Instructions for completing the 'Advance care directive for young people under 18 years of age' form

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These instructions accompany the 'Advance care directive for young people under 18 years of age' form.

Use these instructions to complete the parts of the 'Advance care directive for young people 18 years of age' form that are relevant to you. **Cross out any sections that are not relevant.**

In your 'Advance care directive', you can include:

- a values directive
- an instructional directive.

These documents will help your parent/guardian and the health practitioners caring for you to make the best decisions they can, **when you are not able to do this for yourself**. A **values directive** is a statement of your values and preferences for your medical treatment. If you become too unwell in the future to express your own views, your parent/guardian will use your values directive to guide them when they make decisions for you.

An **instructional directive** is a binding statement in which you consent to, or refuse, future medical treatment.

If you become too unwell in the future to make and express your own decisions, your instructional directive tells your doctors what treatments you agree to or refuse. Your doctors will have to follow the decisions expressed in your instructional directive (except in very limited circumstances).



Part 1: Personal details

Your personal details

To make a valid 'Advance care directive', you must include your full name, date of birth and address. A phone number is optional.

Your current major health problems

This information helps your parent/guardian and your health practitioner(s) understand about your health at the time when you wrote this directive. List your current major health problems. If your health problems change, your parent/guardian and health practitioner will be able to find up-to-date information about this on your patient record.

Advance Statements under the *Mental Health Act 2014*

If you have a mental illness (or have had one in the past) you may have completed an Advance Statement under the Mental Health Act. In your 'Advance care directive', you can also document your preferences for your treatment for mental illness. Find a fact sheet that explains the differences between Advance Statements and 'Advance care directives' on the <u>Office</u> of the Public Advocate (OPA) website <http://www.publicadvocate.vic.gov.au>.

Mark with an X if the statement on the form is relevant to you.

Part 2: Values directive

Completing a values directive is one way to communicate to your parent/guardian and health practitioner about your values and preferences for your medical treatment.

Your parent/guardian must make the decision that they reasonably believe is the one you would have made. Your values directive will help them to do this. Your parent/guardian can rely on what you write in your values directive because:

- you sign your values directive in front of witnesses who certify that you have decision-making capacity to make a values directive and are making it voluntarily
- your witnesses need to check that you understand the nature and effect of what you have written
- one of your witnesses must be the psychiatrist or psychologist who has assessed your capacity to make medical decisions.
- The other witness should be your main treating doctor who can explain the treatments you need to think about and what the likely effects (positive and negative) of those treatments are.

Ways to complete your values directive

There are many ways you can approach your values directive. Keep in mind that you are communicating to your parent/guardian. Your values directive should help them to make the decision(s) you would want.

Before you start on this part of the form, spend some time thinking about your values, preferences, beliefs and any worries you may have about your current and future health. Talk about these things with people you trust.

The prompts in the form are to help you get started. You can complete all or some of the sections in Part 2.

a) What matters most in your life

What matters most in life varies from person to person. Things that make your life worth living may include family, friends, religious or cultural beliefs, spirituality, interests, or maintaining independence. What matters most to you can affect the decisions you would make about medical treatment. This is the opportunity to let your parent/guardian know what quality of life means to you.

For example:

- Do you want to live as long as possible, whatever it takes? Or is quality of life more important to you?
- If remaining independent is important to you, try to give examples of what you mean by this. For some people remaining independent means living in their own home. Other people may be more concerned with being able to take care of their personal grooming, remaining mobile, participating in specific activities, maintaining connections with family and friends, or being able to make decisions for themselves.

 Do you have religious or spiritual beliefs that affect the type of medical treatment you would consent to?

b) What worries you most about your future

For example, you may worry about being in pain, not being able to take care of yourself, being unable to participate in specific activities or live at home.

c) Unacceptable outcomes

It will help your parent/guardian if they understand how you feel about experiencing a range of possible outcomes.

To help you get started, consider the outcomes in the table below and think about how you would feel in these situations.

Situation	Life like this would be: Difficult but acceptable	Life like this would be: Worth living but just barely	Life like this would be: Not worth living	Cannot answer now
I can no longer recognise family/friends.				
I can no longer talk or be understood by others.				
I permanently rely on a breathing machine to keep me alive.				
I can no longer move myself around, in or out of bed, and rely on other people to shift or move me.				
I can no longer feed, wash or dress myself.				
I no longer have control of my bladder and bowels.				

See the My Values website

<https://www.myvalues.org.au> for more information, and the option of completing a questionnaire that may help you to clarify your thoughts on important issues that underpin decisions about future treatment. Other resources are available at the <u>Advance</u> care plans page on the Better Health Channel website <https://www.betterhealth.vic.gov.au/ havetheconversation>.

In Part 2 of the form, at c) write what are unacceptable outcomes for you.

d) Other things you would like known

There may be other things that will help your parent/guardian to understand your values and preferences. These could be your spiritual, religious, or cultural requirements, or your preferred place of care, for example home, hospice or hospital.

You may have specific preferences that you want your parent/guardian to know. Among other things, you can include information about your preferences that relate to:

- treatment with prescription pharmaceuticals (medicine)
- treatment for mental illness
- dental treatment
- medical research procedures.

For example, because of side-effects you have experienced in the past, you may have preferences in relation to particular prescription pharmaceuticals (medicine).

e) Other people I would like involved in discussions about my care

Consider if there are other people you would like your parent/guardian and health practitioner(s) to involve in discussions about your care.

f) If I am nearing death

Consider if there are things you would want known if you are nearing death. These may include who you would like present, any music or photos or spiritual care requirements, or your customs and cultural beliefs.

Part 3: Instructional directive

You should **only** complete an instructional directive if you know the medical treatment that you want or do not want in the future, as this is a legally binding statement.

Keep in mind, if you complete an instructional directive **you** are making the decision, **not** your parent/guardian.

In your instructional directive you can consent to or refuse future medical treatment. These decisions are directed toward your health practitioners, not your parent/guardian.

Be aware that consenting to or refusing treatment in your instructional directive could be acted on in situations you have not considered.

Consulting your doctor

If you choose to complete an instructional directive, you will need to consult with your doctor first, to make sure you have the information you need.

For example, if you have a current health condition, you should understand your prognosis (outlook for the future), treatment options, and the risks and benefits of these options.

You should also make sure your statements and intentions are clear to the doctor. It can be helpful to include the reasons for your statements. If you include statements about treatment for mental illness or dental treatment, consider consulting your relevant health practitioners about these statements.

How your instructional directive will be used

If in the future, you do not have decisionmaking capacity to make a medical treatment decision, your health practitioner will see if you have made an instructional directive. They will read your instructional directive to see if you made a decision about the medical treatment they are proposing. If you made a decision in your instructional directive to either consent to or refuse the proposed treatment, your health practitioner will follow your instructions.

Other things to keep in mind

Make sure you only write binding instructions in the instructional directive section of the form. Any instruction not written in this section or not identified as an instructional directive, will be considered a values directive.

Keep in mind that your health practitioner will only provide a medical treatment that is medically appropriate (helpful). They are not required to offer a treatment just because you have consented to it in an instructional directive.

If you make any statements about palliative care, they will be considered a values directive, even if you include them in your instructional directive.

Keep in mind that your health practitioner(s) cannot do anything that would require them to:

- do something unlawful
- breach their professional code of practice.

Part 4: Expiry date

You have the option of including an expiry date in your 'Advance care directive', but this is not a requirement.

It is recommended that you review your 'Advance care directive' annually, or whenever your medical or personal situation changes.

You may choose to include an expiry date as a safeguard in case you forget to review your 'Advance care directive'. However, keep in mind if you include an expiry date, your 'Advance care directive' could expire at a time that you do not have decision-making capacity to complete a new one.

Part 5: Witnessing

Witnessing requirements

To make a valid 'Advance care directive' you need to sign in front of two witnesses.

For people under the age of 18, one of these witnesses must be a child and adolescent psychiatrist or a psychologist with special qualifications and experience. This is because young people mature and develop the ability to make important decisions at different times. These health practitioners are specially trained in assessing a person's decision-making capacity.

If you are having your advance care directive witnessed by a **child and adolescent psychiatrist**, they must have:

- a current Fellowship of the Royal Australian and New Zealand College or Psychiatrists; and
- one of the following:
 - a Certificate of Advanced Training in Child and Adolescent Psychiatry awarded by the Royal Australian and New Zealand College of Psychiatrists;

 a current accredited membership of the Faculty of Child and Adolescent Psychiatry of the Royal Australian and New Zealand College of Psychiatrists

If you are having your advance care directive witnessed by a **psychologist**, they must have:

- a current endorsement by the Psychology Board of Australia as a clinical psychologist or as a clinical neuropsychologist; and
- be employed as a psychologist providing specialist paediatric care in a health service.

It is highly recommended that the other witness is your main treating doctor. You may have many doctors involved in your care but this should be the one who knows you best and has detailed knowledge of your medical condition/s. They can help you understand the sorts of decisions that may be needed in the future and the likely consequences of choosing different options.

Information for witnesses

To help your witnesses understand their role, the Office of the Public Advocate has a fact sheet for witnesses. Find this on the <u>OPA website</u> <http://www.publicadvocate.vic.gov.au>.

It is important your witnesses are able to communicate with you in a language that you understand.

If an interpreter is present

If an interpreter is present at the time the document is witnessed, they must sign and date Part 5 immediately after the document is witnessed.

Part 6: Interpreter statement

If an interpreter helped you prepare the document

If an interpreter assists you in preparing your 'Advance care directive', they will need to sign the interpreter statement in Part 6. They can fill in this section before the document is witnessed or when the document is witnessed.

If you need an interpreter, it is recommended that you use an independent and qualified interpreter.

After you have completed your 'Advance care directive'

When your 'Advance care directive' will be used

Your 'Advance care directive' is valid as soon as it is signed and witnessed correctly, but it can only be used when you are no longer able to make medical treatment decisions for yourself.

Who to discuss your 'Advance care directive' with

After you have completed your 'Advance care directive', it is important that you share and discuss it with your family and/or friends and relevant health practitioners.

Who to give copies to

Keep the original signed copy of your 'Advance care directive' in a safe place. You are encouraged to give your parent or guardian a certified copy. Other ways to make sure your 'Advance care directive' is readily available to those who might need to refer to it include:

- uploading a copy of your 'Advance care directive' to <u>My Health Record</u> at <http://www.myhealthrecord.gov.au>
- giving a copy to your health practitioner, including your GP and/or your hospital for your medical record
- giving a copy to any other health practitioners who will need to access your directive.

If you change your mind

You can cancel or change your 'Advance care directive' by completing a new directive or by completing the 'Advance care directive' revocation form. Find this on the <u>OPA</u> <u>website</u> <http://www.publicadvocate. vic.gov.au>.

Reviewing your 'Advance care directive'

Your preferences for medical treatment may change over time. For this reason, it is recommended that you review your 'Advance care directive' annually, or whenever your medical or personal situation changes. To receive this publication in an accessible format phone (03) 9096 7498, using the National Relay Service 13 36 77 if required, or <u>email Advance care planning</u> <acp@dhhs.vic.gov.au>

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