Dying with dignity

the role of advance care planning

Advances in medical technology have meant that an individual's life may now be prolonged despite compromise of its quality. Autonomy is the major ethical principle of our healthcare system, but who has the right to decide what treatment should be given for patients with mental incapacity? This article presents a system of advance care planning that enables individuals to preserve their right to self-determination.

ROGER M. CLARNETTE
MB BS, FRACP

Dr Clarnette is Consultant Physician, Department of Geriatric Medicine, Fremantle Hospital, Fremantle, WA.

A case in point

Mrs AB was 74 years old. She had been diagnosed with motor neurone disease 12 months earlier. In June 1994 she was admitted to hospital because her swallowing had deteriorated and she required treatment for a chest infection. She was given appropriate advice by a speech therapist and discharged after one week on a modified diet.

From that point, the patient's motor neurone disease progressed rapidly and she was readmitted in July with severe aspiration pneumonia. Her speech had deteriorated to the point of anarthria, but she was still able to communicate in writing. A gastroenterological referral was sought, and insertion of a gastrostomy tube was arranged. Unfortunately, she did not respond to broad spectrum intravenous antibiotics for her pneumonia, and she developed hypoxia.

Four days into her last admission Mrs AB wrote a note withdrawing consent for the tube insertion, and she wrote to her daughter that she wished to die and have all treatment withdrawn. She stated that she considered her disabilities to be unacceptable and that she could not tolerate a life without speech, swallowing and normal mobility. Later that day she wrote the same request to her doctors. After discussion with her family, antibiotics and intravenous fluids were

IN SUMMARY

- **Incompetent patients have rights. Advance care planning is a legally recognised mechanism for ensuring an individual's wishes for treatment are considered.**
- **For incompetent patients who are not in a life threatening situation, there is legislation in place that clearly recognises the right of family members to make treatment decisions.**
- **Healthcare directives have no role in treatment decision making if a patient is still competent – that is, able to exercise autonomy.**
- **The healthcare directive should not stand alone. If a patient is incompetent, treatment decisions arise from information in the directive and opinions of a nominated proxy and the doctor.**
- **Patients will inevitably want to talk about healthcare directives as their use grows in Australia. GPs are in the best position to ensure individuals understand their choices.**
- **GPs are likely to be responsible for making decisions in the event of a medical crisis, and must be willing to follow the instructions in a directive.**

stopped and she was kept on regular morphine for her pleuritic pain. She died 24 hours later.

It is interesting to contemplate what treatment Mrs AB would have received if she had not been able to communicate her wishes in writing. Making decisions about medical treatment towards the end of life is one of our society's most compelling and controversial issues. Health care consumes over 8% of the nation's budget, and rarely a day goes by when our morning papers do not have a story concerning the cost of health care, waiting lists in public hospitals, declining private insurance rates or euthanasia. The over-65 age group consumes more health dollars than any other age group, and most of the amount is spent in the last year of life.

Advances in medical technology have made it possible to sustain life despite significant compromise of its quality. Who should make these expensive treatment decisions, and how, are issues that the healthcare system has not yet resolved.

Ethics, the law and medical decision making

Ethical principles subconsciously drive our health system. Mrs AB exercised her right of autonomy (her right to make decisions for herself), which is well established in law and health care. Other ethical principles are also well established and have a role in treatment decision making:

- justice – to distribute burdens and benefits fairly
- beneficence – to act to benefit others
- nonmaleficence – to refrain from harming others
- confidentiality – to respect privacy and share information with the patient.

The principles of justice and equity allow doctors the right to refuse requested treatment if it is futile; in this circumstance, it is accepted that autonomy may be overridden. The principles of beneficence and nonmaleficence (to do good and not do harm) may also override autonomy in some circumstances – for example, when the life of an unborn child is at risk.

It is clear, however, that autonomy is the major ethical principle of our healthcare system. This principle is enshrined in the informed consent process that rightly pervades the practice of medicine in Western communities. Performing an operation or procedure on a patient without consent constitutes a battery under law.

Dying with dignity

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Making decisions about medical treatment towards the end of life is a controversial topic in our society. Advance care planning facilitates ethical decision making and helps patients to maintain their autonomy and doctors to make better decisions for patients they do not know.

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Who makes decisions for incompetent patients?

Decision making becomes much more problematic when an individual becomes incompetent – that is, unable to exercise autonomy. Who decides then what treatment should be given? Who has the right to make these decisions?

In a life threatening situation, a doctor has a duty to provide lifesaving treatment (if appropriate) for an incompetent patient. However, this issue is complicated by evidence that doctors do not make uniform decisions. Molloy and colleagues surveyed doctors in seven countries who were asked to state what treatment they would provide for a hypothetical patient with a life threatening illness. They found marked disparity in responses, both within and between countries.[1] Therefore, doctors acting alone may not make the same decision as their colleagues, and there is no guarantee of consistent management in such situations. This finding was later confirmed in an Australian study.[2]

What happens in Australia?

In most States and Territories, there is legislation in place that allows for appointment of a guardian who has the authority to make medical treatment decisions for an incompetent patient. In acute life threatening situations it is impractical to apply for appointment of a guardian. For incompetent individuals with nonacute illnesses, experience shows guardians are infrequently appointed to make medical decisions. It would be prudent to discover the law in your State or Territory.

A commonsense approach is taken in Australia, and doctors and families make treatment decisions for incompetent patients every day. For incompetent patients who are not in a life threatening situation, there is now legislation in place that clearly recognises the right of family members to make treatment decisions. In New South Wales and Victoria, next-of-kin and carers are recognised to be the ‘person responsible’ in the absence of a formally appointed guardian or medical power of attorney. Unlike other countries, however, Australia does not have common law precedents to guide decision making for patients who are or become incompetent.

What happens in other countries?

In the USA, a number of common law cases relating to autonomy and the right of the family began in the New Jersey Supreme Court in 1976. The Court allowed the parents of Karen Quinlan the right to act for her and remove her from a ventilator. This extended Karen’s autonomy beyond her competence by allowing her parents’ substituted judgement.

A more recent case, however, set limits on the right of family members to make decisions in this way. The Missouri Supreme Court determined that the parents of comatose Nancy Cruzan did not have clear and convincing evidence that their daughter would have wanted to have a feeding tube removed. The Court ruled that the tube could only be removed if evidence could be presented that Nancy would have concurred with that decision.

Some directives are disease specific; others are generic.

These and other cases prompted the US Congress to enact the *Patient Self Determination Act 1990*. This legislation made it mandatory for any health facility receiving government funding to give all patients the opportunity to make an advance declaration of their wishes regarding treatment at the time of admission to hospital. Such an advance directive will assist decision making if there is incompetence in the future, and absolve the courts and the health system from making difficult decisions.

Back to Australia

In Australia, legislators are now taking a more active role in protecting the rights of incompetent patients. In Victoria, the *Medical Treatment Act 1988* gives individuals the right to refuse unwanted treatment for existing illnesses. A refusal of treatment certificate can be signed and witnessed. However, declarations about future illnesses are not covered by this legislation.

In New South Wales, Victoria and Tasmania, individuals can appoint an enduring guardian who has the authority to give consent for medical treatment. In Queensland and South Australia, legislation allows for the appointment of medical powers of attorney that function in a similar way to enduring guardianship. In Queensland, the *Powers of Attorney Act 1998* also created an advance health directive enabling an individual to give instructions for future health care.

What is advance care planning?

Advance care planning is a legally recognised mechanism for individuals to make their wishes known about future medical treatment. It can take two forms:

- instructions given in advance by appointment of a proxy decision maker or attorney, or
- specific instructions given either verbally or in written form (a healthcare directive).

Optimal advance care planning should include both proxy and instructional components.

The idea of writing directives regarding individual wishes in advance of their enactment is not new. For example, many people use a will to dispose of financial assets after death. Advance directives concerning medical care have been used for many years, in the form of a ‘living will’.[3] The use of such documents has paralleled the increasing ability of modern medical technology to sustain life – sometimes indefinitely and without quality – with greater recognition of the rights of the individual. The use of directives to allow an individual’s wishes for health care to be known in the event of incompetence has now developed to a level where directives can be used effectively in medical practice.

Instructional directives can take a number of forms, but must have certain characteristics to fulfil their intended role. These requirements are outlined in the box on this page. One document that satisfies these criteria and is currently available in Australia is the 'Let me decide' healthcare directive (information about obtaining copies of the document is given in the box on page 24).

When can a directive be used?

Ideally, a written directive is used in conjunction with a medical power of attorney when a patient is unable to communicate his or her wishes; it is not used when the patient is still competent. Many directives may never be used because the patient is capable of deciding for him- or herself when a life threatening illness occurs. For example, if Mrs AB had a healthcare directive it would not have been necessary to use it because she was competent at the time of her final illness. However, a directive would have helped to answer the question raised earlier – namely, what would have happened if Mrs AB had not written her note?

Types of advance directives

Some directives are disease-specific; others are generic.[4] Disease-specific directives offer the advantage of covering circumstances that an individual is more likely to confront, and the choices are more realistic because the patient has experienced the disease for which the directive is written. However, generic instructional directives have far more applicability for the general public because many people will complete them while they are relatively disease free.

Legal issues

The legal force of directives is often brought into question. It is not necessary for directives to be recognised legally for doctors to be bound by them morally and ethically. Doctors should scrutinise the instructions contained in a directive as they would scrutinise a competent individual's decision about treatment. Registration of healthcare directives is probably unnecessary and could lead to undue encroachment on the doctor–patient relationship by an additional administrative or legal entity.

Advantages of advance care planning

Advance care planning has the advantage of facilitating ethical decision making, but it also:

- removes the need for doctors to make decisions for patients they do not know
- maintains the patient's autonomy despite incompetence
- removes the need for family members to agonise over treatment decisions
- has the potential to increase satisfaction with the healthcare system
- has the potential to reduce unwanted use of medical technology and therefore to reduce costs.

Dresser and Whitehouse wrote that for incompetent patients, 'the premier goal of treatment decision making is to choose as the patient would if he or she were competent and aware of his or her current circumstances'.[5] One suspects that this principle is often ignored in the healthcare system. Informal discussions about medical treatment sometimes occur among family members; however, the outcome of these discussions is not usually recorded.

A directive is a means by which families can record such discussions in a medically meaningful way. In the event

Requirements of a healthcare directive

A healthcare directive is a set of specific instructions outlining an individual's wishes regarding health care in the event that he or she is unable to communicate. The directive can take either a verbal or written form, but certain requirements should be met if it is to fulfil its intended role:

- Medical terminology must be used so that the healthcare directive can be interpreted by doctors. A typical living will states: 'If there is no reasonable prospect of my recovery from physical or mental illness and I am in severe distress and incapable of rational existence…' These phrases are open to interpretation and difficult to act on.
- The directive should be simple and concise enough to allow nonmedical people to understand and use it.
- Nomination of a proxy or medical power of attorney who will assist doctors with the interpretation of the document should ideally be allowed for.
- Provision should be made for both continuation and refusal of treatment for life threatening illnesses. Some directives contain a menu of treatments from which choices can be made.
- The directive should allow an individual to accept or reject artificial nutrition and cardiopulmonary resuscitation.
- The directive should contain a statement that the individual is mentally competent when completing the directive and is making quality of life choices and that he or she recognises the importance of the choices.
- There should be space for updating choices because choices may vary, depending on the person's current state of health.
- The directive should contain a personal statement from the individual about the state of disablement that he or she would consider to be unacceptable. It should also provide choices for different states of disablement.

of a crisis, an incompetent individual's wishes can be taken into consideration (as interpreted from the healthcare directive by a proxy) at the same time as prevailing medical opinion. A triumvirate is therefore constructed (between directive, proxy and health professional) for making decisions involving the incompetent patient.

Criticisms of advance care planning

The major criticism of directives is their hypothetical nature. How can one possibly predict one's choice under unknown circumstances in the future?

It is the essence of one's wishes that can be interpreted by a proxy decision maker and enables one's autonomy to be respected. This will improve the situation in which an individual's wishes are not known and decisions are left to family members and doctors.

The role of the GP

GPs have a crucial role in preparing and implementing advance care planning. They are in the best position to ensure that individuals understand their choices, and they are likely to be responsible for making decisions in the event of a medical crisis. GPs must be willing to follow the instructions in a directive – this is crucial if the process is to succeed.

All GPs need to know about advance care planning because patients will inevitably want to talk about it as its use grows in Australia. A GP may need to spend 30 minutes with a patient to ensure that a directive is completed satisfactorily and that the patient understands the choices being made. GPs should encourage patients, particularly those over the age of 60 years, to consider completing a directive before they become unwell or early in the natural course of a chronic illness.

Further information

For more information or copies of 'Let me decide', contact:

Newgrange Press
PO Box 7077
Shenton Park WA 6008
Fax 08 9389 6455

Cost is $11, including GST, postage and handling. Please make cheques payable to 'Let me decide'.

The original document should be carried by the individual, and copies should be kept by his or her doctor, a proxy (or proxies), a solicitor (if desired) and a healthcare facility (if appropriate). Indeed, it has been suggested that all people who complete a will should initiate advance care planning at that time. A copy of instructional directives should be included in the notes of institutionalised patients.

Concluding comments

Why should doctors encourage their patients to complete advance care planning? There is strong evidence from Canada that directives reduce acute admissions from institutions to acute care facilities, reduce bed days in hospital for the elderly, and improve consumer satisfaction with the healthcare system.[6,7] However, it is the preservation of individual autonomy that is the most compelling reason for the use of healthcare directives. John Stuart Mill wrote:

'What…is the rightful limit to the sovereignty of the individual over himself?…he is the person most interested in his own well being: the interest which any other person…can have in it is trifling compared with that which he himself has…Over himself, over his own body and mind, the individual is sovereign'.[8]

Why should mental incompetence deprive us of a role in determining our own health care? MT

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