

Living with disability—and planning a good death

June 3 2013, by Di Winkler

(Medical Xpress)—Australians have a poor track record of talking about death and dying. A [recent survey](#) of Australians who'd just lost a loved one to a terminal illness found just 15 per cent were told how their relative wanted to be cared for in their final days. Consequently, while most (70 per cent) people prefer to die at home, more than half (54 per cent) die in hospital and 32 per cent die in nursing homes.

For young people living in or at risk of admission to [nursing homes](#), death and dying is often a taboo topic. Many of these people have degenerative neurological conditions and a limited [life expectancy](#). Others have severe acquired [brain injury](#) and, due to their limited mobility, are at a [high risk](#) of a [premature death](#) from complications such as [pneumonia](#).

People with disability are at significant risk of a "disenfranchised death", which is when death is not openly acknowledged with the dying person. In such instances, the dying person is socially excluded from the process of dying and deliberately excluded from the decision-making process.

In their last days, many people want quiet reassurance. They want to know that whatever they are worried about is going to be fine. A disenfranchised death can leave a person feeling lonely, disempowered, frightened and anxious before they die.

A good death does not happen spontaneously; it requires careful consideration and planning to decide what happens, where death occurs

and who is present. This includes:

- knowing that death is coming and having some understanding of what to expect
- having an opportunity to say the things you want to the people who are important to you
- having some control over pain and symptoms.

When it comes to planning a good death, people with disability are marginalised and disadvantaged. Many of the people my colleagues and I support at the Summer Foundation are socially isolated and are less likely to have [close friends](#) or [relatives](#) with whom they can start these conversations or who can advocate for them within hospital settings.

Our research has found that more than half of people with acquired brain injury living in group homes do not have a best friend in whom they can confide and 60 per cent receive a visit from a friend less than once per year.

Among this group, one in four were hospitalised in the past 12 months. They live with a range of complex health conditions that can cause premature death, including pressure areas (28 per cent), epilepsy (24 per cent) and chest infections (18 per cent).

The cognitive and communication difficulties experienced by many in this group means that they are also less able to initiate a frank [conversation](#) about their end of life.

These discussions are often left to disability workers. But while some people with disability have had the same worker support them for many years, often people with [disabilities](#) have a revolving door of support workers and may not have anyone in their life who really knows them well.

The paid workers providing daily support often do not feel comfortable starting these difficult conversations even when it is obvious that the person with disability has limited time left. As with most [Australians](#), when it comes to death and dying, many disability workers are scared of saying the wrong thing, so they don't say anything at all.

Some people find the prospect of being with someone when they die to be frightening. It is not always comfortable but resources are available to help. Remember, just like the rest of us, people with disability need to know they matter and their life is valuable.

People with degenerative [neurological conditions](#) and people with disabilities who are susceptible to pneumonia and other infections are likely to be admitted to hospital, so plans must be in place for unexpected treatment.

In recent years, parents of younger people with severe brain injury have been shocked to find that when their adult children were admitted to hospital with an infection, some medical staff were quick to assume that the patient should not receive active medical treatment, based on their level of disability. Medical staff made quick judgements about the person's quality of life without acknowledging that they were a valued member of a family.

People with disability and families need to think about how active medical intervention should be and have a written plan prior to any hospitalisation. A personalised hospital information pack should be kept up-to-date and include details of who has been appointed enduring power of attorney and decisions regarding a "do not resuscitate" order.

People with cognitive or communication issues should also include details about their means of communication and key likes and dislikes.

The earlier the conversation starts the better: it's much easier to have these conversations when the person is in good health; the more they deteriorate, the harder it can be to discuss death and dying.

In the wider community, patients work with their doctor and family to develop an Advance Care Plan, which covers medical and legal issues related to power of attorney and "do not resuscitate" orders. But such plans are not holistic and are not always offered to people with disability.

With the national disability insurance scheme (NDIS) just around the corner, we have a unique opportunity to tackle this issue head on and build comprehensive advance care planning into the nation's new DisabilityCare system. Embedding end-of-life planning within the DisabilityCare planning is likely to reduce the stigma surrounding discussions about deterioration and [death](#).

Now is the time to begin these conversations.

Provided by Monash University

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