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Trish Johnson
[redacted]

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I wish to describe my father's experience with a terminal, degenerative illness.
My father was diagnosed with motor neurone disease when he was 79 and died in 2014 aged 81. He was fortunate (his words) to have had advance notice that his life was coming to an end, which enabled him to spend time with the people he wanted to, and participating in the activities he chose. Also ultimately to plan what was going to happen when his physical function deteriorated. Not all of his friends of similar age had that opportunity, and he commented on their lack of opportunity to plan what was going to happen to them at the end of their lives. The discussion around end of life care and personal choices needs to be more acceptable in general society, so that everyone feels they have had the chance to decide and plan, and tell appropriate people what is right for them, while they can.

Initially my parents did not want to discuss end of life care for my father, it took some time for them to be able to do that. This means that it is vital that the topic is a common theme for discussion by health professionals interacting with people with life limiting illnesses, so that the discussion can happen when/if the person is ready. This also requires training and support for those professionals to know how to initiate those discussions, so that it can happen whenever it is appropriate. The organisations providing health services to people with terminal illnesses need to have the framework for development and ongoing enhancement of staff skills in this area.

Once my parents were able to consider end of life care, there was one absolutely core premise that assisted my father to maintain reasonable mental health in the face of his prognosis. Because of the readiness of the professionals he was interacting with to discuss different scenarios and treatment options, he felt he had sufficient information to make informed choices, and knew he would have the ability to make decisions regarding what was going to happen to him. This allowed him to maintain control over the treatment and management of his deteriorating physical function. Without the knowledge that he was in control, I believe his mental health would have significantly suffered due to the nature of the disease he was living with.

Options for end of life care then became the primary topic of discussion at every medical/team review (which I attended to provide support to my parents). Every visit, my father started the consultation by re-affirming that he had choice over the treatment he was to receive when very disabled. He recorded his wishes and repeatedly discussed them with everyone in his family and his medical team, so that he was reassured that he had the control. Ultimately when he became very medically unwell, having the ability to rely on decisions made at a less stressful time meant that his death, while extremely distressing for us, was less traumatic than it could have been, as we (his family) were able to be assured that what was happening was occurring according to his wishes.

This has also been important following his death, in that when we remember the event, although it is the most painful memory, we can comfort ourselves with that knowledge. I cannot image how even more difficult it would be to look back at the death of a parent, with the memory of their distress at what was happening to them, that they did not want.

This leads me to believe that palliative care should always be guided by the person's individual beliefs and wishes. Being able to exercise choice should be fundamental to palliative care as it provides a measure of empowerment in a situation where control has ultimately been removed. If a person believes that their own life should be ended at a particular time to relieve suffering and distress when the prognosis of forthcoming death is known, then that is the most important action to undertake. I believe all and any options should be available for people to choose, without pressure or expectations to follow any prescribed course of actions. This relies on the provision of accurate and complete information about the likely course of a disease, the choices available, and the provision of appropriate support to the person and family/carers by a professional team. I am aware that formal palliative care currently provides for as much personal choice as possible, however at times people are forced to act in isolation due to existing law.

I understand that my father's ability to identify what course of actions he wanted and discuss his wishes is not representative of everyone experiencing a terminal illness. That is why it is vital that this topic is discussed more broadly without stigma, so that it becomes an appropriate part of making decision about our lives.

In reading through some of the other submissions I was struck by one comment that medical care is about 'doing no harm'. I believe that my perspective is not in opposition to this – when a person has a terminal illness, assisting them to be able to have control over what is happening to them achieves this principle. By taking away choice and control, that is when the harm is done.

I am agreeable to my story being publically available, however please do not publish my address.
Thank you, Trish Johnson