

Opinion: Defining 'terminal' and 'hopeless'

Dr Rodney Syme, Vice President of the Dying with Dignity Society of Victoria*, has considered the differences between terminal and hopeless illness and provides the following insight.

Terminal illness is a well-recognised concept, referring to the phase in which an illness has reached an inevitable and irrevocable course to death, which is anticipated within a short time frame - possibly six months. Terminal illness is a term particularly appropriate to malignant disease, as advanced incurable cancer is usually associated with a rapid, progressive, predictable and inevitable path to death. A terminal illness is defined by four basic characteristics that may, or may not, be accompanied by intolerable and unrelievable suffering:

- 1 no chance of recovery
- 2 certain progression to death
- 3 rapid progression to death
- 4 a short time-frame to death

A terminal illness may therefore be considered to be 'an incurable illness that is certain to cause death in a very short period of time'.

Hopeless illness shares one characteristic with terminal illness - there is no chance of recovery. Hopeless illness is characterised by permanence; the patient will never recover, and there is associated severity leading to intolerable suffering which is unable to be relieved. A mid-brain stroke, which causes paralysis of all movements except eye movements, together with an inability to speak or swallow, while preserving cognition, would be considered by most as a hopeless illness. Multiple Sclerosis is a permanent, progressive illness, incapable of improvement and causing severe effects that result in intolerable and unrelievable suffering. These two illnesses differ from the terminal nature of cancer, as they have no particular projected time frame. They may cause suffering over a prolonged time, particularly if intensive treatment is provided. In mid-brain stroke the provision of tube feeding may prolong life indefinitely.

It is important to recognise that a critical characteristic of hopeless illness is intolerable suffering. Early stages of MS may be tolerable, and some people may even find advanced stages tolerable, possibly because their minds remain unaffected. While therefore highly subjective, the characteristics of a hopeless illness may be:

- 1 permanence, with no chance of recovery, including a remorseless progression
- 2 severe illness causing significant unremitting symptoms
- 3 no characteristic time frame
- 4 close association with intolerable suffering
- 5 no effective or acceptable treatment to ameliorate suffering, or alter the course of the disease.

Therefore hopeless illness could be defined as 'an incurable illness of certain permanence or inevitable progression, with severity causing intolerable suffering which cannot be relieved by treatment acceptable to the sufferer.'

Arguably the worst hopeless illness will also have the longest time frame. The emotional, psychological and existential components of the illness become more significant the longer it persists. A terminal illness may be a hopeless illness, but it is likely to be one of short duration and therefore involving shorter intolerable suffering. A hopeless illness may be prolonged with treatment. For example, motor neurone disease may be prolonged by tube feeding or artificial respiration. In these situations the patient may end the hopeless illness by refusal or withdrawal of treatment.

However there are some hopeless illnesses which do not provide the opportunity for such an option. If physical, as opposed to emotional, pain is not a major symptom, there is no opportunity to utilise the option of 'double effect' in pain relief or sedation, which offers the possibility of ending the hopeless illness. Huntington's Disease, for example, would fall into this category. The only remaining option for relief of suffering is deliberate starvation or dehydration. It follows that hopeless illness that is also terminal may not cause as much suffering as a hopeless illness which is not. It is the chronic, non-progressive or slowly progressive hopeless illness that may be the hardest to bear. This is why the debate on law reform for voluntary euthanasia needs to focus on hopeless rather than terminal illness.

** Dr Syme was Vice President of DWD Victoria in 2017*

Exerpt from SAVES Bulletin Vol 20: No 1 March 2003