HAVE A SAY IN YOUR HEALTH CARE.

CCLHD CONSUMER FRIENDLY RESOURCE

think about it. **talk** about it. **share** it.

Central Coast Local Health District

advance care planning workbook

None of us know what tomorrow will bring, or can predict what might become of our health and our ability to speak for ourselves. But there is a way to ensure you have a say in health and lifestyle decisions that lie ahead, should there come a time when you are unable to speak for yourself. It's called advance care planning.

What is **advance care planning**?

Advance care planning is a way to help you think about, talk about and share your thoughts and wishes about future care. It gives you a "voice" in decision making, helps you determine who would communicate for you if you are unable to communicate for yourself and should include conversations with your health-care team.

This workbook is a guide to help you through the process of advance care planning. It includes a number of questions to help you explore the values and beliefs that may influence your health and lifestyle decisions.

There are useful tips to consider as you develop and then share your advance care planning decisions with your family and those closest to you.

By making your wishes known, your family, carers and healthcare providers won't be left wondering what you might have wanted or did not want.

think about it. **talk** about it. **share** it.

EVERYONE *should have a say in their health care. Plan today to ensure that your wishes are known, no matter what the future holds for health and lifestyle.*

Who should consider advance care planning?

Everyone. You never know when you may face an unexpected event or illness and will be unable to make your preferences known. It is particularly important for seniors and those living with a chronic disease.

When should I consider advance care planning?

Now. It is important to take part in conversations about advance care planning before you become seriously ill. Planning will ensure that if an unexpected event occurs, your treatment wishes are known. This workbook has been created to help guide you through this process.

Make your future healthcare wishes known

Talk to your GP, family and trusted friends about your wishes. Let them know what care you would be willing to accept or would refuse. This will help to reduce any anxiety that your family and friends may feel. It will also give them the confidence to make decisions for you, if that should become necessary.

You can write an Advance Care Directive (see page 12). This is a legal document, (previously called a "living will"). In it, you write your health and lifestyle wishes and instructions about the treatment you would accept or refuse. You may consider legally appointing an **enduring guardian**, who will speak for you if you are unable to speak for yourself.

Talk with your doctor when writing your Advance Care Directive about specific instructions for health treatment.

Share and update changes. Over time, your feelings might change about choices you've made. That's okay. Changes can be made any time as long as you are able to make decisions for yourself.

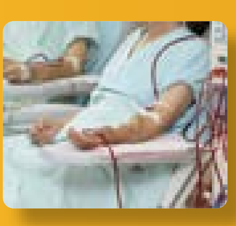
imagine

Think about what you might do in this situation

1 **imagine** that without warning, you are in a serious car crash. You are in a hospital intensive care unit. You are no longer able to communicate with anyone. Your heartbeat and breathing can only continue with artificial life support. Despite the best medical treatment, your physicians believe it is unlikely you will return to your previous quality of life.

2 **imagine** your ability to make your own decisions is gone. You live at a residential care facility. You can feed yourself but you no longer know who you are, who your family members are, or what happens from one moment to the next. You will never regain your ability to communicate meaningfully with others. Your condition will likely become worse over time.

3 **imagine** you have a progressive chronic illness. Your health care team has told you that you may lose your ability to swallow and breathe on your own.



THINK about your values & beliefs

When you plan for your future health care, you need to think about your values and beliefs, as well as your personal goals. In order to prepare yourself for advance care planning conversations, write down your thoughts to the following questions:

What is most important to me about my physical or mental well-being?

FOR EXAMPLE It is important for me to be able to communicate in some way, even if I cannot speak. I enjoy reading, writing and singing. It is important for me to be able to taste and touch.

What makes each day meaningful to me?

FOR EXAMPLE Life has meaning when I communicate with my friends and loved ones, when I can enjoy nature and when I can practice my faith. I need to know I am making a difference to the well-being of others. Creative activities are important to my daily routine.

What beliefs or values do I think will help my family, trusted friends or healthcare providers know what is important to me?

FOR EXAMPLE I would like to stay home as long as it is not too hard on my family or caregivers. Do everything possible to keep me alive until I can say goodbye to family who are coming to see me. It does not matter if I live until my next birthday.

Do I have a memory of a loved one who has died, what did I learn from that experience?

When I think about death, what do I worry about?

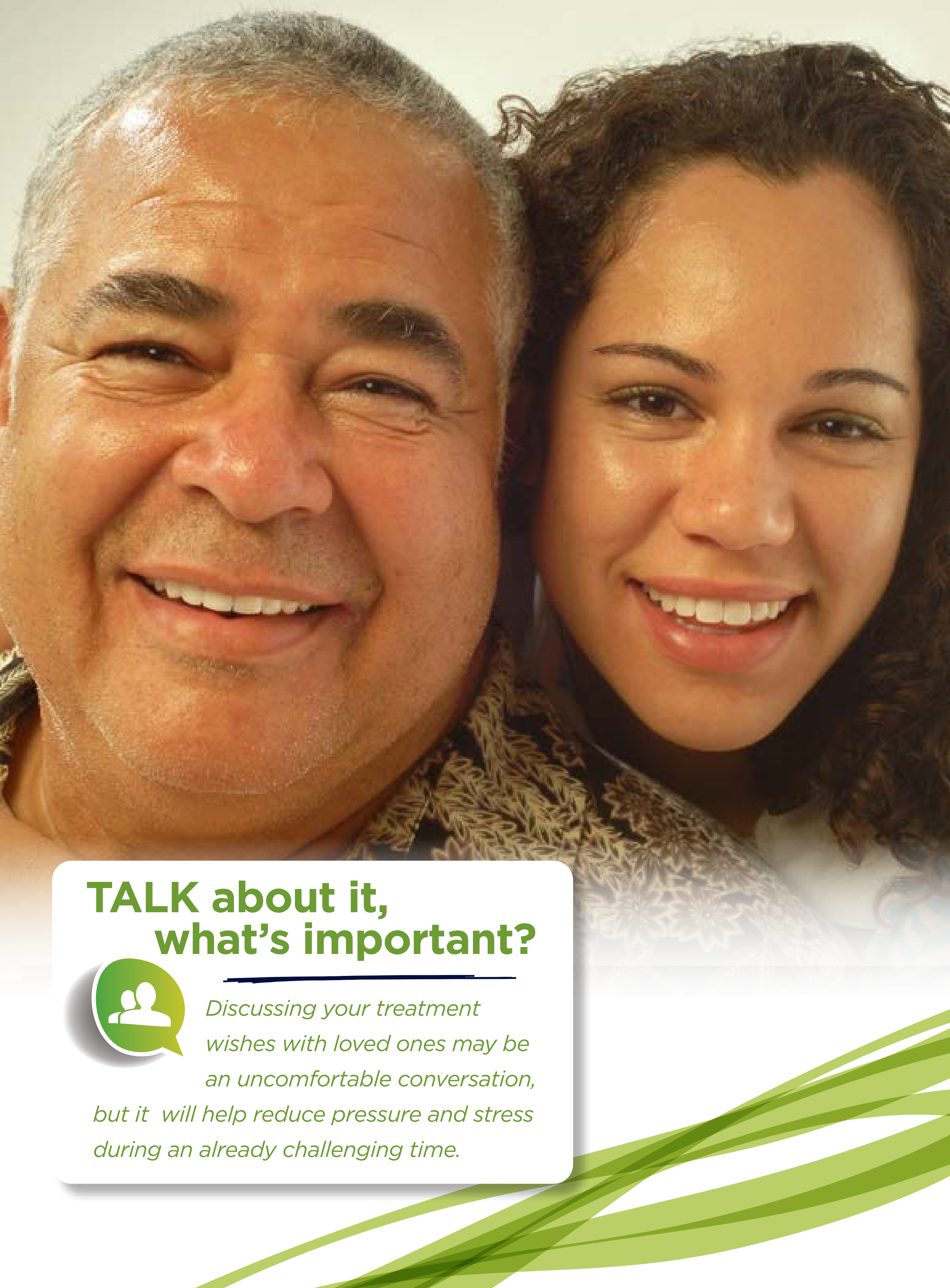
FOR EXAMPLE I worry that I will be in pain. I worry that I will be alone. I worry that my family will not know what to do. I worry that I will struggle to breathe.

When I am nearing death, are there things I would wish for (or do not wish for)?

FOR EXAMPLE I would like music, prayer, religious or spiritual rituals/readings in my own language. I do not want music or flowers in my room. I would value my privacy.

When I am nearing death and cannot speak or be understood, are there things I would like my friends and family to know?

FOR EXAMPLE I love you. I forgive you. Please forgive me. Thank you.



TALK about it, what's important?

Discussing your treatment wishes with loved ones may be an uncomfortable conversation, but it will help reduce pressure and stress during an already challenging time.

TALK about it

Talking with Family and Trusted Friends

The best people to talk with are your family members and/or trusted friends. The people you choose to have these conversations with should know you well.

Talking about your health and future health care may be hard. It may bring up questions, concerns, and uncomfortable feelings. You do not have to talk about your decisions all at once. Give yourself time to make your decisions and to make sure your wishes are understood.

Remember, your health-care team is an excellent source of information regarding your health and future health-care choices.

What if they make excuses like?

"You've got a plenty of life left in you....

....why do we need to talk about this now..."

What might you do/or say to get them to listen?

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How can I start the discussions?

- Tell them that you understand the subject may make them feel uncomfortable, but that you need them to hear what you have to say because it is important to you
- Start by explaining that you are planning ahead for the day that you might be seriously ill or injured/and or dying, and unable to communicate what care you would want.
- Tell them you want them to know your choices, so that they won't have the added stresses of trying to guess.
- Talk to them about what makes your life meaningful, and what would make it unbearable. You can use the Advance Care Planning template on pages 12 – 15 as a starting point for your discussions.

Consider who will be your decision maker

Person Responsible

In NSW, legislation called the NSW Guardianship Act says who can legally consent or decline treatment and care, if you are unable to speak for yourself. This is "Person Responsible".

The treating doctor will decide "Person Responsible" according to a hierarchy, as follows:

a. An Enduring Guardian (a person legally appointed by you) or a guardian appointed by the NSW Guardianship Tribunal

b. Your spouse, de facto or same sex partner with whom you have a close ongoing relationship

c. Your carer – a person who provides ongoing, regular care (not a care worker or volunteer)

d. A close friend or relative with whom you have an ongoing relationship.

Who would you want to make decisions for you, if you were unable to speak for yourself?

(list them here)

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- Have you talked this over with them?
- Are they happy to take on that role for you?
- Do they need support from other people?

If the person who you would prefer to be your decision maker is not comfortable taking on that role, it is important that you respect their decision.

If so, who else might be comfortable to do this for you? (list them here)

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It is in your best interest to understand this process of selecting a Person Responsible. Ensure that you have considered who would be the best person to make decisions for you. Discuss your wishes with that person.

If you have any doubts you should legally appoint the person/s you prefer as your Enduring Guardian (the first person in the hierarchy). For more information about the appointment of Enduring Guardian contact: 1800 451 694 or 4340 4888 or see the resources list on back page.

QUICK TIP:

Use the exercise over the page to help you consider and choose the best decision maker for you.

Choosing a Decision Maker

Think about who you would like to make decisions for you, if you were unable to make these decisions for yourself. Write the names in the 'name' section, and then tick whether they would be able to carry out the responsibilities listed *(based on ABA Commission on Law and Aging, 2005 Tool#1)*.

Responsibilities	Name:	Name:	Name:
Would be willing to speak on my behalf			
Would be able to act on my wishes and separate his/her own feelings from mine			
Lives close by or could travel to be at my side if needed			
Knows me well and understands what's important to me			
Could handle the responsibility			
Will talk with me now about sensitive issues and will listen to my wishes			
Will be available in the future if needed			
Would be able to handle conflicting opinions between family members, friends, and/or medical personnel			
Before making a treatment decision, would s/he ask what life would be like for me 1. following treatment and 2. if treatment was not accepted			

WRITE your wishes AND SHARE

Preparing an Advance Care Directive or having an Advance Care Plan ensures your loved ones and your health care providers know your health and lifestyle wishes in advance.

Writing an Advance Care Directive

An Advance Care Directive allows you to express your wishes about the amount and type of care and treatment you want to receive should you become unable to speak or otherwise communicate this yourself. It also allows you to give another person(s) the power to make health care decisions for you, should you ever be unable to make them yourself. What is right for someone else, may or may not be acceptable to you.

At times of stress and crisis it may be hard for family to recall what you really want so all the more reason to write your wishes down. There is no one form or template to write an Advance Care Directive or Advance Care Plan however we have provided a sample at the back of this workbook to guide you in the process

Frequently Asked Questions

What is an Advance Care Directive (ACD)?

This is a written document made by a competent person (i.e. someone with "capacity") and is recognised by common law. The ACD can:

1. Record your values, life goals and preferred outcomes;
2. Provide directions about care in the event of life-threatening illness or injury;
3. Identify your Enduring Guardian (if formally appointed) or "person responsible" to make decisions on your behalf; or
4. Be any combination of the above three.

What is Capacity?

The ability to make your own decisions is called "capacity." When a person has capacity to make decisions they can:

- understand the facts and choices involved,
- weigh up the consequences,
- communicate the decision

What is an Advance Care Plan?

The Plan can be written by you, for you or with you and it documents your values and preferences for healthcare and preferred health outcomes. The plan is prepared from your perspective and used as a guide for future health care decision making, if you are unable to speak for yourself. It maybe developed for and with a person with limited capacity so therefore is not a legal document.

I have already made a Will, do I need an ACD?

Yes. Your Will is read after your funeral so of no use to guide health & lifestyle choices.

When will it be used?

Only when you are unable to speak for yourself.

Where should I keep the written document?

Make sure a copy goes to your doctor, Enduring Guardian, family and those closest to you. If you come into hospital, bring a copy with you on each admission.

Can my Power of Attorney give health consent?

No. Their role is to manage your business, property & financial matters.

What if I change my mind?

You can change or revoke your ACD at anytime while you have capacity. Ensure that old documents are destroyed and replaced with the new.

Is an ACD permission or consent for euthanasia?

No. You cannot request or direct a doctor to end your life in an ACD.

Some of the common health/medical terms and interventions are described over the page

COMMON HEALTH / MEDICAL TERMS

Life Support In the case of serious illness, or injury there are a number of medical procedures, often referred to as "life support", which can prolong life and delay the moment of death. These include:

- **Cardiopulmonary resuscitation (CPR)** refers to medical procedures used to try to restart a person's heart and breathing when the heart and/or lungs unexpectedly stop working.

  CPR can range from mouth-to-mouth breathing and pumping on the chest, to electric shocks that try to restart the heart and machines that breathe for the individual.

- A **feeding tube** is a way to feed someone who can no longer swallow food. It is a small plastic tube that carries liquid food, which is inserted through the nose or directly into the stomach or intestines.

- **Dialysis** is a medical procedure that cleans your blood when your kidneys can no longer do so.

  These can be life saving however could result in more damage/harm.

An **intravenous line (IV)** is a way to give a person fluids or medicine. A hollow needle, attached to a narrow tube, is placed in a vein in the hand, arm or another location.

A **tracheostomy** is a surgical procedure to create an opening into your windpipe through your neck.

A **transfusion** is when a person is given blood or blood products through an intravenous line.

A **ventilator** is a machine that helps people when they can not breathe on their own. A special machine is attached to a tube that is placed down the windpipe.

CPAP or BiPap is a tight fitting mask that feeds oxygen into the lungs for ventilation rather than the need for a tube placed into the airway.

An **intensive care unit (ICU)** is a unit in a hospital where people are kept alive using machines (such as a breathing machine or ventilator) and special intravenous medications to support the heart.

Palliative Care is the total care of those people who have a condition which is incurable and will shorten their life. This care focuses on maintaining quality living for as long as possible and involves physical, emotional and spiritual support. When comfort becomes the main medical goal, the care includes relief of your pain and other unpleasant symptoms, as well as caring support of you and your family.

With support, including a palliative care team, your GP and others, it is possible for Palliative Care to take place at home, nursing home, or hospital.

Your health-care team will consider your wishes, but will not offer you treatment that is of no benefit.

Advance Care Planning

Please consider all questions on this form. Cross out section/s you do not wish to answer at this time. Remember to make copies of this form and give to your GP, your family and trusted friends.

A. Advance Care Directive

The following has been prepared by me to guide decision-making for health, medical and lifestyle decisions should I be unable to speak for myself.

Name: Date of Birth:

Address:

OR

B. Advance Care Plan

The following has been prepared by a proxy. It is based on information provided to the proxy in the past and is a best estimate of what the person (named below) may have wanted as far as their health, medical and lifestyle decisions.

Name: Date of Birth:

Address:

Proxy Name Relationship:

If I cannot speak for myself, I would like my doctor to talk about my healthcare and medical problems with the following person/s.

Name: Contact No:

Name: Contact No:

Legal Appointments

Enduring Guardian (for health decisions) Yes No

Person Appointed:

Name: Contact No:

Legal Documents held by:

Name: Contact No:

Enduring Power of Attorney (for money/finance decisions) Yes No

Person Appointed:

Name: Contact No:

Legal Documents held by:

Name: Contact No:

Name (or proxy): Signature: Date:

Witness Name: Signature: Date:

Review Dates:

Personal Values

Please consider the following personal values statements.

Note: If written by a proxy, they should consider what the person (they) would have chosen for themselves. The proxy can cross out this section if they cannot answer on behalf of the person.

I (They) would find life to be **acceptable** (even if difficult) OR **unbearable** if, **for the rest of my (their) life**:

I (They) do not recognise family and loved ones	Acceptable	Unbearable
I (They) do not have control over bladder and bowels	Acceptable	Unbearable
I (They) cannot feed myself (themselves) and cannot wash myself (themselves) and cannot do my (their) own person grooming and dressing	Acceptable	Unbearable
I (They) can no longer eat or drink and need to have food given to me (them) through a tube in the stomach	Acceptable	Unbearable
I (They) cannot talk, read and write	Acceptable	Unbearable
I (They) can never have a conversation with other because I (they) do not understand what people are saying	Acceptable	Unbearable
I (They) do not get enjoyment from many of the things that I (they) have always enjoyed	Acceptable	Unbearable

If I am (they are) very sick or badly injured and others need to make decisions for me, please consider the following statements when make decisions:

Cardio Pulmonary Resuscitation (CPR)

If my (their) heart or breathing stops due to old age or irreversible (not curable) health problems my (their) choice, if CPR is a treatment option would be:

Please try to restart the heart and/or breathing **(attempt CPR)**

Please allow me (them) to die a natural death. Do not try to restart the heart or breathing **(No CPR)**

I cannot answer this question. Let the doctor decide.

Name (or proxy): Signature: Date:

Witness Name: Signature: Date:

Review Dates:

Thinking about End of Life

Please tick the statement which is closest to your personal belief at the time of preparing this document.

Note: The following table may not be appropriate for a proxy to complete.

I am frightened of dying and do not want to think about it happening to me or my loved ones. I do not discuss death or dying with others.

Dying is a fact of life. You just have to deal with it when it happens. I hope that I can talk about it with loved ones before my time comes.

Dying is a natural part of life. I am comfortable discussing death and dying with my loved ones and others. I want to be prepared for when my time comes.

When my (their) time for natural dying comes, if possible I (they) would like to be cared for:

At home or in a home like environment.

In a hospital or hospital like environment.

I (they) do not know. I am (they are) happy for the family/person responsible to decide.

Specific requests with regard to medical care. Tick the box and identify specific treatment limitations. If you (they) **do not** have any specific requests cross out this section.

I (they) **do not want** to have the following life prolonging medical treatments:

Personal, religious and spiritual care requests

If I am (they are) unable to communicate my (their) wishes, please consider that I (they) **would not want** to receive the following care:

Name (or proxy): Signature: Date:

Witness Name: Signature: Date:

Review Dates:

Request for organ and tissue donation

Please cross out this section if there is no request.

I (they) have registered as an **organ and tissue donor** with the Australian Organ Donor Register. Yes No

My (their) organ donor registration number is

I (they) have discussed organ and tissue donation wishes with family and friends and they are aware of the decision. Yes No

I (they) understand that my (their) donation wishes may, in some situations, require the use of life sustaining treatment in an intensive care unit. I (they) understand and accept that I (they) may receive this additional care so the donation wishes can be carried out. Yes No

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Request for body (cadaver) and other donation

I (they) have registered as a **cadaver/other donor**. Yes No

Please contact the following number to arrange collection

I (they) understand that their may be specific instructions that need to be followed shortly after death for cadaver and/or other body part donation to occur. I (they) have discussed what needs to happen with family/friends. Yes No

Additional Items (if applicable)

The following items are important and need to be considered in any decisions that are made on my behalf:

Attach/complete an additional page for this section if required. Remember to sign, date and have witnessed.

Name (or proxy): Signature: Date:

Witness Name: Signature: Date:

Review Dates:

Adapted from the Advance Care Panning template developed by Hunter New England Health Service 2011

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Need more information?

Talk to your GP – consider your thoughts beforehand then discuss your ideas during an extended appointment.

To obtain a free copy of this Advance Care Planning Community Workbook to guide and prompt discussion and develop a written plan. Contact Carer Support Unit 4320 5556 or download at: www.cclhd.health.nsw.gov.au and search ACP

Contact the Office of the Public Guardian for information on the appointment of an Enduring Guardian 4320 4888 or 1800 451 694 www.publicguardian.justice.nsw.gov.au

The Capacity Toolkit is a free resource available from Department of Justice and Attorney General, Diversity Services www.justice.nsw.gov.au or 8688 7777

Planning Ahead tools website online information on future legal, health & asset decisions www.planningaheadtools.com.au/

NSW Health - Advance Care Planning information package. www.health.nsw.gov.au/patients/acp/

Advance Care Planning Australia – information and resources to support Advance Care Planning. 1300 208 582 or www.advancecareplanning.org.au

think about it. **talk** about it. **share** it.

Make sure your health and lifestyle wishes are known. Consider what's important to you and discuss it with your loved ones and your health care team to help guide future decisions about your care.

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