HAVE A SAY IN YOUR HEALTH CARE.

advance care planning

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

Health
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. But there is a way to ensure you have a say in health-care 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 health 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 thought provoking questions to help you explore the values and beliefs that influence your health-care 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, as well as your health-care team (eg. your GP).

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 your family and your health.*

THERE ARE SEVERAL WAYS TO MAKE YOUR FUTURE HEALTH-CARE WISHES KNOWN:

Talk to your GP, family and trusted friends about your concerns. Let them know what care you would be willing to accept or would refuse. Talking about the kind of care you do and do not want will help 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, sometimes called a "living will." In it, you write your 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.

You can work with your health care team to complete your Advance Care Directive with specific instructions regarding preferred health treatment.

Communicate and update changes. Over time, your feelings might change about the goals of care choices you've made during advance care planning. That's okay. Changes can be made any time as long as you are able to make health-care decisions. Health-care providers will also consult you directly if your health situation changes.

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.

imagine

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 health-care 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)?

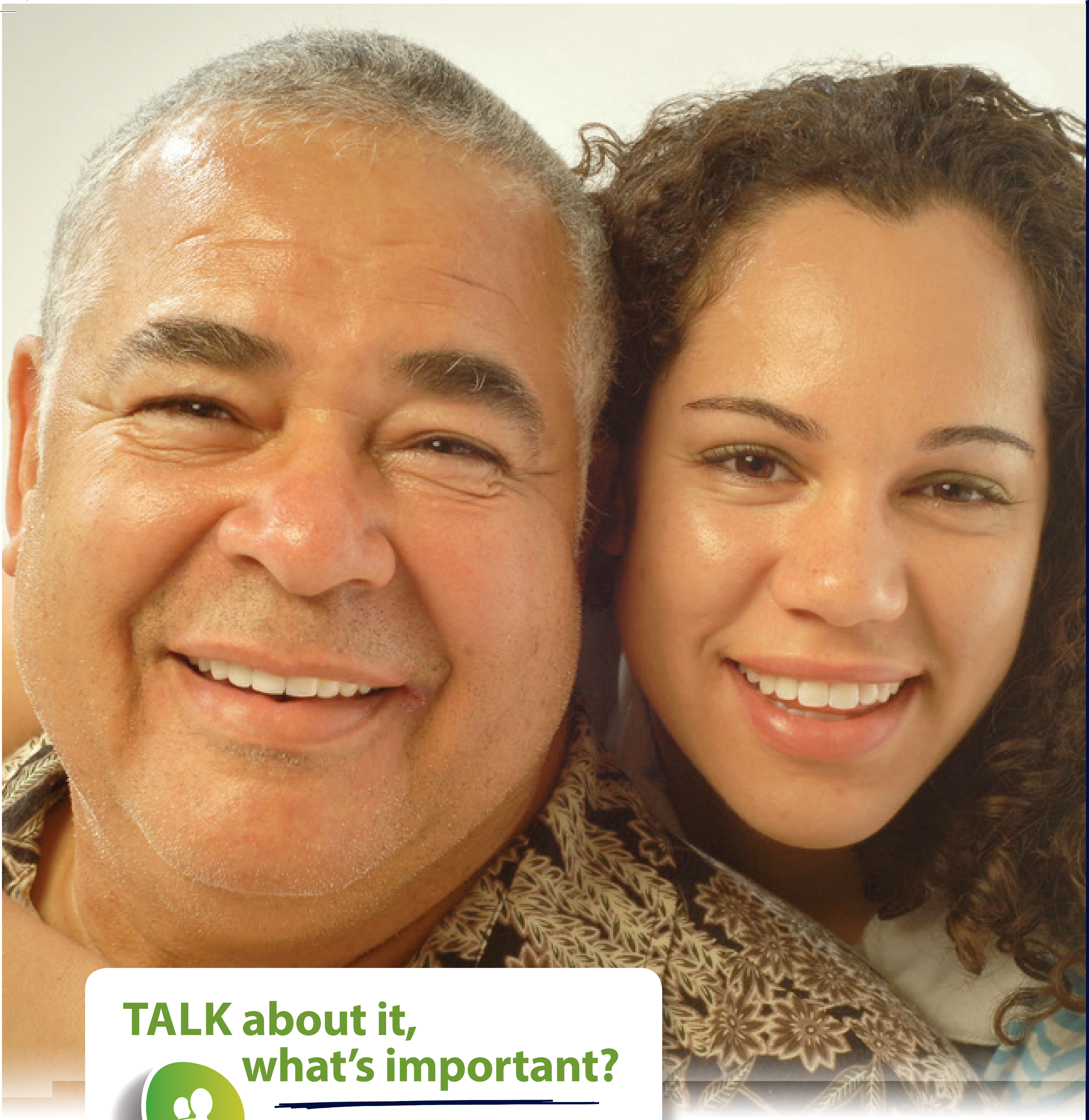
FOR EXAMPLE I would like music, prayer, religious or spiritual rituals/readings in my own language. I do not want music or flowers in my room. I would value my privacy.

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.

It is important to know that the choices you make now for future health-care decisions may not be ideal if you become very ill.

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



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.

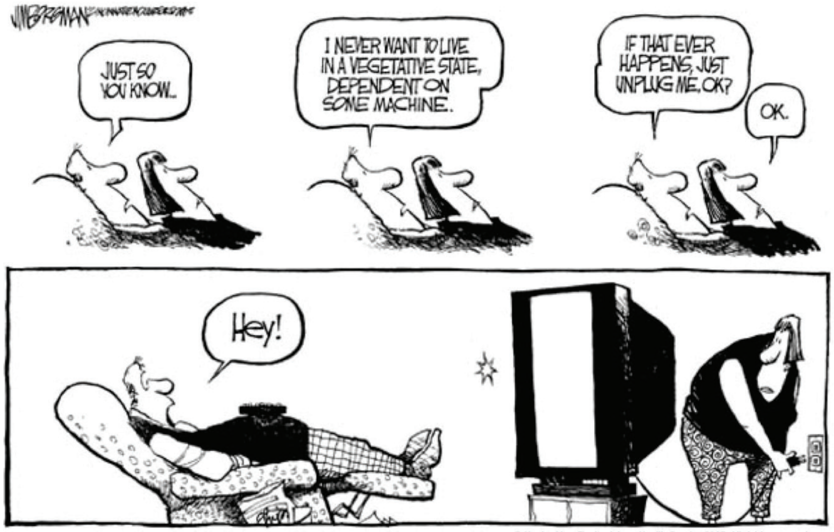
TALK about it

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.



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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?

- Show/ give them a copy of the DVD "A Family's Journey" and let them know that you would like to talk more about your choices.
- Acknowledge 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 medical 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 12-14 as a starting point for your discussions.

Consider who will be your medical decision maker

Person Responsible

In NSW, legislation contained in the NSW Guardianship Act determines who can legally consent or decline treatment being offered to you 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.

Have you thought about who you would 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 substitute 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 451 510 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 Medical Decision Maker

Think about who you would like to make medical 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			

SHARE your plans.
WRITE it down.

Filling out an Advance Care Directive form ensures your loved ones and your health-care providers know your health-care and treatment wishes in advance.

WRITING AN ADVANCE CARE DIRECTIVE

The Advance Care Directive allows you to express your wishes about the amount and type of health 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 future planning discussions so all the more reason to write your wishes down. There is no one form or template to write an ACD or Advance Care Plan however we have provided a sample at the back of this workbook to guide you in the process.

What is an Advance Care Directive?

Advance Care Directive (ACD)

This is a written directive 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

Advance Care 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.

Frequently Asked questions:

I have already made a Will, do I need an ACD?
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 ACD / ACP?
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 (or by any other means). Euthanasia is Illegal in Australia.

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

HEALTH CARE TREATMENTS

Medical Interventions:
In the case of serious illness, or injury there are a number of medical procedures (interventions), often referred to as life support, which can prolong life and delay the moment of death. These include CPR (cardiopulmonary resuscitation), artificial breathing using a machine, tube feeding and artificial hydration (intravenous), kidney dialysis etc. These can be both life saving and could result in more complications.

Comfort Care or Palliative Care, focuses on providing the person with a dignified death without the use of medical treatments to prolong life. 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. This type of treatment also includes following your wishes and those of the people closest to you while always being respectful to your body, mind and spirit. With support, including a palliative care team, your GP and others, it is possible for Comfort care to take place at home, nursing home, hospice or hospital.

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.

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

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.

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. It is important to understand that the special equipment and medications used in an ICU do not cure diseases. If you have a potentially curable or treatable disease, the machines and special intravenous medications used in the ICU may provide you with more time to heal so that hopefully you can resume your life without machines or special intravenous medications.

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.

High Dependency Units (HDU). Many hospitals have HDUs which can give non-invasive ventilation (called CPAP or BiPaP) and use drugs that are not available on regular wards due to risk or need for heart monitoring. HDU stays are usually short, giving time and medical support while the treatment starts to work.

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.

Advance Care Plan / Directive Template

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

Name: ________________________ Date of Birth: ____________________________

Address: ____

Completed by proxy: Name: ___________________ Relationship: _________________

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

Name	Contact numbers

I have legally appointed the following:

	Yes/No	Name and contact number of person appointed	Copies of legal documents held by (name and contact)
Enduring Guardian (*for health decisions*)			
Enduring Power of Attorney (*for money/finance decisions*)			

If I am very sick or badly injured and others need to make medical decisions for me, please consider my following statements when making substitute decisions:

The following things are important to me, and I want them to be considered in any decisions that are made on my behalf: (should you wish to attach an additional page for this question – please remember to sign, date and witness)

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Cardio Pulmonary Resuscitation (CPR) (*Initial the box that matches your choice*)
If my heart or breathing stops due to old age or irreversible (not curable) health problems my choice, if CPR is a treatment option, would be

☐ Please try to restart my heart or breathing (**Attempt CPR**)

☐ Please allow me to die a natural death. Do not try to restart my heart or breathing (**NO CPR**)

☐ I cannot answer this question. Let my doctor decide.

Name: ______________________ Signature: _________________ Date: ____________
or Proxy

Witness name: ________________ Signature: _________________ Date: ____________

Review date/s: ____________ _____________ _____________ _______________

Personal Values

Please consider my personal values for the following statements if I am unable to make my own decisions in the future. (Put your initials in the box that is your response to each statement)

I would find life to be *acceptable* **OR** *difficult but bearable* **OR** *unbearable* if, for the rest of my life:

	Acceptable	**Difficult but bearable**	**Unbearable**
I do not recognise my family and loved ones			
I do not have control over my bladder and bowels			
I cannot feed myself, and cannot wash myself, and cannot do my own personal grooming and dressing			
I cannot move myself around in or out of bed and rely on other people to reposition (shift or move) me			
I can no longer eat or drink and need to have food given to me through a tube in my stomach			
I cannot talk, read and write			
I can never have a conversation with others because I do not understand what people are saying			
I do not get enjoyment from many of the things that I have always enjoyed			

Thinking about end of life:

Please initial the statement which is closest to your personal belief

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 and others 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 time for natural dying comes, if possible, I would like to be cared for

☐ At home or in a home like environment

☐ In a hospital or hospital like environment

☐ I do not know. I am happy for my family / person responsible to decide

Name: ______________________ Signature: _________________ Date: ____________
or Proxy

Witness name: ________________ Signature: _________________ Date: ____________

Review date/s: ____________ _____________ _____________ _______________

Specific requests with regard to medical care *(Please initial the box if you wish to identify specific treatment limitations. If you DO NOT have specific requests, please cross out this section)*

☐ I DO NOT WANT to have the following life prolonging medical treatments:

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My personal, religious and spiritual care requests

If I am unable to communicate my wishes, please consider that I would want to receive the following care:

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Specific Requests for Tissue, Organ and / or Body Donation *(Please initial the small box that is next to the statement you are completing. please cross out this section if you do not want to make a request)*

☐ I have registered as an ORGAN AND TISSUE donor with the Australian Organ Donor register. My organ donor registration number is

____

I have discussed my organ and tissue donation wishes with my family and friends and they are aware of my decision **YES / NO**

I understand that my donation wishes may, in some situations, require the use of life sustaining treatment in an Intensive Care Unit. I understand and accept that I may receive this additional care so my donation wishes can be carried out.

Body (Cadaver) and Other Donation

☐ I have registered as a cadaver / other donor. Please contact the following number to arrange collection ________________________________

I understand that there may be specific instructions that need to be followed shortly after my death for cadaver and / or other body part donation to occur. I have discussed what needs to happen with my family / friends **YES / NO**

Name: ______________________ Signature: _________________ Date: ____________
or Proxy

Witness name: ________________ Signature: _________________ Date: ____________

Review date/s: ____________ _____________ _____________ _______________

Acknowledgement: Based on the Advance Care Planning template developed by Hunter New England Health Service 2011

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 451 510
www.publicguardian.lawlink.nsw.gov.au

The Capacity Toolkit is a free resource available from Department of Justice and Attorney General, Diversity Services
www.lawlink.nsw.gov.au/diversityservices
or 8688 8460

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

Planning what I want: website offering a range of planning templates and resources
www.planningwhatiwant.com.au

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

None of us can predict what tomorrow may bring. Make sure your health care 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 health care.

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