

Who Can Make Decisions About Your Health?

In Western Australia, the law allows you to write an Advance Health Directive to say what treatments you want or don't want in specific circumstances. Or you can appoint someone to make medical treatment, personal or lifestyle decisions on your behalf, when you are unable to make or communicate your decision.

This information has been translated into 7 languages and presented to you in a Question and Answer format, as originated from a radio interview. We also included a flyer produced by the Department of Health and the Office of the Public Advocate.

We hope that you will find this information useful in making decisions relating to your own personal circumstances, that of family members or members of your community.

1. What is an Advance Health Directive?

An Advance Health Directive is a legal document in which a person may indicate whether they would consent or refuse particular treatments in particular circumstances.

For example, let's say that I'm a patient who has been diagnosed with cancer. My disease has reached a stage where I know and my doctors know that I am incurable. The medical treatments which I am receiving are simply to keep me comfortable. I may wish to write in an Advance Health Directive that if the situation arose wherein I developed a condition e.g. pneumonia which could end my life, I will refuse treatments which can treat the pneumonia but will wish to accept treatments such as oxygen, nutrition and pain killers to keep me comfortable.

Another example, many people have a fear of an accident or other trauma which may leave them in a coma, sometimes called a persistent vegetative state. They worry that they may be kept alive indefinitely in an intensive care unit, being supported by drugs and ventilatory support and other treatments. In that case, they may wish to say that they will accept these treatments for a finite length of time until it is clear that they will not make any significant recovery. For example, they may indicate that if after 3 months of this treatment if it is clear that they will not recover from the coma, then they wish the treatments to be withdrawn.

Some people will be familiar with the term "living wills". An Advance Health Directive is a similar document, which people can use to indicate what treatments they consent or refuse to receive in particular situations. The important thing to remember is that the Advance Health Directive only comes into effect if and when the patient is unable to make or communicate decisions for themselves. It is also important to remember that you can change your mind about an Advance Health Directive – you can either update it or revoke it.

2. What is an Enduring Power of Guardianship?

The Enduring Power of Guardianship enables a person to appoint someone or several people whom they trust and who knows them well to make decisions about their medical, lifestyle

and other personal matters on their behalf if and when they are unable to make or communicate those decisions for themselves.

This is particularly useful because it is not always possible in either an Advance Health Directive or a living will to anticipate every scenario that may happen to you. Therefore, having someone who can speak on your behalf is another way of ensuring that what you want to happen to you when you are unable to communicate actually happens.

It may also be a useful way of respecting different cultures. For example, in many cultures, you don't talk to the patient, but instead to a tribal elder. In other cultures, the most senior uncle or oldest son may be the one who has the responsibility for making important decisions.

Different groups can decide to use the Enduring Power of Guardianship to acknowledge these culture norms. Or a patient may wish that they don't want this to happen.

For example, I may be an elderly woman and I may be ashamed to have my son making decisions about matters which are intimate to me. Maybe, I prefer my daughter to make those decisions and I choose to appoint my daughter instead of my son.

The important thing to remember is that the Enduring Guardian can only make decisions on your behalf if they know what you want.

Finally, a person can have both an Advance Health Directive and an Enduring Guardian, or just an Advanced Health Directive or just an Enduring Guardian.

3. How long has the Advance Health Directive been available in WA?

The laws which introduced both the Advance Health Directive and Enduring Power of Guardianship came into effect on the 15 February 2010.

This means that there are now both common laws as well as statutory laws which support a person's right to make decisions about their medical treatments. And importantly, the law expects that the people looking after a patient with either an Advance Health Directive or Enduring Guardian honour the patient's requests as outlined in either of these instruments. This applies to doctors, other health care professionals as well as the staff in a nursing home or other care facility.

4. What acts of parliament needed to be amended to accommodate this new piece of legislation? Why?

All together, there were three pieces of legislation which were changed: the Criminal Code; the Civil Liabilities Act; and the Guardianship and Administration Act.

Before the 15 February 2010, there was common law which supported a person's right to make their own decisions around healthcare. Although this law existed, there was still confusion around the legal standing of living wills and in particular, where doctors and other healthcare professionals would sit in respecting a living will.

In the example of the person with incurable cancer – they may have made a living will when they were in the terminal stages of their disease saying that they didn't want to receive antibiotics for their pneumonia. Without the antibiotics, they may die. The legislation such as the Criminal Code had in it the expectation that doctors have a duty of care to their patients i.e. if they could preserve life, not to do so would be a failure of their duty of care. So while doctors may agree with the patient, they were frequently uncomfortable with this aspect of the Criminal Code.

The Criminal Code has now been changed so that it now states that if a person does not provide a treatment and they do so in good faith, they are not criminally responsible if this is found to be reasonable.

The other important change which occurred was in the Guardianship and Administration Act. In addition to now allowing a person to appoint an Enduring Guardian, the Guardian may refuse consent to treatments on the person's behalf. So if they know that the person has refused a particular treatment, they may refuse it being commenced and even ask that it is withdrawn (on that person's behalf).

5. Are Doctors obligated to respect the directive if there is one in place?

Doctors and other health professionals are obliged to respect the directive, be it an Advance Health Directive or one given by an Enduring Guardian on behalf of the patient. It is important to remember that it is not only doctors who are bound by this legislation. The law applies to all health professionals that are caring for a patient.

For example, a person who is at a terminal stage of their illness and who lives in a care facility e.g. a nursing home with which they are familiar, can decide that they don't want to die in a hospital. Instead, they may just wish to be kept comfortable in their current nursing home. If they indicate this in their Directive, the care facility is bound to respect it.

6. How will they know that someone has written an advance health directive?

Healthcare professionals cannot honour something that they do not know exists. It is the responsibility of the patient to make sure that everyone who may be involved in their care is aware that they have written an Advance Health Directive or appointed an Enduring Guardian or both.

We suggest that they give copies to their general practitioners, other doctors looking after them, the hostel or nursing home if they are in one, their family members and so on. They may wish to carry a card in their wallet to indicate that they have an Advance Health Directive and where to find it. If they have an Enduring Guardian, they may wish to have this information and the contact details of the guardian in their wallet. They may also wish to have a MedicAlert bracelet to indicate this.

Likewise, if a person revokes their Advance Health Directive or updates it, it is the person's responsibility to let everyone who needs to know, know this.

7. Will these directives be available in a language other than English?

I acknowledge that it is very difficult to write an Advance Health Directive in any language but, I would suggest that if you want the healthcare professional to respect your wishes, you have to make it easy for them to do so. And, at present, that means that your directions need to be clear and therefore in English.

Imagine the situation where you were in an emergency situation and your Advance Health Directive is written in a language other than English. It is not possible to respect an Advance Health Directive if one doesn't know whether the Directive gives orders for a particular emergency situation and if so, what those orders may be. Although in an ideal world, a translation could be obtained quickly, we need to anticipate that this may not happen.

Sometimes, you have to make it easy for people to do what you wish them to do. That means making the Advance Health Directive easy to understand. The Office of the Public Advocate provides advice as to what a patient may do in this situation e.g. get the Advance Health Directive translated in advance.

8. Should everyone make an advance health directive?

By doing an Advance Health Directive or appointing an Enduring Guardian, you will hopefully be having conversations with your doctors and therefore have a better understanding of what is happening to you. Also, this will allow your carers to have a better idea of what medical treatment you want and what is unacceptable to you.

If you appoint an Enduring Guardian, hopefully you will be having many discussions with them, not only about what treatments you will or will not have, but also about what is important to you, what you think is a reasonable quality of life and so on. Rather than encouraging everyone to make a directive, I would be encouraging people to talk about these issues, which are often very difficult to start.

9. Can people review their Advance Health Directives? And if yes, how often should they do so?

Certainly, we would encourage people to review their Advance Health Directive whenever their condition or situation changes or every 2-5 years. Just remember, that if you do update your Advance Health Directive, you must let everyone who is involved in your care know about the changes.

10. How do people access these documents?

People can access these documents several ways. They can go to the department of health website for information on Advance Health Directives. The address is: www.health.wa.gov.au/advancehealthdirective/. They can also call us on 9222 2300.

For information about Enduring Power of Guardianship, they can contact the Office of the Public Advocate on 1300 858 455. Information is also available on the website of the Office of the Public Advocate which is <http://www.publicadvocate.wa.gov.au/>.

Many hostels and nursing homes also have information and likewise, many GP practices have requested this information so patients and their families can also try these.

Also both the Department of Health and the Office of the Public Advocate have additional materials for patients and their families which can provide more information or give ideas of things to consider or the conversations to have with their families.

Furthermore, if you need any assistance or information, please call EDAC on (08) 93887455. If you need an interpreter to contact these agencies, please call 131450.