

Voices4Care.

One member's personal story - Janet Moffett, Lisburn, Northern Ireland

I'd never heard of Voices4Care when by chance in 2016 I saw an email calling for new members. It explained that Voices4Care, an all-Ireland group, provides an opportunity for people to use their experience of palliative care to help shape the future direction of services. It asked for applicants who were either receiving palliative care services, carers, former carers, or interested members of the public. I actually felt quite excited because I qualified on the latter two counts.

In 2012, I retired from a 35 year career as a Social Worker, fifteen years as a practitioner, then as a manager. During this time, I had real interest in palliative care from the Social Work perspective and my role enabled me to promote the development of services. Since my retirement I had continued to follow how those developments were progressing. I was definitely an "interested member of the public".

I am also a former carer. My 94 year old father had been diagnosed with prostate cancer in 2009. At his age he was advised that he would probably die "with" and not "of" his cancer. They didn't know my Dad! Coming from a long-lived family (his aunt lived to 114 years), he was looking forward to celebrating his 100th birthday. Sadly he didn't quite make it, and despite harassing his poor consultant for every available treatment - bar surgery which he had to accept was not an option - he began to go downhill rapidly in 2013. We could see that his needs were now palliative. Dad was a lovely, charming man, widely respected and much loved. We all wanted to do the best for him, not least my Mum. He made it very clear that he wanted to be cared for at home, and she was determined that we would achieve that - not that he ever accepted that he was actually going to die! We had excellent community services from the generalist palliative care team, supplemented by a full care package, until he died in March 2014 in his 99th year.

I learned hugely from that experience. There were two main lessons. The first was that in supporting carers, while good practical services are vital, equally important is time taken to listen carefully to the carers' concerns, no matter how trivial they seem. Don't make assumptions about their knowledge or understanding. We are an articulate family which includes doctors and other professionals. Maybe we gave the impression that we knew what we were doing and it did help that we knew our way around the system, but we floundered in some areas.

My Mum had little experience of death and worried greatly about what the moment would be like. Dad had a growth on his neck and a couple of weeks before his death Mum was warned that it could begin to bleed and would be extremely difficult to stop. She was given instructions about how to deal with this (it never happened) but she was terrified and from then she needed another family member there every night.

But the other, more positive lesson was that of the value of a “good death”. With support from our great care team, we persevered, and Dad died very peacefully at home with family by his bedside. My Mum, though naturally very sad and even though Dad didn’t make his 100th birthday, got tremendous satisfaction from knowing she had given him the care he wanted, that she had done her best and had nothing to regret. She lived for a further two years and often repeated how happy she was that he hadn’t had to go to hospital or nursing home. This “good death” made the grieving and bereavement process much easier not only for Mum, but for the whole family.

This is what just one individual brings to Voices4Care. My story as a carer is a positive one of my father’s long life, well lived, which ended in a way most people would choose. Other stories are much less positive, even harrowing. The many heartbreaking stories of people dying alone during the Covid pandemic brought home to all of us just how important it is to be able to give people the end of life care that they need and deserve. But every story, positive or otherwise, teaches us something which can and should inform the future development of palliative care services.

In Voices4Care, we have continued to meet virtually during the pandemic but obviously the work we could do has been limited. Many development projects were paused due to health service pressures and staff redeployment. However, we always had the opportunity to discuss our experiences and to identify areas where we think improvements can be made. More importantly Voices4Care provides us with a mechanism to have these ideas brought to researchers, service providers and commissioners across Ireland, including Northern Ireland’s Palliative Care in Partnership group.

My membership of Voices4Care is coming to an end because, although extended due to the pandemic, it is normally rightly limited to four years. After that time the personal experience becomes less fresh and relevant and less significant to current planning and research. It has been a privilege to be part of Voices4Care and to know that collectively we have been able to influence the policy makers and ultimately the continuing improvement of palliative care services in both Northern Ireland and the Republic.

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