

# Information for clinicians working with young people under 18 years of age

## Contents

<b>What is the difference between advance care planning and an advance care directive</b> .....	<b>2</b>
<b>How do advance care directives work?</b> .....	<b>2</b>
<b>Advance care planning and advance care directives in the paediatric setting</b> .....	<b>2</b>
When and how to help a young person make an advance care directive .....	3
Amending or revoking an advance care directive .....	3
Assessing capacity and witnessing an advance care directive made by a young person under 18 years of age .....	4
Decision-making for a young person.....	5
Locating and acting on an advance care directive .....	6
<b>Conflict</b> .....	<b>7</b>
What to do if the young person’s medical treatment decision maker (person with parental responsibility for the young person) is challenging an advance care directive .....	7
What to do if you feel a directive should be challenged .....	7

New legislation (the *Medical Treatment Planning and Decisions Act 2016*) will take effect from 12 March 2018. The Act is focused on upholding people’s preferences and values.

The Act will make it possible for young people under the age of 18 years (who are formally assessed as having decision-making capacity) to make a written advance care directive.

Just like adults, a person under 18 years of age (young person) who is assessed as having decision-making capacity will be able to make an advance care directive. There are special witnessing requirements for young people. One of the witnesses to an advance care directive for a young person under 18

years must be a child and adolescent psychiatrist or a clinical psychologist or clinical neuropsychologist working in a paediatric setting, who has assessed the young person as having capacity to make an advance directive.

An advance care directive only comes into effect if the young person loses the decision-making capacity that they previously had.

An advance directive may include a values directive and/or an instructional directive. An instructional directive is a legally binding statement in which a patient can consent to, or refuse, future medical treatment. A doctor is legally obliged not to administer a treatment which has been refused in a valid instructional directive. However, an advance

care directive which states a desire for particular forms of treatment cannot legally compel a doctor to provide a futile or non-beneficial treatment.

The young person's parent or guardian or doctor cannot override an instructional directive, but in certain circumstances the Victorian Civil and Administrative Tribunal (VCAT) or the Supreme Court can.

Unlike an adult patient, a young person who is assessed as having decision-making capacity cannot appoint a medical treatment decision maker. **If the young person does not have or loses decision-making capacity, the default decision maker is the person with parental responsibility for the young person, usually their parent or guardian.**

## What is the difference between advance care planning and an advance care directive

Advance care planning is a process of discussions between a person, their family or carer and health care providers about preferences for treatments and goals in the context of their current and anticipated future health. This may or may not result in documented decisions, for example a Not for Resuscitation form or Goals of Care document. These forms are not recognised in any legislation but they remain an important communication tool.

An advance care directive is a document that outlines a person's preferences, values and any specific decisions they have made in relation to their future medical treatments. This may arise out of a process of advance care planning. An advance care directive will inform medical treatment at a time when the person no longer has the decision-making capacity to make decisions for themselves. From 12 March 2018, the *Medical Treatment Planning and Decisions Act 2016* will give

legislative recognition to advance care directives.

## How do advance care directives work?

An advance care directive will only take effect at a time when the person no longer has decision-making capacity in relation to a medical treatment decision. Until this time, the person will continue to make their own medical treatment decisions. There are two forms of statement a person may include in their advance care directive – an instructional directive and a values directive.

- In an **instructional directive** a person may either consent to or refuse a particular medical treatment. If the person subsequently does not have capacity to make a decision about that treatment, the instructional directive will apply as though the person has consented to or refused the treatment.
- In a **values directive** a person may make more general statements about their preferences and values and what matters to them. The medical treatment decision maker must consider this and make decisions that they believe the person would have made if they could.

## Advance care planning and advance care directives in the paediatric setting

Advance care planning will continue to be the most common way of planning and documenting decisions for young people under the age of 18 years. Doctors, parents and young people consider together the treatment decisions that need to be made and if made, these decisions are documented. Although the resulting documents are not legally binding, they remain important communication tools and like any part of the clinical record,

are taken into account in the event of any legal proceedings. A framework and discussion guide for clinicians has been specially designed to help with this process in the paediatric setting (Thinking Ahead – planning care for children with life-limiting conditions).

The new legislation allows young people to make an advance care directive if they are formally assessed by a prescribed specialist as having decision-making capacity for the medical treatment decisions and statements they would like to make in their advance care directive. Parents, guardians and health professionals cannot overrule a valid advance care directive, but Victorian Civil and Administrative Tribunal (VCAT) or the Supreme Court can do so in certain circumstances.

### **When and how to help a young person make an advance care directive**

Discussing an advance care directive may be helpful in the following circumstances:

- The young person has a life-threatening or life-limiting condition;
- You believe the young person may have the capacity to make significant treatment decisions;
- You believe they may have important views about those decisions that should be documented; and
- They are at risk of losing the capacity to make decisions for themselves.

The first step is to ask the young person whether:

- they would like have their preferences, values and/or decisions documented; or
- they would prefer their parent or guardian or other person with parental responsibility to make decisions for them, if they lose the capacity to do so.

Young people who wish to make an advance care directive should initially have their capacity to do so formally assessed (see 'Assessing capacity and witnessing an advance care directive made by a young person under 18 years of age' on page 4). Those that have capacity can then be assisted through the decision-making process. The treating paediatrician and the clinician assessing capacity (if different) should work closely together on this task.

Written instructions (Instructions for completing the advance directive form) and a dedicated advance care directive form (Advance care directive for young people under 18 years of age) are available on the [Advance care planning forms page on the Health.vic website](https://www2.health.vic.gov.au/acp-forms) <<https://www2.health.vic.gov.au/acp-forms>>.

### **Records**

Once created, the advance care directive should be uploaded to My Health Record, placed in the clinical record(s), and with the patient's permission given to the medical treatment decision maker, the ambulance service and any other health care provider or facility who should be aware of the document.

Care needs to be taken to ensure accurate records of the distribution of the advance care directive are retained. This will ensure that any variation or revocation of the document is communicated to all persons or entities who received a copy of the original document.

### **Amending or revoking an advance care directive**

A young person may amend or revoke their advance care directive while they have decision-making capacity to do so. This must also be witnessed (see 'Witnessing an advance care directive made by a person under 18 years of age') and amendments must be made on the face of the original document. The revocation document must

be distributed to all persons or entities who received a copy of the original advance care directive.

### Assessing capacity and witnessing an advance care directive made by a young person under 18 years of age

**A young person can only make an advance care directive if a specialist determines they have the decision-making capacity to do so.** This is a critical decision in relation to young people.

The new legislation specifies that the person making an advance care directive must demonstrate the capacity to understand their situation and the implications of any decisions they make. Decision-making capacity is assessed depending on the specific decision to be made. This means that while a person may have the capacity to make a relatively simple decision, they do not necessarily have the capacity to make decisions that are more complex. In assessing capacity to make an advance care directive, regard needs to be given to the nature of the decision being made and the finality of that decision.

The capacity of a young person to complete an advance care directive **can only be assessed** by one of the following health professionals:

1. A Fellow of the Royal Australian and New Zealand College of Psychiatrists who:
  - (a) holds a Certificate of Advanced Training in Child and Adolescent Psychiatry awarded by the Royal Australian and New Zealand College of Psychiatrists; and/or
  - (b) is a current accredited member of the Faculty of Child and Adolescent Psychiatry of the Royal Australian and New Zealand College of Psychiatrists.
2. A registered psychologist who has:
  - (a) a current endorsement by the Psychology Board of Australia as a clinical psychologist or clinical neuropsychologist; and
  - (b) current employment as a psychologist in a health or related service providing specialist paediatric care.

Two individuals must witness the advance care directive and in the case of a young person, at least one must be a child and adolescent psychiatrist or a clinical psychologist or clinical neuropsychologist as described above. In witnessing the advance care directive they certify that the young person has the necessary capacity. The witnesses must sign the advance care directive in the presence of each other and the young person. **It is highly recommended that the young person's main treating doctor be involved in witnessing the advance care directive to ensure the relevant medical treatment options are discussed and that the young person fully understands these options.**

#### Support person

The legislation introduces a new concept of 'support person' as distinct from the medical treatment decision maker. While a young person under the age of 18 (assessed as having capacity) cannot appoint a medical treatment decision maker, they can appoint a support person who may also be under 18 years of age. The role of a support person is to help the young person make their own decisions and to help them ensure these decisions are enacted. The support person's role will vary depending on the assistance the young person needs.

Once formally appointed, a support person will be authorised to access medical records in order to assist with decision making. This means the support person may help a person make their own decision by collating relevant information from a range of sources or by helping to present the information in a way the person can understand. This may, for example, include collecting information from a range of specialists the person is engaged with and collating it in a single document for the person to read. Once the person makes a decision, the support person may also assist in ensuring the decision is enacted. This may include, for example, helping the person explain why they have made their decision and informing all the relevant health practitioners of the decision.

### **Decision-making for a young person**

#### **Young person was never assessed as having capacity**

In this situation, the person with parental responsibility is the medical treatment decision maker, if reasonably available, willing, and able to make the decision. Medical treatment decision makers (i.e. the parent or guardian) should consider:

- any relevant preferences that the young person has expressed and the circumstances in which the preferences were expressed; and
- the young person's values, whether these are expressed or inferred from their life.

If there are not relevant preferences and values, the medical treatment decision maker must make a decision that will promote the young person's personal and social wellbeing, having regard to the person's individuality.

#### **When does a young person's advance care directive come into effect?**

An advance care directive only comes into effect when the young person who made the directive **loses the decision-making capacity which they previously had. It does not come into effect at the time when the advance care directive is made.**

- If the young person had made an instructional directive, this must be followed provided that:
  - it is valid (appropriately completed and witnessed); and
  - the doctor has no reason to believe that the circumstances have changed to the extent that the advance care directive should be legally challenged (see 'What to do if you feel a directive should be challenged')
- If the young person had made a values directive, this must be considered and the young person's medical treatment decision maker (person with parental responsibility) is required to make the decision they reasonably believe the young person would have made if they still had decision-making capacity.
- If there is neither an instructional directive nor a values directive, the medical treatment decision maker must make a decision that will promote the young person's personal and social wellbeing, having regard to the person's individuality.



## Locating and acting on an advance care directive

If a young person under 18 years of age is acutely unwell and has lost decision-making capacity, reasonable efforts should be made to determine if they have made an advance care directive and to view that document. In general, a young person's decision-making capacity grows as they age, so the extent of enquiries required will change over time. Without any specific knowledge to the contrary about the young person's individual maturity and interest in their health care, the following may be a useful guide:

- for a young person under 12 years, it would generally be reasonable not to make any enquiries about the existence of an advance care directive
- for young people between 12 and up until they turn 14 years of age, the young person's parent or guardian may be asked whether or not an advance care directive exists.
- A young person who is 14 years or older could well have capacity to make some decisions about their health care. Accordingly, from this age, efforts to find an advance care directive where appropriate should include:
  - asking the young person's parent or guardian or other person with parental responsibility for the young person whether an advance care directive has been made;
  - checking the clinical record;
  - contacting the person's main treating doctor;
  - contacting the person's general practitioner or primary health clinic;
  - checking My Health Record.

## Emergencies

In an emergency, a health practitioner may administer medical treatment to a person who does not have decision-making capacity without consent from the medical treatment decision maker or without the authority of an advance directive, if the treatment is necessary, as a matter of urgency to:

- save a person's life;
- prevent serious damage to the person's health; or
- prevent the person from suffering or continuing to suffer significant pain or distress.

This recognises that there are situations where it would not be possible to obtain consent or authority in time and that the preference in these circumstances is to proceed with treatment. In these circumstances the medical practitioner is only required to use an advance care directive that is 'readily available'. This means 'readily available' in the circumstances. A medical practitioner acting in good faith and without negligence will determine what that means in the particular circumstances, but note that the medical practitioner is not required to 'search' for the advance care directive in emergency circumstances.

The Act also recognises that an emergency does not justify overriding a person's known preferences and values. If a person has validly refused treatment, a health practitioner must respect this refusal.

If a young person under 18 years of age is too unwell to participate in decision-making and has made a valid 'instructional directive', this must be respected. In this situation, a health practitioner must follow a valid and relevant instructional directive, and this takes precedence over the medical treatment decision maker (a person with parental responsibility).

## Conflict

Conflict may occur in the stressful and upsetting circumstances in which medical treatment decisions often need to be made. No laws will ever fix this. The *Medical Treatment Planning and Decisions Act 2016* seeks to make clear legal obligations so it is at least clear who has authority to make decisions.

The Act recognises that if a person has validly made an instructional directive and this is relevant to the current circumstances, it should be respected even if family members disagree with the directive. Many people may make an 'instructional directive', because they recognise that their family will not implement their preferences and values. If a person under the age of 18 had decision-making capacity and made an advance care directive, their parents cannot override this simply because they disagree with the decision that has been made. For example, a 17 year old may make an 'instructional directive' consenting to a blood transfusion, because they know their parents would refuse it based on their own beliefs. In these circumstances a parent cannot impose their own values on their child.

### **What to do if the young person's medical treatment decision maker (person with parental responsibility for the young person) is challenging an advance care directive**

A young person's medical treatment decision maker does not have authority to automatically override a valid advance care directive or to instruct a health practitioner to do so. It is important to listen to the medical

treatment decision maker for a young person and to allow them to express their fear and distress about the young person's medical circumstances. This does not always resolve the conflict between their wishes and the young person's advance care directive, but it can assist in supporting them to respect the young person's preferences. In some cases, urgent medico-legal advice may be required.

### **What to do if you feel a directive should be challenged**

#### **1. VCAT**

Health practitioners and a young person's medical treatment decision maker cannot override an advance care directive simply because they disagree with the directive. An application can be made to VCAT if the health practitioner (or other eligible applicant) forms the view that:

- the advance care directive is not valid (for example decision-making capacity was not properly assessed); or
- circumstances have changed to the extent that the practical effect of the instructional directive would no longer be consistent with the young person's preferences and values.

If a health practitioner believes circumstances have changed to the extent that the practical effect of the instructional directive would no longer be consistent with the young person's preferences and values and the delay caused by an application to VCAT would result in a significant deterioration in the person's condition, they may refuse to comply with an advance care directive.

Advice should be sought from the health service's medico-legal advisor.

## 2. Supreme Court of Victoria

The Supreme Court's *parens patriae* jurisdiction is not affected by the Medical Treatment Planning and Decision Making Act. The Supreme Court may, therefore, make orders to uphold the 'best interests' of a person under the age of 18. This means the Supreme Court may override an advance care directive to protect the best interests of a person under the age of 18.

If a health practitioner believes on reasonable grounds that circumstances have changed and the advance care directive is no longer consistent with the young person's preferences or values, or is otherwise invalid, he or she should apply to VCAT or the Supreme Court for appropriate ruling. However, if the delay that would be caused by an application to clarify matters before proceeding would result in a significant deterioration in the young person's health, and the medical practitioner acts in good faith and without negligence, the medical practitioner may determine to treat or not treat the young person in accordance with this reasonable belief.

If a document clearly does not comply with formal requirements, it does not take effect as an advance care directive, but can be taken to be a statement of the person's preferences and values. As a consequence, the medical treatment decision maker needs to take it into account in determining what decision the young person would have made had they had capacity at the time of treatment.

To receive this publication in an accessible format phone [email Advance Care Planning](mailto:acp@dhhs.vic.gov.au) <acp@dhhs.vic.gov.au>

Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne.

© State of Victoria, Department of Health and Human Services June 2018.

ISBN 978-1-76069-317-6 (pdf/online)

Available at [Advance care planning forms page on the Health.vic website](https://www2.health.vic.gov.au/acp-forms) <<https://www2.health.vic.gov.au/acp-forms>>