

## Terminally ill patients must have greater choice

Deciding when and where we die should not be dictated solely by health care experts

By SARAH RUSSELL

The debate about dying needs a new lease of life. It needs to include those people with terminal illnesses who want to live. For them, the choice is not between living or assisted suicide. Instead they face a complex range of decisions and choices. There are, for example, choices about where to die (home, hospital, hospice). Choosing where we die often impacts on how we die.

Who should make decisions about how and where we die? Should people who are dying make these decisions about their own lives? Or should health care professionals, family

members, priests, policy makers, or hospital managers make decisions on behalf of those who are dying?

We are often told that people who are dying 'negotiate' their care with so-called 'experts'. This implies that people who are dying have a voice that will be heard by 'experts'. Yet most of us have experienced just how hard it is to exercise individual choice within our health care system. Take for example the introduction of Medical Treatment Act in 1988 which legislated people's right to refuse medical treatment. Despite this legislation, health care professionals too often disregard an individual's wishes expressed in a living will.

When people are dying, 'experts' within the health

care system often assume control of treatment decisions. While health care 'experts' may have expertise in medical care, surely those who are dying are experts about their own lives. As such, they are often able to make decisions about their own lives. This includes decisions about their own care and treatment when they are dying.

If a person's choices about the manner and location of their dying are determined by others, is it not the case that society has already allotted them a reduced status, that of the 'living dead'?

To make informed decisions about their individual care, people who are dying require access to information. This may include fundamental information, such as telling

a person that they are in fact dying. When health care professionals (or indeed family members) decide to withhold this information, they inevitably limit an individual's end-of-life choices.

**If "experts" decide, we deny the importance of all we have learnt about ourselves during our lives.**

Choosing how and where to die is often based on individual beliefs about what "dying with dignity" means. For example, a person who is dying may believe that 'dying with dignity' involves dying at home with the absence of medical interventions. While it is true that there are occasions when death at home without the intrusion of medical technology may be peaceful and beautiful, there are other times when it

may be a painful, undignified and traumatic time for all concerned. On the other hand, there are times when death in hospital with a vast array of state-of-the-art medical technologies may be a dehumanizing experience.

Clearly there are choices about how and where to live while dying. People need to make these decisions about dying based on individual choices and needs. Such choices also require a flexible and well-funded health care system.

The health care system should support people to play an active role in their end-of-life decisions. This requires the provision of high quality health care services, including palliative care services and respite care. It also requires the provision of information about options. Without

being aware of options, people living with a terminal illness often have no choice but to accept the health care professionals' 'expert' opinion.

If we allow 'experts' to decide how and where we die, we deny the importance of all that we have learnt about ourselves during our lives. Our 'lived experience' influences all our decisions, including those taken when we are dying.

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