Consent: End-of-Life Care

Decisions to withhold or withdraw life-sustaining treatment are ethically, professionally and legally complex, especially when the patient has lost decision-making capacity. This article discusses some of the legal principles associated with the provision of end-of-life care and outlines the consent process which underpins these decisions.

Legal principles

Doctors are not under a legal duty to provide "futile" care, even if this is requested by the patient and/or their family. In end-of-life care, medically futile treatment can be considered to be treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient.[1] That is, where the treatment is of no medical benefit to the patient, or the burdens of the therapy are out of all proportion to any potential benefits.

Futile treatment may include life-sustaining treatment. The determination of futility must be appropriately made and, ideally, there should be consensus with the patient and/or their substitute decision-maker with respect to the assessment of futility. A patient, their family or substitute decision-maker can challenge a decision not to provide futile treatment in the courts.

It is a crime to deliberately take another person's life or to assist another person to commit suicide. A doctor should never provide treatment with the intention to end a patient's life, or to assist the patient in doing so. However, a doctor can administer medication to a patient with the sole intention of relieving pain and suffering ("good effect"), even though this may hasten their death ("bad effect").

This is commonly referred to as the "doctrine of double effect" and is an exception to the general rule that taking active steps to end a person's life is unlawful. In this situation, administering medication to the patient should not achieve pain relief by hastening their death, and the need to relieve the pain and suffering must be such that it outweighs the consequences of hastening death.

Adult patients who *have* capacity to make their own treatment decisions

By law, all patients who are 18 years or over are assumed to have capacity to make decisions, but that presumption can be rebutted where the need and evidence arises. Generally, a person with capacity will be able to:

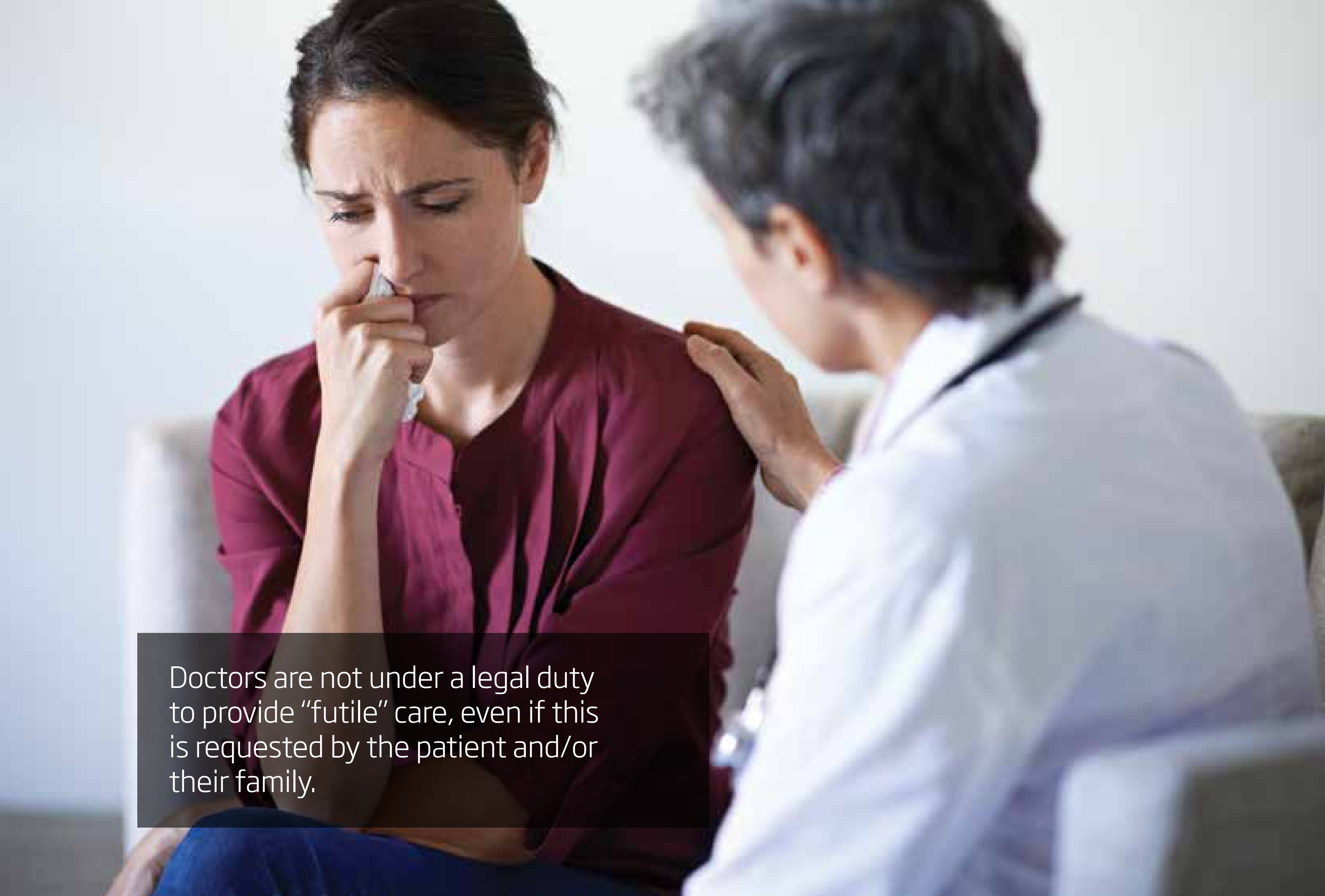
- understand the facts of the situation
- understand the main choices available
- weigh up those choices, including benefits and risks
- make and communicate their decision
- understand the ramifications of the decision.[2]

An adult patient who has capacity can refuse any medical treatment, even if this refusal will result in their death.[3]

Advance care directive (ACD)

Life-sustaining medical treatment can also be refused through an ACD. An ACD is generally a written document, intended to apply to future periods of impaired decision-making capacity, which provides a legal means for an adult to record preferences for future health and personal care and/or to appoint and instruct a substitute decision-maker.[4] ACDs are not clinical care or treatment plans, but clinical care and treatment plans can and should be informed by ACDs.

The common law recognises, as part of the right to self-determination, that an individual can complete an ACD that will bind a health practitioner who is treating that person, even if the directive refuses life-sustaining treatment. A 2009 NSW Supreme Court judgment confirmed that if an ACD is made by a competent adult, is clear and unambiguous, and extends to the situation at hand, it must be respected.[5]



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Legislation governing ACDs has also been enacted in every state and territory, except NSW and Tasmania, although the legislation varies from state to state and is subject to change.[6,7] In some states, the legislation places limits on the application of an ACD – for example, in some states the ACD may only operate if the patient is suffering from a terminal illness or has no reasonable prospect of regaining capacity.

Adult patients who *lack* capacity to make their own treatment decisions

As outlined above, where a patient lacks capacity to make their own decisions, priority must be given to a valid ACD, if it exists. In the absence of an ACD, consent should be obtained from a substitute decision-maker.

Every state and territory has guardianship legislation which regulates, to varying degrees, medical treatment decisions for adult patients who lack decision-making capacity. The legislation outlines a hierarchy of decision-makers. This may include an enduring guardian who was appointed by the patient when they still had capacity; or a spouse, other family member or unpaid carer. These substitute decision-makers must act in accordance with the patient's wishes (if known) or in the patient's best interests. Where there is no available substitute decision-maker, an application can be made to the relevant Guardianship Tribunal for the appointment of a guardian.

Decisions to withhold or withdraw life-sustaining medical treatment are complex and serious, especially in view of the gravity of the outcome. In some states and territories, the legal authority of a substitute decision-maker to decide to withhold or withdraw a patient's life-sustaining medical treatment is not clear. There are also differences in the definitions of life-sustaining treatment or measures. This is a complex area of the law and you should contact MDA National for advice in a particular case if you are uncertain how to proceed.

Further Reading

End of Life Law in Australia.
Available at: **end-of-life.qut.edu.au**

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For a full list of references visit **defenceupdate.mdanational.com.au/articles/consent-end-of-life**.