last time she went into hospital she had a chest infection.

"At the time, we were told she had about 12 hours to live.  But she rallied – which we were told was not uncommon – and was moved to a general ward.  At this point, she was able to talk to us.

"For 10 days we took turns being with Mum on the ward.  We slept on chairs and got as comfortable as we could – we didn’t want to leave her totally vulnerable and on her own.

"It was noisy all the time and staff were always in a rush to do their tasks.  At times, we felt powerless as we could see other patients in distress and requiring more support than was available, particularly at night.

"We often felt like we were in the way when the nurses came to look at Mum, or turn her because of her bed sores.  We felt pushed out when we had always been there for our Mum.  It bothered us a lot.

"About three to four days before she died, we were told that she was dying.  Those final days were torture at times.  Mum was constantly thirsty and in a lot of distress.

"At the end, I was there for Mum.  We wanted it to be a quiet time – it was very difficult.  I felt the staff were intruding on a really private moment and I just wanted to be left alone with Mum in her final moments. I kept asking staff to call my family.

"Beyond the closed curtain there was so much noise – with visitors coming and going; and staff going about their rounds.  It wasn’t peaceful or serene.  It wasn’t nice.

"Mum deserved a dignified end, it should have been more dignified and calm."

After all their years together, Dad would have loved the chance to have cared for Mum one last time.

"At no point did anyone talk to us about Mum’s final wishes or whether it was possible or not for Mum to leave hospital.

"She was in hospital for 10 days before she died.  Surely, it wouldn’t have been too difficult to organise an ambulance to move Mum from the hospital ward to a local hospice, or even home.

"Dad would have loved the chance to have cared for Mum one last time, during her final days at home.

"We know it would have been more peaceful and dignified and less stressful for all of us.  Even now, we feel guilty and wonder if we could have done more for Mum."

**Given the choice, many of us would choose to spend our last hours of life at home, surrounded by the people and the things that we love. But every year, up to 10,000 people are dying in hospital because they can’t get the care they need at home or in the community.** [**Join our campaign to change this.**](https://www.mariecurie.org.uk/policy/campaigns/help-dying-people-get-home)

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