

Submission to the Legal and Constitutional Affairs Committee on Voluntary Assisted Dying.

From Kevin Hubble, [REDACTED]

I am writing in support of Voluntary Assisted Dying (VAD). I am proud that the NT was one of the first places in the world to recognise people should be given the option of relieving their pain and suffering.

During the course of the last few weeks I have found out I have a serious condition, Parkinson's Disease, which will affect my quality of life. While I supported the concept of VAD previously, this diagnosis has brought the issue into sharp relief and I feel I need to contribute to this discussion.

I feel the terms laid out in the consultation paper are too narrow, and would not allow the relief of suffering for a number of people, including myself. The requirement that the person should have a terminal disease that will kill them in the next 6 to 12 months leaves out many who will suffer, sometimes for decades, with severe disability, because they are not likely to die in the next 12 months.

My own prognosis is that I will live to an average age, so no reduction in life span, but severe negative changes to my quality of life. I am likely to have manageable symptoms for 10 to 20 years then, over a period of 5 to 10 years I will decline rapidly, with loss of mobility, loss of continence and probably dementia. Under the current suggested rules I would not be eligible to access VAD, despite what could be a complete loss of quality of life.

I would like to see the laws cover these situations. Have a way of determining quality of life and be able to specify at what point in that continuum I would like to end my suffering. This could be in the form of a living will / advanced care plan which sets out exactly where in the continuum I will access VAD. As long as these decisions are made before the loss of mental faculties, they should be respected by the new law.

In terms of all people in the NT having safe access I have been lucky enough in my career to travel to many remote communities across the NT and Kimberley. One thing that is clear to me is that these are all individual communities filled with individual people. I think the law should allow a community to vote to not allow VAD in their community, if they wish. There should then be a process to allow a person to leave the community to access VAD, if they wish. I realise this would be hard for the person accessing VAD, who may wish to die on country, but I think the will of the many must, in this case, come before the will of the individual.

I also read with interest a submission by a doctor who does not want to be involved with VAD and feels that having to give information about VAD would infringe their right not participate. I can understand that and perhaps something as simple as requiring the doctor to advise the person that they do not believe in VAD and the person would need to seek that information or help elsewhere.

I do not have any comments on monitoring of the process, other than to say any case where death was not quick and painless needs to be examined to ensure patients accessing VAD are not subjected to unnecessary pain and suffering.