



NSW Advance Care Directive Comprehensive Form

based on form by **Professor Colleen Cartwright**

*Completing
an Advance Care Directive
and appointing an Enduring Guardian
gives you the best chance of ensuring that you
will not be given unwanted medical treatment at the
end of your life. It can also make it easier for your
family and health care providers to understand
and respect your wishes.*

The Committee of Dying with Dignity NSW wish to thank Professor Colleen Cartwright and the ASLaRC Aged Services Unit of Southern Cross University for their permission to reproduce parts of this NSW Advance Care Directive.

For further information supporting this document please see the ASLaRC Aged Services Unit website www.scu.edu/aslarc/ or Cartwright Consulting Australia <http://cartwrightconsultingaustralia.com.au>

*For further information about ACDs and Enduring Guardianship please see the Dying with Dignity NSW document **Guide to NSW Advance Care Directive and Appointment of Enduring Guardian** - printed July 2015.*

SECTION A: YOUR DETAILS

It is strongly recommended that, before completing this directive, you discuss it with your General Practitioner or a specialist medical practitioner who knows your medical history and views. The doctor will be able to explain any medical terms that you are unsure about and will also be able to state that you were not suffering from any condition that would affect your ability to understand the decisions you have made in the document. Complete this section by writing on the lines.

1. To my family, friends and health-care providers

I, _____
[Print your full name here]

of _____
[Print here your address here]

New South Wales Postcode: _____ Date of Birth: _____

being over the age of 18 years, make this directive after careful consideration and of my own free will. If at any time I am unable to take part in decisions about my health care and medical treatment, let this document stand as evidence of my views and wishes in relation to the care and treatment I do or do not want.

This directive should never be used if I have the capacity to speak competently for myself or if there is evidence that it has been revoked. I request that all who are responsible for my care respect and uphold the instructions given in this Directive.

SECTION B: GENERAL TREATMENT INSTRUCTIONS

In this section you are asked to identify and explain how any existing health conditions or religious values might impact future health care and medical treatment decisions. You are also asked to think about treatment you do or do not want if you are temporarily unable to communicate your wishes. Complete this section by ticking the appropriate boxes and writing on the lines.

2. Are there any special conditions that your health-care providers should know about, such as asthma or any allergy to medication?

Yes – complete 2(a)

No

2(a). Describe these special conditions here (for example, 'I develop a severe rash when given penicillin' or 'I have insulin-dependent diabetes'):

3. Do you have any religious beliefs that may affect your health care and medical treatment?

Yes – complete 3(a)

No

3(a). Describe here how your religious beliefs might affect your health care and medical treatment (for example, 'Because of my religious beliefs, I do not want to receive any blood transfusions or organ transplants').

4. If you have **temporarily lost capacity** and were unable to give directions for your health care and medical treatment because of injury or illness, what level of treatment would you want your health provider to give you? (for example, there may be some treatments that you would not wish to receive under any circumstances). Please tick one of the two options below.

- all available treatment
- all available treatment except for:
-
-
-

SECTION C: END-OF-LIFE TREATMENT INSTRUCTIONS

In this section you are asked to give specific instructions for future health care and medical treatment decisions you do or do not want, if you are terminally ill.

Definitions of terms used in this section

- **Irreversible:** unable to be turned around – there is no possibility that the patient will recover.
- **Terminal phase of an irreversible illness:** the person is dying and the process is irreversible. Life expectancy is usually considered to be just a few days.
- **Permanent unconsciousness (coma):** when brain damage is so severe that there is little or no possibility that the patient will regain consciousness.
- **Persistent vegetative state:** severe and irreversible brain damage, but vital functions of the body continue (e.g. heart beat and breathing).
- **Palliative care:** compassionate care for people with a terminal illness, focused on prevention of suffering and relief from pain and other distressing symptoms.
- **Life-sustaining measures:** treatments (medical procedures) that replace or support an essential bodily function (e.g. cardiopulmonary resuscitation, artificial ventilation, artificial nutrition and hydration, dialysis).

(i) cardiopulmonary resuscitation: emergency measures to keep the heart pumping (by massaging chest or using electrical stimulation) and artificial ventilation (mouth-to-mouth or ventilator) when breathing and heart beat have stopped.

(ii) assisted ventilation: use of a machine, such as a ventilator, to help the patient breathe when he/she is unable to breathe unaided.

(iii) artificial feeding and hydration: provision of food and fluid by artificial means when the patient is unable to eat or drink. This may be done by passing a tube through the nose into the stomach or by inserting a tube into a vein or directly into the stomach. (If you do not have artificial feeding, your mouth will still be kept moist.)

5. If in the opinion of my treating medical practitioner I am:

*(NB: Your **treating medical practitioner** may not always be your usual doctor if you become extremely ill. He or She will be the medical practitioner (doctor) who is providing your treatment at the time your directive will be used to inform your care and treatment.)*

- in the terminal phase of an irreversible illness or condition; or
- in a persistent vegetative state; or
- permanently unconscious; or
- so seriously ill or injured that I am unlikely to recover to the extent that I can survive without the continued use of life-sustaining measures

Or I am in any of the following states that I consider to be an unacceptable quality of life, and the state is permanent (tick all that apply):

- Not being able to recognise people important to me
- Not being able to communicate
- Not being able to eat by mouth
- Not having control of my bladder and bowels
- Other (please specify)

Then, I request that everyone responsible for my care (tick all that apply):

- Provide treatment for my comfort and dignity ONLY, with particular emphasis on pain relief
- Withhold or withdraw treatment that might obstruct my natural dying
- Do NOT perform surgery on me, unless required for my comfort and dignity

In the following optional section you can give more specific instructions for treatment you do or do not want, under four specific conditions. If you think that your decisions listed in statement number 5 above would be sufficient to guide your treating doctors, you may draw a line through each of the following sections and write your initials on the line.

6(a). If I am in the terminal phase of an incurable illness:

I do not want cardiopulmonary resuscitation.	Initial here: _____
I do want cardiopulmonary resuscitation.	Initial here: _____

I do not want assisted ventilation.	Initial here: _____
I do want assisted ventilation.	Initial here: _____

I do not want artificial hydration.	Initial here: _____
I do want artificial hydration.	Initial here: _____

I do not want artificial nutrition.	Initial here: _____
I do want artificial nutrition.	Initial here: _____

I do not want antibiotics unless needed as part of my palliative care.	Initial here: _____
I do want antibiotics.	Initial here: _____

Other treatment (specify):

I do not want _____ *Initial here:* _____
I do want _____ *Initial here:* _____

6(b). If I am permanently unconscious (in a coma):

I do not want cardiopulmonary resuscitation. *Initial here:* _____
I do want cardiopulmonary resuscitation. *Initial here:* _____

I do not want assisted ventilation. *Initial here:* _____
I do want assisted ventilation. *Initial here:* _____

I do not want artificial hydration. *Initial here:* _____
I do want artificial hydration. *Initial here:* _____

I do not want artificial nutrition. *Initial here:* _____
I do want artificial nutrition. *Initial here:* _____

I do not want antibiotics unless needed as
part of my palliative care. *Initial here:* _____
I do want antibiotics. *Initial here:* _____

Other treatment (specify):

I do not want _____ *Initial here:* _____
I do want _____ *Initial here:* _____

6(c). If I am in a persistent vegetative state

I do not want cardiopulmonary resuscitation. *Initial here:* _____
I do want cardiopulmonary resuscitation. *Initial here:* _____

I do not want assisted ventilation. *Initial here:* _____
I do want assisted ventilation. *Initial here:* _____

I do not want artificial hydration. *Initial here:* _____
I do want artificial hydration. *Initial here:* _____

I do not want artificial nutrition. *Initial here:* _____
I do want artificial nutrition. *Initial here:* _____

I do not want antibiotics unless needed as
part of my palliative care. *Initial here:* _____
I do want antibiotics. *Initial here:* _____

Other treatment (specify):

I do not want _____ *Initial here:* _____
I do want _____ *Initial here:* _____

6(d). If I am so seriously ill or injured that I am unlikely to recover to the extent that I can live without the use of life-sustaining measures:

I do not want cardiopulmonary resuscitation. *Initial here:* _____
I do want cardiopulmonary resuscitation. *Initial here:* _____

I do not want assisted ventilation. *Initial here:* _____
I do want assisted ventilation. *Initial here:* _____

I do not want artificial hydration. *Initial here:* _____
I do want artificial hydration. *Initial here:* _____

I do not want artificial nutrition. *Initial here:* _____
I do want artificial nutrition. *Initial here:* _____

I do not want antibiotics unless needed for my comfort and dignity
I do want antibiotics.

Initial here: _____
Initial here: _____

Other treatment (specify):

I do not want _____
I do want _____

Initial here: _____
Initial here: _____

End of Optional Section 6

SECTION D: PERSONAL STATEMENT

If you have any specific views about particular types of health care or special health matters that have not already been covered in this directive, you can record them in this section. It is recommended that you discuss this section with your doctor before completing it, as it is important that anything you write should be readily understood by medical staff who are treating you.

It is your legal right to refuse any medical treatment. However, you may not be entitled to insist on receiving a particular treatment (for example, if your doctor's professional opinion is that the treatment would not be of benefit to you). You also cannot demand access to treatments which are currently deemed to be against the law of NSW, such as medically assisted dying.

7. Do you have any other particular wishes about your health care or medical treatment that have not already been covered in this form? (for example, you may wish to write something like: 'I value life, but not under all conditions. I consider dignity and quality of life to be more important than mere existence' or 'I request that I be given sufficient medication to control my pain, even if this hastens my death').

- Yes – complete 7(b)
- No

7(b). Record your wishes here.

SECTION E: TISSUE / ORGAN DONATION

8. Have you given consent for the removal of your tissue/organs after death with the Australian Organ Donor Register

- Yes
- No

For more information about tissue and organ donation go to www.donatelife.gov.au/decide or call 1800 777 203 or visit your local Medicare Customer Service Centre

8(b). (Optional) Record any comments about tissue donation that you would like to make.

SECTION F: RESIDENTIAL CARE (OPTIONAL SECTION)

On this page you may record your wishes for care or treatment that you want, or do not want, if you are ever living in a Residential Aged Care Facility (RACF). (Note: Residential Aged Care Facilities were previously called hostels or nursing homes). **If you are currently living in a RACF it is strongly suggested that you complete this Section now.** If you are not currently living in a RACF you may still choose to complete this Section but you should review it if, at some future time, you do become a resident in a RACF.

If you are living in a RACF, it is highly likely that you need assistance with basic activities of daily living. Despite this, we hope that you still find life interesting and enjoyable. However, there may come a time when you feel that your quality of life is no longer acceptable to you and at this time you may prefer that the focus of your care be on maintaining your comfort and dignity. The care required to achieve these goals can usually be well managed by the nursing staff in the RACF together with your General Practitioner.

Question 9 provides a list of conditions that some people would consider unacceptable. Not everyone will have the same list. Read through the list, and circle the number that matches how acceptable that condition would be to you. You may also add anything else that you would consider to be unacceptable for a good quality of life in a RACF.

9. How acceptable would the following levels of functioning be to you? (Please circle one number for each statement)

Level of Function	Unacceptable	Neither	Acceptable
(a) not being able to recognise people who are important to you	1	2	3
(b) not being able to communicate	1	2	3
(c) not being able to eat by mouth	1	2	3
(d) not having control of your bladder and bowels	1	2	3
(e) Other (Please specify) _____ _____	1	2	3

10. If you were in a RACF, and your condition included a level of functioning that you have said would be unacceptable to you, **would you prefer to be kept comfortable in the RACF or would you rather go to hospital, if you experienced any of the following conditions** (remember, your directive will only be used if you can no longer speak for yourself):)

(Please circle one number on each line)	Stay in RACF	Go to Hospital
(a) a severe infection	1	2
(b) breathing difficulties	1	2
(c) pain that was difficult to control	1	2
(d) a broken bone (e.g. arm or hip)	1	2
(e) chest pain	1	2

Palliative Care at the end of life.

Palliative Care (defined in Section C) at the end of life can usually be provided in the RACF, by the nurses you know and your General Practitioner. Alternatively, your end-of-life care could be provided in a local hospital. This would require that you be transferred to hospital in an ambulance and admitted to a ward via the Emergency Department.

The way in which your end-of-life care is managed should be the same, whether you are in the RACF or if you go to hospital. However, what will be different will be whether you require transportation to hospital, the location of care and the staff who provide the care.

11. If you were in a RACF and could no longer speak for yourself, and you had reached a stage where you required end-of-life palliative care, would you prefer to remain in the RACF or would you prefer to be transferred to hospital?

(Please circle one number on each line)	Stay in RACF	Go to Hospital
(a) Preferred place for end-of-life care	1	2

Note: If you choose not to complete this section, please draw a line through both pages before you sign the document. If at a later stage you are admitted to a RACF you may wish to complete a new Advance Care Directive, including this Section.

End of Optional Section F

SECTION G: ENDURING GUARDIANSHIP

This section relates to whether you have appointed an Enduring Guardian to make decisions on your behalf about your health care and other personal matters, if you are no longer able to do so, and to advocate on your behalf to ensure that your wishes are respected.

12. Have you appointed an Enduring Guardian?

- Yes – *attach a copy of your Appointment of Enduring Guardian form to this ACD*

- No - *consider whether you would like to appoint one or more Enduring Guardians*

Note: Dying with Dignity NSW supports the position of NSW Health that completing both an Advance Care Directive and an Appointment of Enduring Guardian nomination form gives you the best chance of ensuring that you will not be given unwanted medical treatment at the end of life. These forms can also make it easier for your family and health care providers to understand and respect your wishes.

SECTION H: DOCTOR'S INVOLVEMENT

The creator of this directive strongly recommends that you obtain your doctor's signature to confirm that you have discussed the instructions in this directive with him/her and that the doctor is confident that you understand the nature and likely effect of the directions stated in the directive. Your doctor and your independent witness (see Section J) do not have to sign on the same day.

Doctor's name: _____

Doctor's address: _____

_____ Postcode: _____

Doctor's telephone number: _____

Statement of nominated doctor

(a) I have discussed this document with the principal and, in my opinion, he/she is not suffering from any condition that would affect his/her capacity to understand the things necessary to make this directive, and he/she understands the nature and likely effect of the health care described in this document, **and**

(b) *(tick one box only)*

the principal signed this document in my presence,

in my presence, the principal instructed another person to sign for the principal, and the person signed it in my presence and in the presence of the principal.

(c) I am NOT

the person witnessing this advance care directive, or

the person signing the advance care directive for the principal, or

an Enduring Guardian of the principal, or

a relation of the principal, or of an Enduring Guardian of the principal, or

a beneficiary under the principal's will.

x _____
[Principal signs here]

x _____
[Doctor signs here]

[Doctor writes the date here]

13. If this directive is ever required for your health care and medical treatment, do you want the doctor named above to be consulted by your treating medical practitioner?

Yes

No . This is not necessary.

SECTION J: WITNESS' CERTIFICATE

To give this directive the best possible legal status, it is recommended that you sign it in front of a qualified witness, including a Justice of the Peace or a Solicitor. The witness should not be your Enduring Guardian, a relation of your Enduring Guardian, your current paid carer* or your current health care provider. (*Note: "Paid carer" does not mean someone receiving a carer's pension or similar benefit.)

In this section your witness is required to certify that:

- the signature of the principal (the person making the directive) is genuine AND
- the principal appears to sign this directive of his or her own free will, without threats or offered inducements AND
- the principal appears to understand the matters stated in Section I

If the witness is in doubt about the principal's capacity, the he or she should insist that the directive has been signed by the principal's doctor in Section H. The doctor should be in the best possible position to assess the principal's capacity.

I, _____, state that:

- (a) I am at least 18 years of age;
 - (b) I am a Justice of the Peace/ Solicitor/ Registrar of the Court; (cross out whichever does not apply)
 - (c) I am not an Enduring Guardian for the principal, or a relation of the principal, or a relation of the principal's Enduring Guardian or a beneficiary under the principal's will or a current paid carer or health-care provider for the principal.
 - (d) the principal signed this directive in my presence; OR
 in my presence, the principal instructed another person to sign for the principal, and the person signed this directive in my presence and in the presence of the principal;
 - (e) at the time that this directive was signed, the principal appeared to me to be acting by his/ her own free will and without threats or inducements.
 - (f) I have verified that Section H of this document has been signed and dated by a doctor.
- and/ or
- at the time that this directive was signed, the principal appeared to me to understand the matters stated in Section I.

[Witness signs here]

_____/_____/20_____
[Witness writes the date here]

SECTION J: REGULAR REVIEW OF THIS DOCUMENT

In this section you can indicate when you have reviewed this document. Your care or treatment wishes may change or there may be advances in medical technology, therefore it is strongly recommended that you regularly review this document (i.e. ideally every two years or earlier if the state of your health changes significantly).

Each time you review your document and your wishes have not changed, sign and date one of the acknowledgments below. If your wishes have changed a great deal, you should complete a new advance care directive.

REVIEW OF DOCUMENT: #1

I affirm that I have reviewed this document and that there is nothing I would like to change.

Signature: _____

Date: _____ 20 ____

REVIEW OF DOCUMENT: #2

I affirm that I have reviewed this document and that there is nothing I would like to change.

Signature: _____

Date: _____ 20 ____

REVIEW OF DOCUMENT: #3

I affirm that I have reviewed this document and that there is nothing I would like to change.

Signature: _____

Date: _____ 20 ____

DWDnsw thanks Professor Colleen Cartwright and ASLaRC Aged Services Unit of Southern Cross University for permission to reproduce parts of this document.