ADVANCED CARE PLANNING

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WHAT IS ADVANCED CARE PLANNING (ACP)?

In simple terms:

- An important way of letting people know your wishes about health care and treatment should you find yourself in a position where you are seriously ill or injured and not able to make decisions.

WHAT IS ADVANCED CARE PLANNING?

A voluntary and beneficial process in which an individual can think about and plan for their future care.

It can bring to light an individual's values and beliefs such as:

- What characterises acceptable or non-acceptable health outcomes
- Who should be involved in making decisions about individual care
- What type of medical response they would like for different stages of illness
- Preferred end of life care or carer arrangement

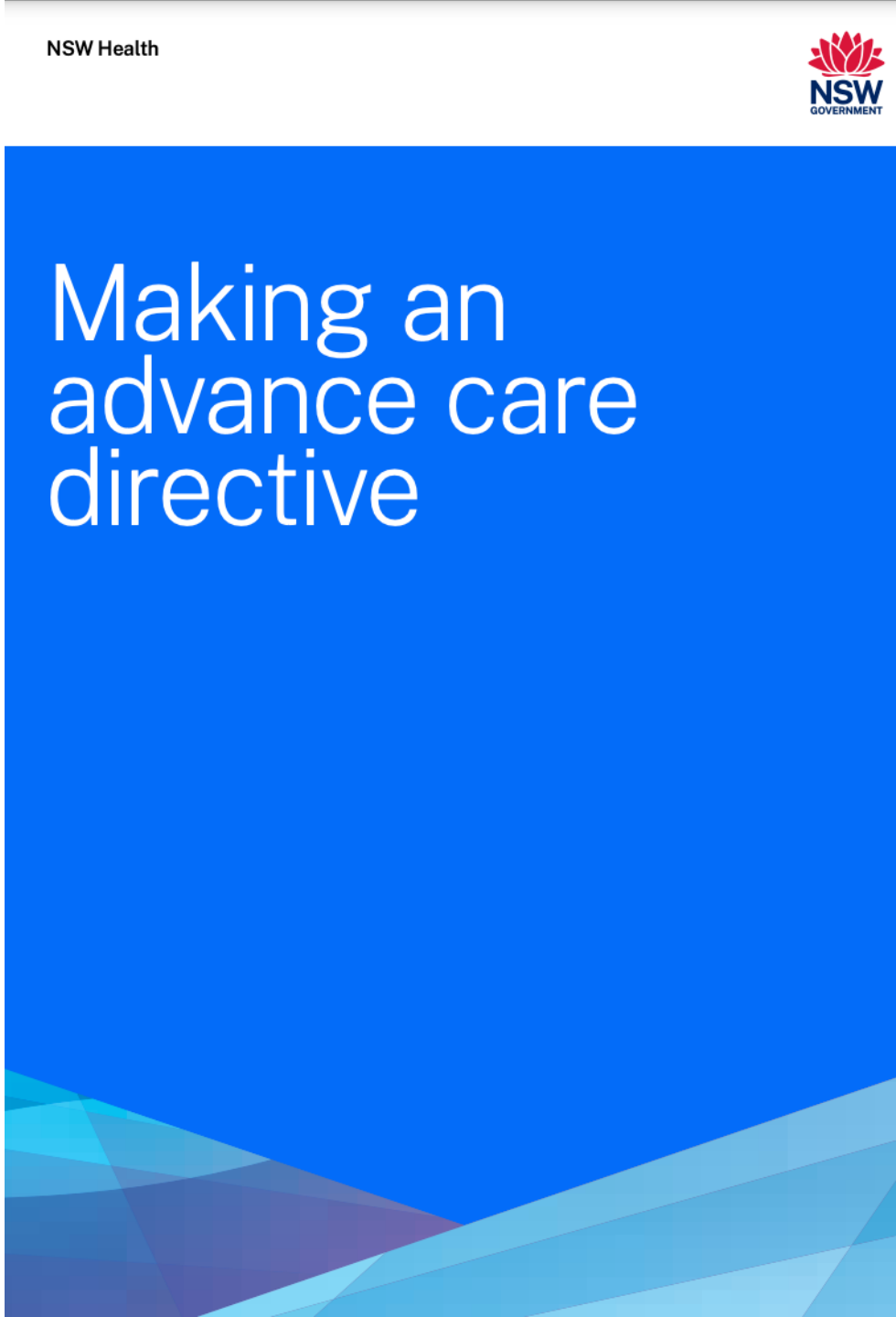
KEY TERMS

Advanced Care Planning

- Process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision making at a future time.

Advanced Care Directive

- A voluntary, person-led document completed and signed by a competent person that focus on an individual's values and preferences for future care decision.
- A legal document



INTRODUCTION

Many individuals will go through periods where they are unable to make informed decisions for themselves in any particular moment

- Sudden injury
- Cognitive decline
- Periods of acute mental illness
- Other times when competency levels are fluctuating

BENEFITS OF ADVANCED CARE PLANNING

Improved quality of life

Decreased anxiety and depression amongst family members

Reduced hospitalisations

Increased uptake of palliative care services

Care that concurs with patient preferences

However, uptake amongst the general population remains very low

WHEN CAN IT OCCUR?

Can occur at any time including when an individual is in full health.

Could be an iterative conversation where the individual's values, beliefs and preferences change and evolve over time.

Conversation are valuable in their own right, however completion of a document may provide important information to inform future care decisions.

Advanced care planning is not limited to palliative or end of life care.

WHO SHOULD UNDERGO ADVANCED CARE PLANNING?

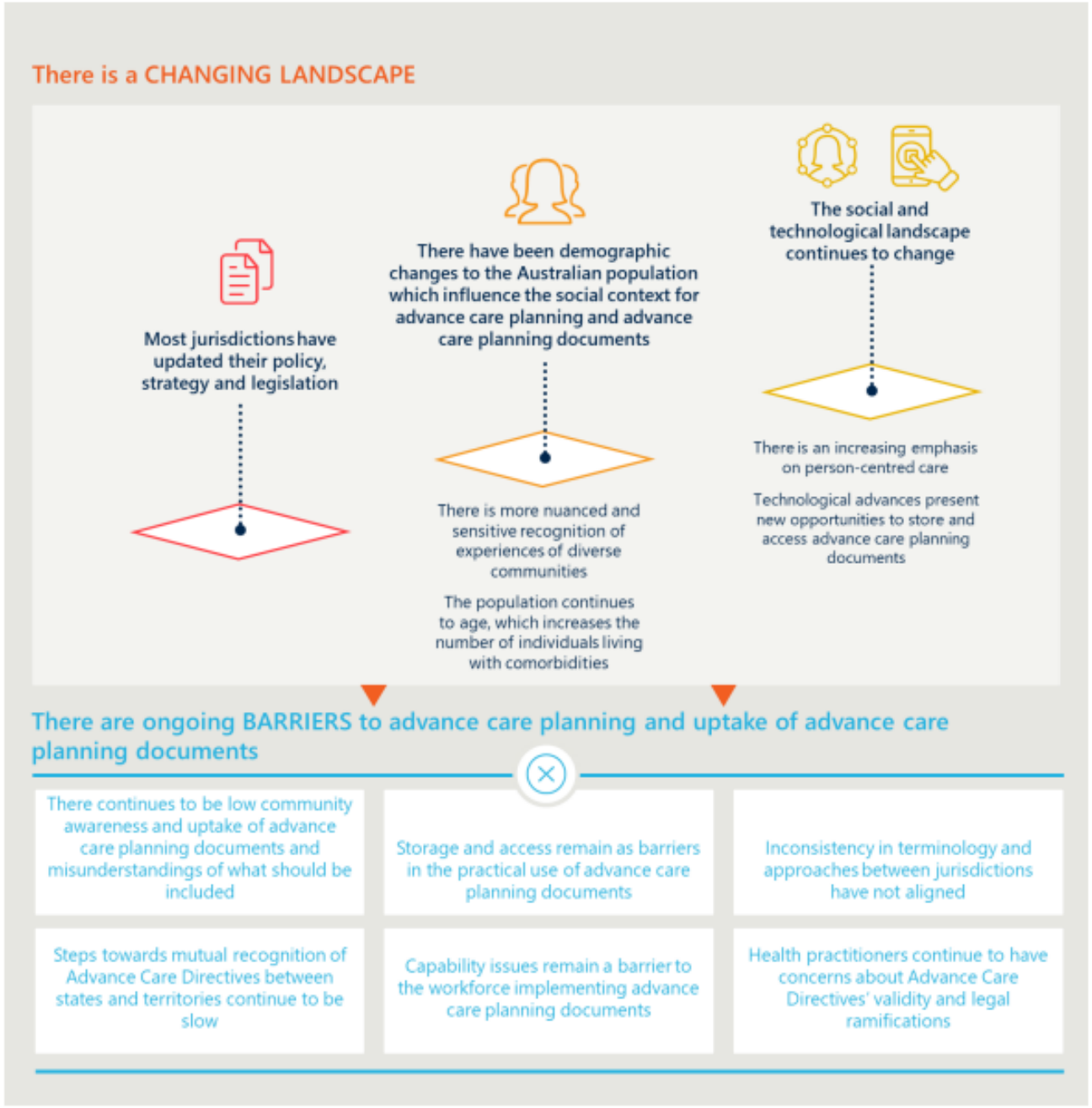
All competent patients, irrespective of age, who fulfil one or more of the following criteria :

- Those with life-limiting illnesses such as end stage renal failure, advanced cancer, early dementia*, neurological disorders etc
- Prognosis < 12 months as per nephrologist
- Two or more significant co-morbidities
- Poor quality of life
- Chronic malnutrition
- Poor functional status

RECENT CHANGES IN THE ADVANCED CARE PLANNING LANDSCAPE

Reference: National framework for advanced care planning documents

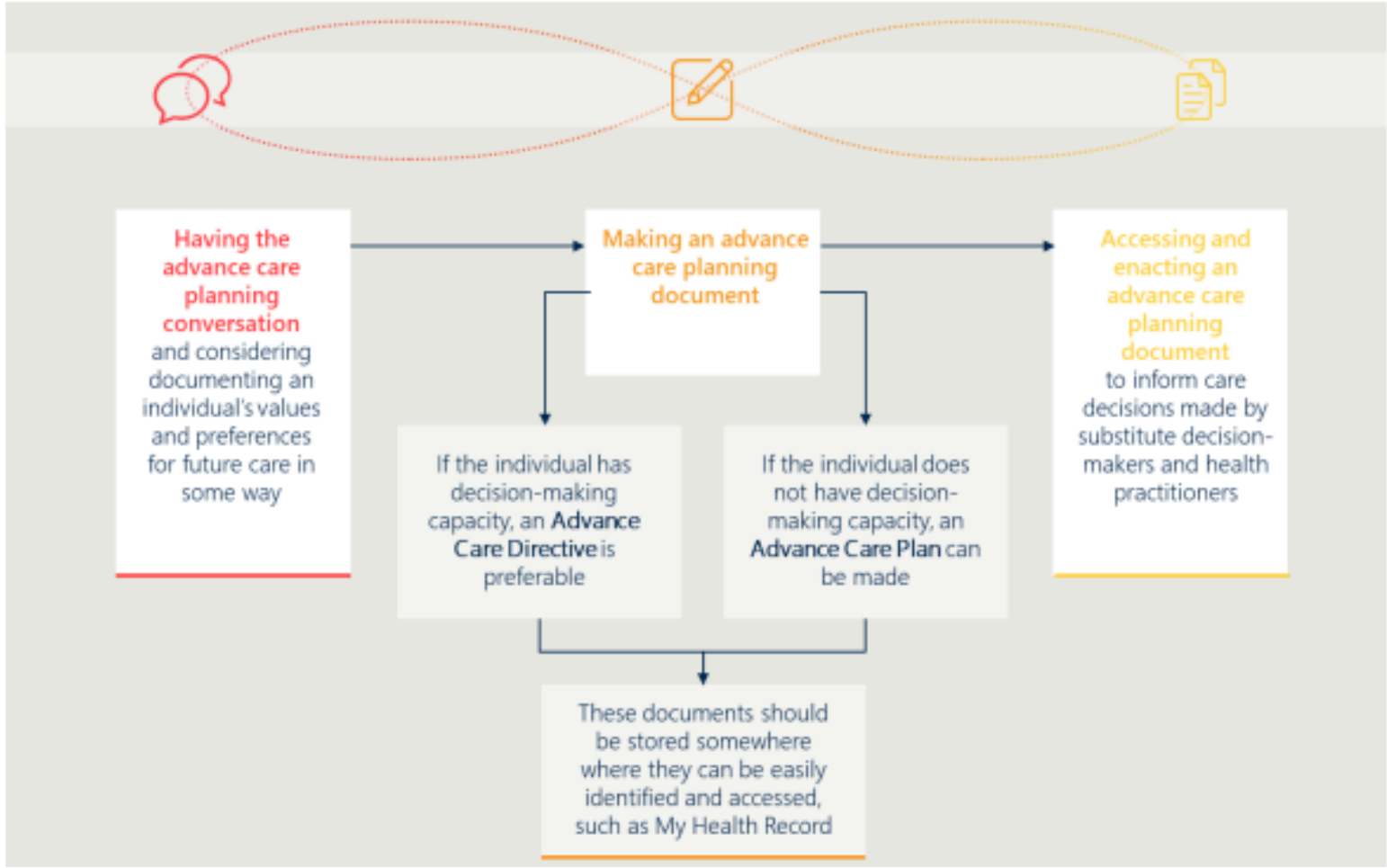
Figure 4 | Key changes to the advance care planning landscape and known barriers to developing and enacting advance care planning documents



STAGES OF ADVANCED CARE PLANNING

Can viewed in 3 stages

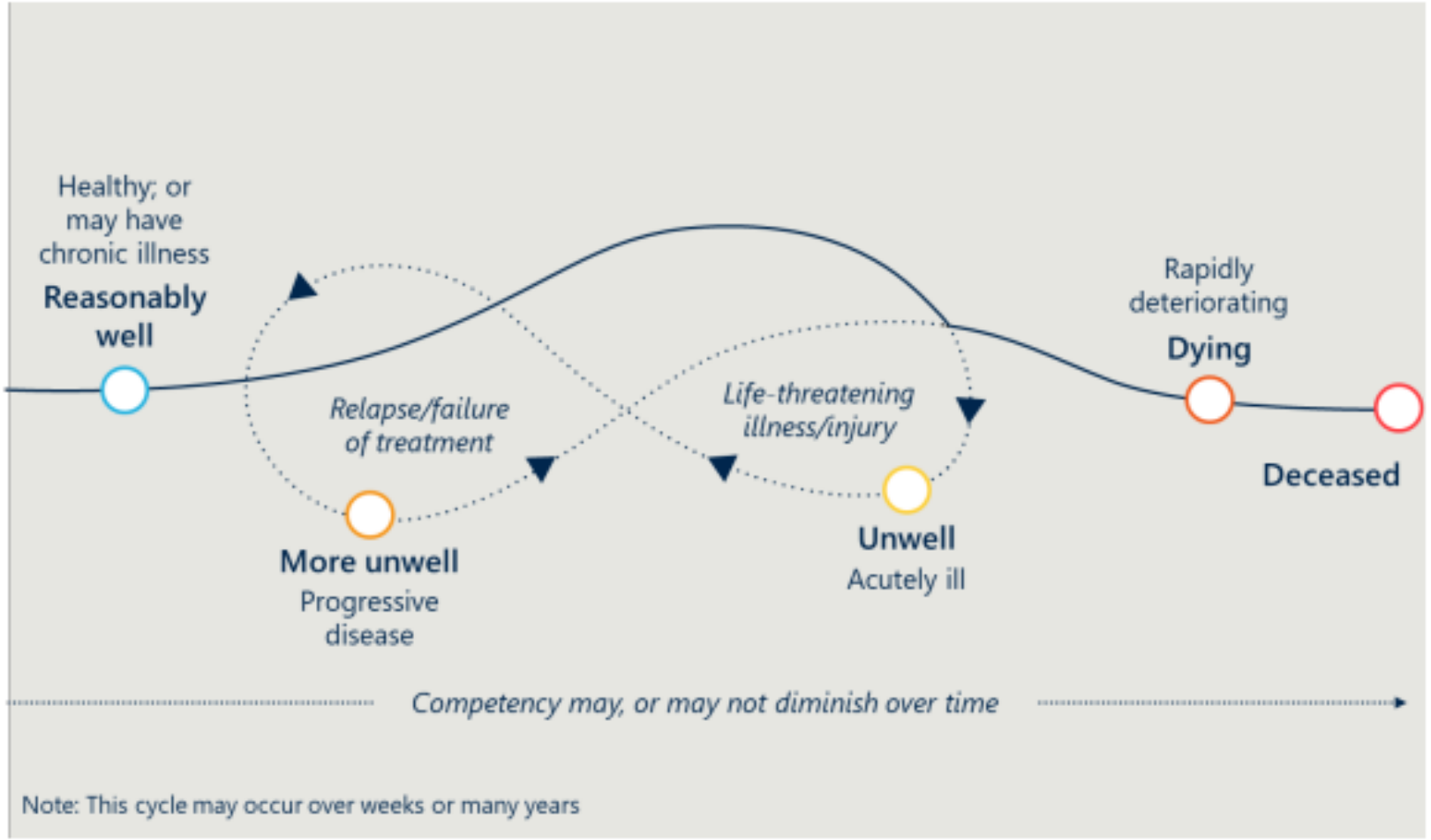
Figure 1 | The 3 iterative stages of advance care planning



Reference:

ADVANCED CARE PLANNING TRAJECTORY

Figure 2 | Individuals may consider advance care planning at any point in time, including in response to certain triggers



Reference: National framework for advanced care planning documents

COMMON TRIGGERS

- Proactive future planning such as advance care planning that is concurrent to financial or estate planning during periods of good health
- Diagnosis of a life limiting illness
- Diagnosis of a chronic condition
- Involvement in someone else's advance care planning process
- Prior to admission to aged care services
- Beginning palliative care
- Advent of new medical treatment
- Change in family dynamic such as births or deaths
- Illness or death of a loved one

Houben CHM et al, 2014

HAVING THE ADVANCED CARE PLANNING CONVERSATION

Is an opportunity for individuals to think about their future care

It is a process rather than an event

Advanced care planning process is likely to lead to several possible outputs:

- Conscious decision not to make decisions about future care or a decision to allow other people to make choices about future care in the absence of any recorded instructions
- Decision to compete or update an Advanced Care Directive for preferences or care
- Decision to complete or update an Advance Care Plan outlining what is important to the individual to inform future care decisions or directions on treatment.

ACCESSING AND ENACTING ADVANCED CARE PLANNING DOCUMENT

Advanced care planning documents should be enacted only when an individual cannot make decision for themselves

- Existence of an advanced care planning document should not preclude or replace the individual's right to make decisions whilst they are able to do so

Advance care planning documents should be accessible

Advance care planning document can be presumed valid

The values and preferences set out in an advanced care planning document should be reflected into medical treatment decisions.

BEST PRACTICE PRINCIPLES IN HAVING ADVANCED CARE PLANNING CONVERSATIONS

Advanced care planning documents are not mandatory and might not be appropriate for everyone

The advanced care planning process should be undertaken in a way that is sensitive to the individual's needs

- i.e. using interpreters, in a culturally safe context, linking with health services to underserved population groups

Information about future care and advance care planning should be available to all individuals

Individuals can develop and update advanced care planning documents any time in their life

It should be up to individuals to choose whom they would like to involve in discussions

Individuals should be informed that advanced care planning documents should not substitute a will that manages financial and legal affairs

BEST PRACTICE PRINCIPLES IN HAVING ADVANCED CARE PLANNING CONVERSATIONS

Substitute decision makers should be involved in the advance care planning as early as possible.

- Individuals should appoint a substitute decision maker who can make decisions that align with their own values.
- Substitute decision makers should deeply understand individuals' values and preferences in order to be involved in the advanced care planning process.

- Some problems with substitute decision makers - don't reflect the patient's wishes
- Way to solve this – substitute decision makers need to have many discussions to fully understand the individual they are representing

BEST PRACTICE PRINCIPLES IN HAVING ADVANCED CARE PLANNING CONVERSATIONS

An Advanced Care Directive (ACD) must comply with the local legal requirements to be valid.

An individual requires decision-making capacity to make a valid ACD

- Understand the facts
- Evaluate reasonable implications
- Use reasoned processes to weigh the risks
- Communicate relatively consistently

BEST PRACTICE PRINCIPLES IN HAVING ADVANCED CARE PLANNING CONVERSATIONS

ACP documents should focus on communicating an individual's preferences in a way that can be understood and enacted by others.

ACP documents should be in plain language.

ACP documents should be afforded the same privacy as other health records.

Reasonable steps should be taken to locate ACP documents when required – they should be available at short notice.

BEST PRACTICE PRINCIPLES IN HAVING ADVANCED CARE PLANNING CONVERSATIONS

Substitute decision makers should follow a specific pathway when making decisions about an individual's care.

Established hierarchy of decision makers when enacting ACP document

1. The individual, to the extent that they are competent and capable to make decisions either on their own or with support.
2. A legally appointed substitute decision-maker or, if required, another substitute decision-maker set out in state and territory law.

Decisions made by others should align with records according to the following hierarchy:

1. Advance Care Directive
2. Other verbal or written expressions by a competent individual
3. An Advance Care Plan

HOW TO DISCUSS ADVANCED CARE PLANNING WITH YOUR PATIENT?

"Steps" of Advance Care Planning

STEP 1: THINK ABOUT YOUR VALUES AND BELIEFS

What makes your life meaningful?

How do you feel about being…

If you were nearing death, what would you want to make the end more peaceful?

When you think about care at the end of your life, do you worry more about; not getting enough care, getting overly aggressive care, anything else?

Do you want your doctor to be focused on maximising the length of your life, the quality of your life, anything else?

If possible, would you prefer to die…

STEP 2: LEARN ABOUT INFORMATION THAT IS RELEVANT TO YOUR CURRENT HEALTH SITUATION

Other questions that could be asked by the patients when planning their ACP

- What your life will look like 6 months / 1 year / 5 years from now
- Odds of recovery picking one course of treatment over another
- Possible big changes in your health to prepare for
- Your ability to function independently
- If you decide against treatment

STEP 3: DECIDE ON SUBSTITUTE DECISION MAKER(S)

Who do you trust to make decisions based on your values and wishes?

Who is able to communicate clearly?

Who is willing and available to speak for you?

Who can make difficult decisions in stressful situations?

If you were diagnosed with a terminal illness, who would you tell first?

Who would you turn to for advice? Who would you NOT turn to for advice?

STEP 4: HAVE THE TALK!

Advance care planning means having discussions with your substitute decision maker(s), with family and friends, and your health care team.

Ideas for starting the conversation with others

- "I need your help with something"
- "I was at a workshop today and I would like to share the information I learned with you"

Awkward? Maybe.
Important? Definitely!

STEP 5: DOCUMENT YOUR WISHES

It is important to write your wishes down or make an audio or video recording

Remember to Review and Revise

- When there are life changes – births, deaths, marriages, transitions, moves
- When there is a change in your health status
- If you change your mind about your preferences
- When new information is available
- Annually

File in hospital records and/or My Health Records

PRACTICAL TIPS ON HOW TO START THE CONVERSATION…

Setting up: Be well prepared, privacy, involve significant others, build rapport, allow time

Perception: "What is your understanding of your current state of health?"

Invitation: "So you are wondering how long you might have – is that something you want to talk about now?"

Knowledge: Avoid medical jargon, give a few facts at a time then pause and check understanding

Emotion: non-verbal skills/verbal

Strategy: Summarise the conversation – present treatment options i.e. plan, goals. Ensure it aligns with information you gathered

RESPOND WITH EMPATHY AND EMOTIONS

Name it"…it looks to me like you are concerned, or maybe worried?"

Understand"…Sounds like you have had a difficult few weeks"

Respect/Reassurance"…I am impressed you've managed…"

Support"…I like to make this situation better – so I will be here to help, and so will my team"

Explore"…Tell me more…I'd like to have a better picture of what is going on for you"

…Allow for pauses and silences…

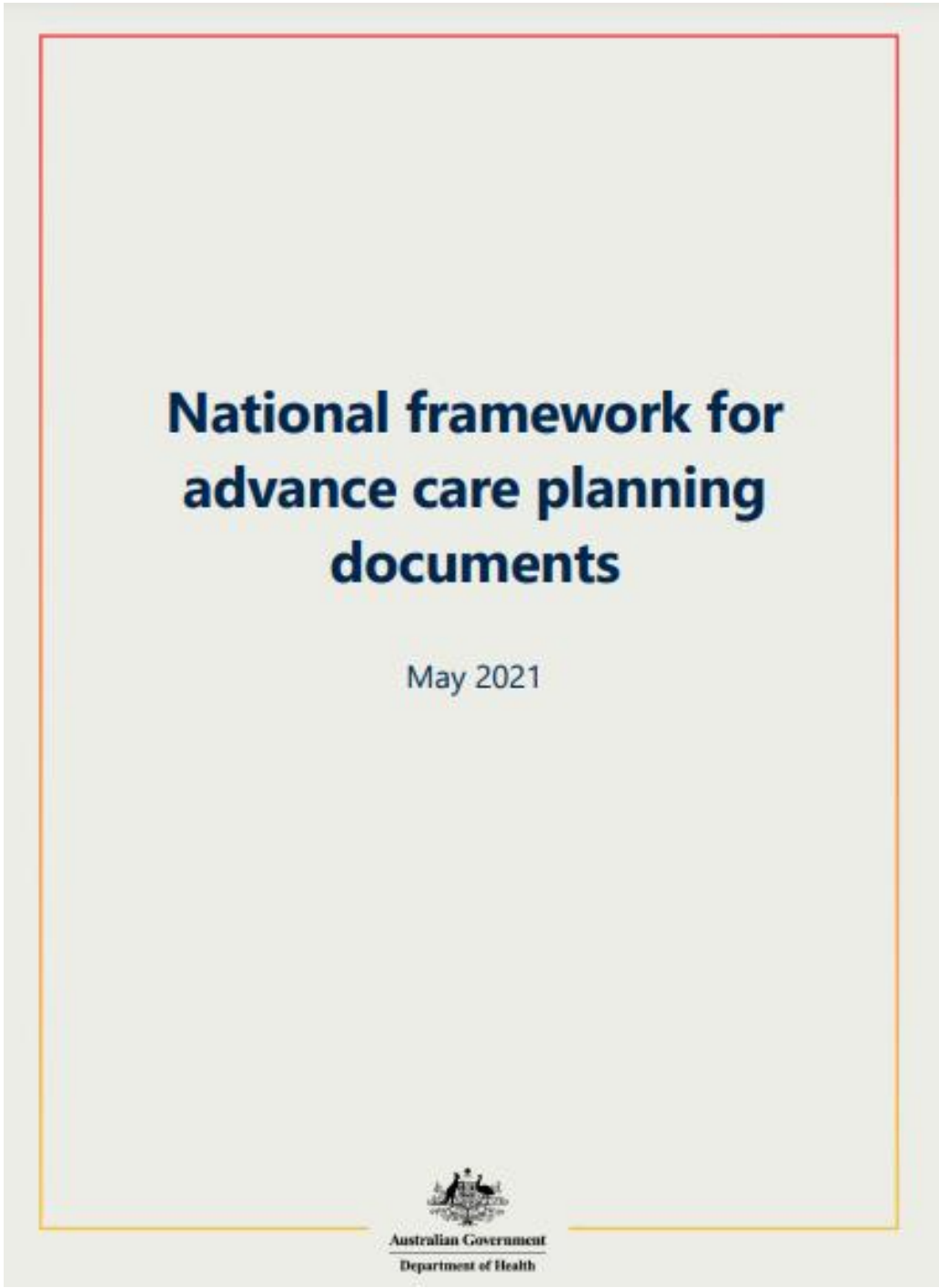
WHY DO WE NEED A GUIDE TO IDENTIFY PEOPLE WHO MAY BENEFIT FROM ACP?

"Clinicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions, to increase the likelihood of delivering high-quality end of-of-life care aligned with the patient's values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations."

(Australian Commission on Safety and Quality in Healthcare, 2015)

BASED ON:

Reference:



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