

Choosing the future: advance directives

Treating a patient who is no longer able to make their wishes known due to illness, accident or incapacity can be difficult both for health professionals and families. What is best for the patient, and what would they want? Advance directives can help in this situation, but can also pose ethical and legal challenges for the health care team.

WE have a greater ability to lengthen life, and stave off death when it is imminent, than ever before. This power can be a boon. It can mean that people with a terminal illness have longer to farewell their family members, and arrange their affairs. It can mean valuable days, months and even years in which life can be enjoyed. But it can also mean that the process of dying is painfully prolonged or deferred, sometimes beyond a patient's wishes, or against them.

Making treatment decisions, especially regarding end-of-life care, is not always easy. In some cases, treatment may be futile or burdensome, failing to offer a reasonable hope of benefit, or enhance quality of life.

If a patient's wishes and medical case history are not known, they cannot be taken into account. This may happen in an emergency, when ambulance officers are called in to assist someone, when an incompetent patient is attended to by someone who is not their regular doctor and does not have access to their full details, when a delirious patient from an aged care facility is brought to hospital with pneumonia, and a range of other scenarios.

Even in the event of a terminal illness, or towards the end of a long life, people may be hesitant to broach the topic of end-of-life decisions and preferences, for themselves or for a family member. Patients can, however, leave instructions about who is to make health and medical decisions on their behalf if they are not able to – or what treatments they would wish to accept or refuse – through an advance directive, or 'living will'. This can ease the burden on family members, who may face great guilt when dealing with life or death decisions about their loved ones.

SA Health Minister John Hill himself has a 'living will' and told *medicSA*: "I'd urge everyone to take time to consider the type and the extent of any medical

intervention they would like if they're injured or become seriously ill. It's not an easy conversation for families, but it could be one of the most important they have."

End-of-life care and advance care planning became front page news in South Australia in May when *The Advertiser* ran a feature with the headline 'Live and let die', with comments from the Minister about end-of-life care. Although the headline was sensational, reader responses via the paper's online poll were notably positive, with respondents speaking of the importance of people "starting



the conversation" with their families. It can be a difficult topic to broach, but many people welcome the opportunity to discuss their wishes and values.

The AMA code of ethics upholds the right of patients to refuse treatment, and instructs that, while doctors have an obligation to preserve life, in situations where death is deemed to be imminent and where curative or life-prolonging treatment appears to be futile, medical practitioners should "try to ensure that death occurs with dignity and comfort."

But even when life-prolonging treatment is futile, health care workers may feel bound to take action. This may be at the behest of the patient's family, through concern about potential litigation, or

simply because it is medically possible. As Minster Hill has noted, if a patient's wishes are not known, "the machinery of health kicks in". And once treatment to sustain life has commenced, it can be hard to stop.

Advance directives can help in these situations, but they are generally poorly understood by the public and not universally understood by those working in the health sector. Matters are further complicated by the fact that legislation governing directives differs from state to state, and not all states recognize directives from other states. In South

Australia, there are currently four kinds of advance directive under three different Acts, as well as less formal documents (see box on page 12).

Although people may complete medical advance directives without medical advice or support, it can be hard for people to anticipate what future health issues they may face, what treatment options would be available to them, and what their instructions will mean in practical terms for those that treat them. Doctors have an important role to play in providing information and guiding choices, as well as raising people's awareness and understanding of advance directives.

That may be set to become an easier task. In 2007 the State Government launched a review of South Australia's advance directives, with the goal of improving and simplifying them. It involved three government departments – Health, Families and Communities and Justice – and resulted in a list of 67 recommendations, that are currently being considered by the Attorney-General. Following this, new legislation will be drafted to simplify and streamline South Australia's advance directives, taking into account national activity in this area.

Australian Health Ministers have also established a national working group to develop uniform standards for health advance directives across Australia, and the National Health and Hospitals Reform ►

Commission has recommended that advance care planning be funded and implemented nationally, commencing with all residential aged care services, and then extended to other relevant groups.

The State Government's 2007 *SA Health Care Plan* foreshadowed the development of an Informed Patient Choices Program to help "patients and their families to make the right choices about care needs at the end of life", and this program is flagged for statewide roll-out in the recently-published *Palliative Care Services Plan*.

Although details of the new program are few at this stage, it sounds similar, in principle at least, to the Respecting Patient Choices Program (RPCP), which has been trialled around Australia and, in South Australia, based at The Queen Elizabeth Hospital (TQEH). The Government has indicated that the RPCP will "be considered" in the final design of the Informed Patient Choices Program.

The Respecting Patient Choices Program has educated over 400 clinicians in South Australia, and introduced systems to TQEH, aged care facilities and general practices to help patients establish advance directives and communicate their wishes regarding end-of-life care, lowering inappropriate admissions to emergency departments, and providing support to families and peace of mind for patients.

Dr Roger Hunt, clinical leader of RPCP in South Australia, says: "This is an evidence-based program with proven cost-effectiveness that works well within our legal framework. A systematic roll-out across the health system could be achieved with modest investment. This would result in better tailoring of care to patients' satisfaction, and curb the inappropriate use of expensive treatments at the end of life."

For doctors and other health professionals, advance directives can pose challenges. On the one hand, doctors welcome the support an advance directive can provide to the health care team and family members in making difficult decisions that are in keeping with a patient's wishes. On the other, they fear being hemmed in by a prescriptive legal directive that may appear at odds with good medical practice, be difficult to interpret, or not account for a scenario that the patient did not envisage, but that could have made their decision different. Some of

these issues, as well as the benefits, are explored in the AMA's position statement on advance care planning (2006).

AMA(SA) president Dr Andrew Lavender emphasises that advance directives need to be simple to understand and clear in their intention. While he sees a need for them to outline possible courses of action in a variety of circumstances, he stresses that there has to be recognition that, in some circumstances, health care workers must be able to intervene where a potentially reversible and unforeseen event has occurred.

"Circumstances are not always 'black and white' ... The problem with trying to establish advance directives is that they must be regarded as a person's true intent, and all involved should respect that intent, but they can not reasonably be expected to countenance all circumstances, and there must be the possibility of flexibility in interpretation for the health workers and family, and for the patient themselves."

In its submission to the Advance Directives Review, the AMA(SA) made a number of practical recommendations on advance directives, including the design of forms, witnessing requirements, the establishment of a central, easily accessible registry for advance directive documents, the need for legislative safeguards to protect doctors who follow a directive (or fail to follow a directive, on sound clinical grounds), and better education about advance directives.

Patient autonomy is one of the key principles of medicine, and advance care planning and advance directives can provide an important way to ensure a patient's wishes are respected, even when they are unable to express them. While there are significant challenges – clinical, legal and ethical – in crafting the right instruments to preserve these wishes clearly, meaningfully and helpfully, if these challenges are successfully met, our health system will be the better for it.

Eva O'Driscoll

For more information about advance directives in South Australia, you can contact the Office of the Public Advocate or visit the SA Health website. For information on AMA views and advocacy, visit www.ama.com.au.

What's what?

Advance Care Planning – a facilitated process of future health care planning that can be supplemented by legislated advance directives and may include less formal documents or expressions of a patient's wishes.

Advance Directives – South Australia uses advance directives as a collective term that includes both surrogate and instructional legal documents. There are four kinds (detailed below).

Medical Power of Attorney – a surrogate advance directive which allows the appointment of a Medical Agent to consent to or refuse medical treatment (*Consent to Medical Treatment and Palliative Care Act 1995*).

Enduring Power of Guardianship – a surrogate advance directive which allows the appointment of an Enduring Guardian to make decisions about not only medical treatment and health care generally, but also lifestyle matters – such as residential, employment and holiday arrangements (*Guardianship and Administration Act 1993*).

Enduring Power of Attorney – a surrogate advance directive which allows the appointment of an Attorney to make financial decisions (*Powers of Attorney and Agency Act 1984*).

Anticipatory Direction – an instructional advance directive, and South Australia's 'living will'. It is limited to the end of life and records the level and type of medical treatment a person wants (or does not want) to receive if they are ever in the terminal stage of a terminal illness or a persistent vegetative state and unable to communicate their consent or refusal (*Consent to Medical Treatment and Palliative Care Act 1995*).

A Statement of Choices and a *Good Palliative Care Plan* – are both less formal instructional documents used to record patients' personal values and preferences, and can be used by patients who do not have the capacity to complete an advance directive.

Source: *South Australian Advance Directives Review Background Paper* (2007)