

'It's my life - so let me decide!'

Through age, illness or accident, people can lose their capacity to understand the nature and consequences of proposed medical treatment. Health care decisions then fall to families, friends and physicians who may not be aware of the patient's wishes.

Thanks to our friend Garry Barnsley for this article

Ever imagined yourself as a medical practitioner? Try this scenario: you're the only medico on duty in the emergency department of the local hospital - and there **are more** patients than you **can cope** with. A young girl is there with her anxious parents. She has acute appendicitis. A middle-aged man is having a heart attack. And a 60-year-old woman has been brought in with a broken hip. But the patient you are examining now is 85 years old, a resident of the nearby nursing home. You have treated him before - and you know that he no longer recognises his own family, and has no control over his bowel or bladder. He is bleeding to death from a ruptured stomach ulcer. Do you give this gentle old man morphine and let him die? Or do you use your limited resources to try to save him?

Preserve life - at all costs?

Without guidance from your patient, you may feel that it is your obligation to do everything to preserve life, using everything that a modern hospital has to offer - surgery, life support systems, overwhelming technology ... Just doing *your* job...

Now imagine that you are the old man. What would you want? Maybe you would decide that you had had enough - and that it was time to go peacefully and as painlessly as possible. But when we are too old to make decisions, family, friends or doctors must make them for us - and usually decide on more treatment than they would want for themselves. "Yet this only prolongs the dying process," says Canadian Professor, Doctor Willie Mallow, Director of Research in the Division of Geriatric Medicine at McMaster University.

"The purpose of the health care system is to preserve life at all cost. It doesn't accept death. The problem is, how do you call off the system?"

Your 'living will'.

Dr Mallow strongly advocates increasing patient's right in health care and urges everyone to have "living wills" - to let their doctors and family know, in advance, what level of medical intervention they will want at the end.

Dr Mallow observes that we use wills to tell others what we want done with our possessions after our death, but rarely leave instructions about our care in case we are not able to make health care decisions for ourselves at a later time.

"For example, we could at some future time be incapacitated by a stroke or a serious head injury. These illnesses affect our ability to think, reason and speak. A health care directive allows us to give instructions in advance" he says.

"As long as we remain competent, able to consider and communicate health care choices, we must make these decisions for ourselves. An advance directive is designed to be used only if we are unable to make our wishes known.

A "no-win" situation

Without written guidelines from the patient, relatives can be in a "no-win" situation.

"When the family asks doctors to do 'everything possible' to keep a loved one alive and that person dies in a few weeks or months, the family may feel guilty that they put the patient through needless tests and treatments. They may feel that all they had done was prolonged the patient's suffering and postponed death.

"On the other hand, if they let the family member die with 'dignity' without treatment, they may feel that they should have done more. "Another problem develops if the family cannot agree on the best treatment. Some may want everything done to keep the person alive. Others may want only palliative care - that is, care that provides comfort and relief from pain, but does not aim to cure the condition. "Children from divorced marriages may resent step-parents or de-facto spouses making decisions for their parents. Children who have not been in contact for years may turn up when their parents are dying and involve themselves in the decisions. They may not know their parent's wishes. These children may demand that doctors do everything possible to bring their parent back, so they can have time to make peace with them. Friends and other family members who have stayed in close contact may accept the parent's

death more easily, treatment varies according to the doctor's sex, religion, and medical training.

If faced with an 80-year old with dementia who has had a heart attack, 55% of doctors says they would simply keep her comfortable, 42% would try to save her, and 3 % would transfer her to intensive care.

However, if the doctors know the wishes of the patient or family, then they generally abide by those wishes, according to the results of the study.

"Family conflicts and disagreements can cause lasting bitterness" said Dr Mallow "How can we protect ourselves to make sure we get the health care we want? How can we let others know our wishes? How can we protect our families and friends from this dilemma?

"When we discuss these concerns in advance, we can prevent conflict later among those who are forced to act on these decisions.

If we have clearly stated our wishes, then doctors and family don't have to guess what kind of treatment we would have asked for. It prevents potential conflict and guilt in the family. It removes the need for "second-guessing" - that is, trying to guess what we would want.

Document your wishes.

"The draw-back of informal discussions about these matters is that family and friends may not recall them accurately in the time of crisis, perhaps years later. By documenting our wishes in writing, we can prevent this problem, and give clear instructions for our health care in the future. This way, if the time comes when we are too sick to decide for ourselves, our doctors, family and friends would know our wishes, and we can receive the treatment we want." Dr Mallow has designed a personal health care statement - to be consulted only when the patient is no longer able to make or communicate his or her own decisions.

"The personal statement should define what irreversible condition you would consider intolerable. This is the irreversible condition so severe that you would probably want only palliative care.

In this condition, you would probably not want aggressive care that would prolong life at all costs ... people have different ideas about what disabilities and medical treatments would be intolerable to them."

Dr Mallow encourages people making a personal statement to describe an irreversible condition in terms of everyday living, such as:- "If the time should ever come when I am unable to wash, dress or feed myself or, if I can't speak to my family or make my wishes known and there is no hope of recovery". The directive lets you state what level of care you would like to receive - depending upon whether the condition is reversible or irreversible. You can then choose from four treatment options - palliative, limited care, surgical intervention or intensive care.

Comfort care directive.

Even for those people who find it too confronting or troublesome to try to distinguish between the definitions of an acceptable disability and an unacceptable disability, and try to relate the condition to the range of treatments medically available, most of us have no difficulty about defining the circumstances in which we would choose not to have our life artificially prolonged. In that case, a written statement, solemnly signed, can direct that procedures that serve only to artificially prolong the dying process be withheld or withdrawn, and that the patient be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide comfort care.

A well-planned life certainly includes a will (to dispose of worldly belongings) and a power of attorney (to let others act for us should we be unable to make decisions ourselves).

Now, a "living will" can give instructions about our health care should the time come when we are not capable of letting others know our wishes about our medical treatment.

You can discuss your wishes with me in a confidential, friendly atmosphere. Phone our office to make an appointment.