Advance Care Planning Procedure V0.2
CC-CC-Adv-7651
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Aim:
These guidelines are designed to assist the health professional(s) support an individual to think about, discuss, plan, review, and potentially document their wishes for their future health and end-of-life (EOL) care. The guidelines are underpinned by the Catholic tradition of a culture of life that affirms “all life is to be valued and nurtured until the moment of death”.(1)

Objectives:
This guideline is intended to assist St Vincent’s Care Service staff to support the individual with ACP if that is their expressed wish by:
• Ensuring the topic of ACP is introduced in a sensitive and empathetic manner
• Structuring discussions to elicit ACP care and wishes
• Recording ACP care and wishes on an appropriate document if required
• Reviewing and updating ACP as required
• Assisting the individual to inform others of their decisions
• Ensuring the ACP is followed when the need arises

Related policy:
• CC-CC-Adv-7650 Advance Care Planning Policy

Applies to:
• All staff

Delegation of Authority and Responsibilities:
Manager
• To implement this policy and ensure that all staff are informed of what is expected of them
• To ensure staff are provided with or have access to this and related policies / procedures
• To monitor, discuss and document the implementation of the policy
• To address ongoing issues with implementation of policy as they arise

Staff
• To be familiar with policy and related policies / procedures
• To seek clarification on any aspect of the policy / procedure from either their manager or other nominated staff if unsure.

Definitions:
Advance Care Planning: The process by which an individual, together with their chosen representative, family and healthcare practitioners, considers their values and goals and articulates their preferences for future care.(2)

Advance Health Directive (AHD) or Advance Care Plan (ACP): A formal or informal document containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios.(4)
Formal legal advance care planning document in QLD is the “Form 4 Advance Health Directive”

Informal documents e.g. St Vincent’s Care Services “Statement of Wishes for Future Health Care”, or any other written instruction (not legally binding)

ACP Facilitator: A staff member who has completed the St Vincent’s Care Services ACP Education Program.

Capacity: When an adult can understand the nature and effect of decisions (including the consequences of refusing treatment), can freely and voluntarily make those decisions, and then communicate the decisions in some way.(7)

End-of-life: Umbrella term to denote that part of life where a person is living with, and impaired by an eventually fatal (or terminal) condition even if the prognosis is ambiguous or unknown. End of life care may refer to varying prognostic time spans where it is acknowledged that the person’s condition will no longer respond to curative treatment, and may be used to describe deteriorating illness trajectories for up to 2 years before eventual death.(4)

Health Practitioner/Professional: A health practitioner or health professional has the appropriate accreditation, authority and/or expertise to assist a person in the process of informed decision-making and can include medical, dental, and nursing practitioners, pharmacists, physiotherapists, social workers and other allied health professionals, radiographers, ambulance paramedics, Aboriginal and Torres Strait Islander health workers and linguistic interpreters.(5)

Representative: Is a person who by nature of the authority of their relationship to the individual, or by appointment by the individual, or by legal appointment, can make decisions on behalf of the individual in the event the individual cannot speak for him/herself.(6)

Procedure Overview:

Although definitions vary slightly, ACP commonly refers to an individual reviewing their wishes for future health care and health care professionals supporting them throughout the process. ACP is relevant to all people, but becomes closer to people’s thinking when their condition is such that they perceive their lives could be coming to a foreseeable close, even if that is over a period of years.

There are several parts to ACP. Some, all, or only one of these parts may be relevant for an individual, their representative/s and families.

- They may simply consider their values and wishes about their own life and death, and the care they would wish for
- They may talk to health care professionals about the dying process and future scenarios in their health
- They may talk to family and friends about these matters
- They may determine a substitute decision-maker (representative) and/or may make this a legally formalised arrangement
- They may consider organ donation, wills, and/or funerals
- They may record any of these elements in written form, either formally or informally. (4)
The Role of Staff in ACP:

Each member of the care team has a role to play in ACP. A staff member, who does not feel confident in a part or all of the ACP process, must refer to the ACP Facilitator and/or their manager for assistance. The responsibility for each designation of staff is outlined below.

**Assistant in Nursing (AIN) / Community Service Worker (CSW):**
- Awareness of the Ethos of Catholic Health Australia and St Vincent’s Care Services ACP Policy and Guidelines
- Be able to identify and support an individual’s wishes to pursue ACP
- Refer the individual to their supervisor for ongoing ACP discussions
- Attend/access education on ACP as appropriate
- Provide EOL care as directed

**Pastoral Carer:**
- Awareness of the Ethos of Catholic Health Australia and St Vincent’s Care Services ACP Policy and Guidelines
- Be able to identify and support an individual’s wishes to pursue ACP
- Initiate purposeful discussions on ACP on the request of the individual or their representative and family. Pastoral Carer completing purposeful discussions on ACP must have completed St Vincent’s Care Services ACP e-Learning and facilitated learning modules
- Involve the Registered Nurse /GP should the discussion relate to clinical issues
- Provide support to staff around EOL care
- Provide EOL care as required

**Enrolled Nurses (EN):**
- Awareness of Ethos of Catholic Health Australia and the St Vincent’s Care Services ACP Policy and Guidelines
- Identify and support an individual’s wishes to pursue ACP
- Initiate purposeful discussions on ACP – this is a delegated activity from a Registered Nurse (RN) in line with the ANMC Nursing Practice Decision Flowchart. EN completing purposeful discussions on ACP must have completed St Vincent’s Care Services ACP e-Learning and facilitated learning modules prior to delegation by the RN
- General discussion with the individual that leads to a conversation on ACP can be initially managed by the EN with referral to the RN. It is expected that detailed discussions regarding specific health scenarios are performed by RN’s, General Practitioners (GP) and other medical specialists.
- Attend/access education on ACP as appropriate
- Provide EOL care as directed

**Registered Nurses (RN):**
- Knowledge of Ethos of Catholic Health Australia and the St Vincent’s Care Services ACP Policy and Guidelines
- Provide education and information to the individual and their representative on ACP
- Document ACP as per the individual’s wishes on an appropriate form (as required)
- Plan, implement and deliver, monitor and review the ACP and EOL care with the individual, their representative, family and the care team as required
- Communicate care needs and outcomes to the care team including the individual’s GP and other medical specialists
- Educate and support CSW/AIN and other staff in regards to ACP

**Managers:**
- Knowledge of Ethos of Catholic Health Australia and the St Vincent’s Care Services ACP Policy and Guidelines
- Oversight of ACP processes to ensure compliance with the Ethos of Catholic Health Australia and St Vincent’s Care Services ACP Policy and Guidelines
- Promote a culture that supports ACP
- Enable staff to participate in ACP educational activity

**St Vincent’s Care Services Support Services:**
- Ensure organisational ACP Policy and Procedures are written in-line with the Ethos of Catholic Health Australia
- Promote a culture that supports ACP
- Make educational resources available to support staff that are initiating and/or facilitating ACP

**Risk Management:**

**Spiritual Distress:**

It is neither expected nor deemed appropriate for staff to advise, counsel or investigate to seek solutions to spiritual distress if that is outside their scope of practice and expertise. If spirituality or family related issues arise during ACP, the individual and/or their representative should be encouraged to seek an appropriate professional/s to support them in their exploration. Staff should provide assistance in the referral process if this is unable to be completed by the individual. An appropriate professional could include:
- St Vincent’s Care Services Pastoral Carer or other pastoral worker of the individual’s faith / religion
- Clergy or similar of the individual’s faith / religion
- Social Worker

**Legal issues:**

Witnessing of St Vincent’s Care Services ACP documents can only be done by an ACP Facilitator, Health Professional, or Community Program Manager/Coordinator. Staff must not witness or complete any external ACP documents e.g. Form 4, Advance Health Directive.

**Capacity:**

In law, all adults are recognised to have capacity to decide if they wish to receive healthcare or not, except when it can be shown that they lack the capacity to do so. Discussions about ACP should ideally involve the individual, but when they lack capacity to make an informed decision it becomes a much more complicated situation. To be deemed to have capacity an individual must have the ability to:
- Receive, comprehend, retain and recall relevant information
To process the information received and relate it to one’s own situation, and to evaluate the possible outcomes in relation to one’s goals, values and beliefs

To take responsibility for one’s choices

To communicate a decision (8)

Any question as to whether an individual lacks capacity to make an informed decision is to be referred to the individuals General Practitioner (GP) or Specialist. The RN should ensure all relevant nursing assessment is current and completed in full to assist with the assessment process e.g. Psychological Assessment Scale (PAS).

It must also be remembered an individual’s capacity to make an informed decision can fluctuate. In this instance and where possible, decisions should be delayed until the individual can participate in the decision-making process.

**Appointing a representative:**

If an individual lacks capacity a ‘representative’ can speak on behalf of the individual. There are three ways in which someone may become a representative (4, 9):

- The representative is appointed via a legal process in a court or tribunal e.g. Guardian
- The representative is appointed by the person
  - Enduring Power of Attorney for Health and Personal Matters - appointed via a legal process
  - A nominated representative - appointed in an informal document
- The representative has legal authority automatically as the person’s spouse, carer, other next of kin or close friend e.g. Statutory Health Attorney

**Decision making by the representative:**

Issues of informed decision-making may also relate to the individual’s representative. If the RN, in consultation with the Clinical Manager and/or Facility Manager and the individual's GP feels the representative is not making decisions which are in the best interest of the individual then a case conference should be initiated inclusive of the key stakeholders involved in the individual’s care to discuss concerns.

**Starting the Conversation about ACP:**

**ACP Resources:**

The minimum information to be offered to an individual, their representative and family who request or agree to discussions about ACP is the following Catholic Health Australia (CHA) documents which can be downloaded from the St Vincent’s Care Services Intranet:

- CHA ‘A guide for people considering their future health care’
- CHA ‘Brochure on End of Life Decisions’
- CHA ‘Brochure Nutrition and Hydration in End of Life’

St Vincent’s Care Services has an informal ACP available on the intranet. This document is known as the ‘Statement of Wishes for Future Health Care’. This document can be offered to individuals and/or their representative to record the outcome of ACP discussions. It is not a mandatory requirement for the individual or their representative and they may choose to record their wishes in another way.
This form can also be accompanied by an information sheet 'Information Sheet Statement of Wishes for Future Health Care’ to assist the individual and/or their representative understand the form.

Additional information for individuals and their families can be accessed via the following websites:

- Queensland Health Booklet: “Advance Care Planning”, February 2010

Services should also make ACP material generally available where appropriate (on notice boards or information tables, at reception or nurses stations) for visitors to access.

When to offer ACP resources

Pre Admission:
Due to the sensitive nature of the topic it is suggested that services formally introduce ACP post admission. However, staff need to be ready to provide information to an individual, their representative and family or significant others upon request.

On Admission:
It is not an expectation that every individual entering a St Vincent’s Care Service will want to discuss or develop an ACP. It is expected that:

- An individual will be informed an ACP process is available
- The CHA ‘A guide for people considering their future health care’ is offered to the individual and/or their representative
- Staff will allow a period of time for everyone involved to respond regarding their interests in an ACP conversation which may extend to one month or more as they come to terms with their needs and if they wish to progress
- Trained staff is made available to provide them with information and support

Note on Trained Staff:

Health professionals and non-health professionals facilitating ACP discussions and making records of those discussions should have completed the internal St Vincent’s Care Services ACP Education Program or a recognised external education program on advance care planning e.g. Respecting Patient Choices. They must be able to relate ethical codes and guidelines of CHA as they apply to advance care planning and end of life care. Staff members completing the St Vincent’s Care Services ACP Education Program are referred to as an ACP Facilitator.

During Ongoing Care:

Initiating ACP may also be prompted at other times in an individual’s journey with St Vincent’s Care Services and hence may start at any time after admission.

Conducting Planned ACP Conversations:
When conducting ACP conversations, the ACP Facilitator will use person-centred communication to build a therapeutic relationship so the individual, their representative and family can express their wishes in comfort and with clarity. ACP conversations should flow through a loosely standard format to ensure that it is fully informed and consistent with St Vincent’s Care Services processes. However,
there is an expectation that there is flexibility within the format to allow for the nature of the people involved and the situation which has led to the conversation.

**Preparation:**

Things to consider before the conversation (if it is a scheduled one):
- Does the individual have capacity to participate in decision making about ACP?
- Establish if there is an EPOA (Health) or an appointed representative
- Does the EPOA have capacity to make decisions on behalf of the individual?
- Does the individual wish to have family member/s present (this is to be encouraged)?
- Check the knowledge and understanding of the EPOA/representative/family about their loved one's condition and future health wishes

**Content:**

The ACP conversation should include the following:
- Introduce yourself and explain the purpose of the conversation
- Provide introductory materials to ACP and CHA documents
- Establish an understanding of what they know about their health status
- Time and encouragement is given to establish important elements of their beliefs, needs, wishes
- Do not push the need for a written document if they are not ready, or accepting of it
- Discuss benefit verses burden of treatment/s and likely scenarios for example: resuscitation, dialysis, intubation, antibiotics and artificial ventilation

**Reaching Agreement:**

One of the goals of ACP is for the individual, their representative and family to have enough time to consider and discuss what is important to them at the end of life, so that there is an opportunity to address disagreement and reach, if possible, a common understanding of the individual's wishes. Questions that can assist to facilitate a shared understanding are:
- What did the individual involved want (if anything is genuinely known about that)
- Any signs as to what the individual in fact wants now
- The capacity of the family or others to look after the individual
- The views of the family and relevant others regarding the appropriateness of the proposed care
- Any relevant authority required by law (11)

**Medical Futility & Benefits verses Burdens:**

CHA supports an “obligation to use those means of sustaining our lives that are effective, not overly burdensome and reasonable available...that people have the right to refuse treatment that is futile, or that is overly burdensome or morally unacceptable...treatment is futile if it provides no benefits”. (10)

Providing information to support decision making by assisting the individual, their representative and family to weigh up the difference between the benefits and burdens of treatment is an integral part of the ACP conversation. The following table provides some guidance to inform conversations. (11)
The benefits of treatment include:

- Slowing down the progress of disease
- Sustaining the patient’s life or
- Relieving the patient’s distress or discomfort

Treatments are burdensome when they:

- Cause distress or suffering
- Cause difficulties for the patient or the family (or the community)
- Are costly to obtain or provide

Issues which can be discussed regarding treatment may include:

- Pain and discomfort
- Nutrition & hydration
- Loss of lucidity
- Breathlessness
- Extreme agitation
- Alienation
- Repugnance
- Cost to the person
- May also include excessive demands on family, carers or healthcare resource

Recording of ACP Wishes:

Existing Documents:

If an individual enters into a St Vincent’s Care Services service with an existing AHD / ACP or the individual or their family member states there is an existing AHD / ACP staff should:

- Request the original and make a copy (as appropriate to the type of document)
- File the document in the ACP section in the individual’s file

Recording of future health care wishes on the ‘Statement of Wishes for Future Health Care’:

St Vincent’s Care Services has an informal ACP called ‘Statement of Wishes for Future Health Care’. The following individuals can complete this form:

- The person themselves
- The appointed representative
- An ACP Facilitator
- Health Professional

On completion of the Statement, a record must be made in the progress notes that the ACP process has taken place. It is appropriate to head the progress note with ‘Advance Care Planning’. The following is an example of wording for a progress note entry:

‘Advance Care Planning: ACP conversation finalised with Alice and her daughter Mary. Statement of wishes for future health care completed and filed in ACP section. Dr. Smith informed’.

The Statement of Wishes for Future Health Care must then be filed in the ACP section of the individuals file.

Recording future health care wishes on other informal documents

It is accepted that some individuals will not wish to use the St Vincent’s Care Services form and may opt for an informal document e.g. a letter. If possible, an individual, their representative and family should be encouraged to ensure these documents are dated and signed appropriately. They should also be encouraged to ensure that the residential aged care facility or community service has a copy...
along with the individual’s General Practitioner (GP). Informal documents related to ACP must be filed in the ACP section of the file.

**Recording of future health care wishes by internal Health Professionals / ACP Facilitators**

Some individuals may not wish to record their ACP wishes on a pre-prepared form or letter but still want their wishes written down. In this instance, the Health Professional or ACP Facilitator must record details of the individual’s wishes on a progress note ensuring the intent as well as the individual’s own words are captured. The progress note should be clearly identified as the Advance Care Plan and filed in the ACP section of the file.

**Recording of future health care wishes by external Health Professionals**

If an external health or professional person (GP, lawyer) facilitates a discussion with the individual and/or their representative about ACP whilst they are receiving services from St Vincent’s Care Services, staff should request a copy of the document and/or recorded conversation to store in the ACP section of the file.

**Recording of future health care wishes without Representative/s, family and/or GP support**

Completing an ACP without the involvement of a representative/s, family or GP does not meet the principles and ethos of ACP. However, it is recognised this situation may occur. If intervention to gain involvement is not successful, the staff should seek consent from the individual to release information and provide copies of the ACP to the individual’s representative, family, GP and other relevant key stakeholders.

**Recording of future health care wishes on “Form 4 Advance Health Directive” (AHD)**

If an individual wants to complete a formal AHD, the staff member can:

- Suggest where the form can be acquired (post office or downloaded from the internet)
- Advise what information the form covers
- Inform the individual and their representative how the form is completed
- Liaise with the resident’s/client’s GP or other professional to facilitate the process

Under no circumstances can a St Vincent’s Care Services staff member:

- Complete an AHD on behalf of the individual or their representative
- Witness an AHD

**Communicating ACP to the Care Team**

Once an individual has completed the ACP process or alternatively enters the facility with an AHD/ACP a notation is placed permanently onto the handover sheet to identify those individuals.

**Storage of ACP Documents/Information**

Having ACP documents readily available is crucial to decision making particularly in an emergency situation when things can get emotionally charged. Access to ACP documents will be supported by having a standard ACP section in all St Vincent’s Care Services resident and client files. The ACP section will be placed at the front of the file identified by an appropriately named divider and/or plastic folder.

- All documents related to ACP must be stored within this section
If the resident or their representative has declined then a record of this conversation must also be included in the ACP section of the file.

Staff working directly with the individual must have access to ACP information regardless of the time e.g. weekends and night duty. Where separate administrative and clinical files are maintained, the original ACP is stored in the administrative file and a copy stored in the working clinical file.

**Declining to complete an ACP**

An individual, their representative and family have the right to decline to participate in an ACP process. This information will be recorded in the progress notes:

‘Advance Care Planning: Offered ACP. Alice and her daughter Mary decline at this stage.’

A copy of the progress note must be placed into the ACP section of the file.

**Transfer of ACP Information: DO NOT SEND ORIGINAL DOCUMENTS**

In the event an individual with an ACP is transferred from the facility, staff should make every effort to inform the receiving facility and treating doctor of the documents existence.

- If the individual is from a small community or regularly attends a private hospital it is advisable they hold a copy of the ACP information. This can be achieved by:
  - Individual representative providing the hospital with a copy of the ACP documents and/or having a discussion with staff about the individual wishes
  - Staff copying the ACP document or any document/record that outlines the individual’s ACP wishes and including it in the transfer information
- If the individual is from a large metropolitan area where there are a number of potential hospitals to which they can be sent, the ACP information is to be copied and sent with the transfer information. This must occur each time the individual is transferred.

**Review of ACP Information:**

As people’s experiences change, their wishes related to their future health care may also change. Treatment that once provided a benefit may seem burdensome in the light of ongoing deterioration, or a change in life events and the development of new treatment/s may focus the individual on a more aggressive care pathway.

Individuals who have an ACP document must be followed up to ensure their recorded wishes are reflective of their current situation. If they have lost capacity since the ACP was developed then their relatives or other identified representative must be asked to review the ACP information.

As a minimum, an ACP must be reviewed:

- Three monthly with the care plan review
- If the person experiences a change in their health status or cognition
- When the person or their representative requests a review
- If there is a change in the representatives situation
- Before an individual is transferred to another facility (if time allows)
Supporting ACP in End of Life:

When EOL care is invoked according to the individual’s wishes, all staff directly involved in care should be informed. How much information is provided is directly related to the staff member’s level of responsibility and allocated tasks.

Whilst attempts should be made to honour the individual’s wishes, there may be circumstances where these wishes cannot be followed due to the nature of the emergency or situation. It is important for staff involved in EOL care to understand the complex nature of the decision making that surrounds ACP and to understand that the individual’s best interests are at the centre of decision making.

Conflict from any source regarding what decision/s are to be made at EOL according to the individual’s Advance Care Plan is best supported by analysing the current situation against the individual’s expressed wishes and those of the representative. The analysis is expected to include senior staff, the appointed representative and the treating medical officer. Samples of questions to support analysis are:

- Do the present circumstances correspond to the situation that the individual imagined when he or she recorded his or her values and wishes?
- Do the treatment and care options available correspond to those of the individual’s future health care plan?
- Do the effects of implementing the individual’s values and wishes correspond to the effects that the individual understood would be their consequence?
- Are there new or changed factors in the present circumstances that the individual may not have taken into account but might have wanted to be considered in the present circumstances? (4)

Getting help

When conflict or ethical issues arise it can be very distressing and emotional for everyone involved.

In this situation:

- Staff should speak to their RN or Program Coordinator who will escalate the issue to the Clinical / Facility or Service Manager as necessary
- The Clinical / Facility or Service Manager can contact the Mission Executive, St Vincent’s Care Services for assistance.

Medical Officers:

Although decisions about EOL care may be documented on an Advance Care Plan, “doctors have multiple legal and ethical duties in caring for people including duties to take reasonable care, to inform, to preserve life, to maintain confidentiality and to meet professional standards”(12). Here in Queensland a doctor must ensure decisions made about an individual’s medical treatment is based on ‘good medical practice’. This expectation is supported by law and as such allows the doctor to:

- Follow the choices and wishes as documented on the Advance Care Plan and/or
- Provide treatment based on good medical practice which is contrary to stated wishes on the Advance Care Plan
Appendix 1 - Advance Care Planning (ACP) – Sustainability Model

1. ACP Education Program is delivered as part of the orientation program for the following staff:
   - **Residential:**
     - Pastoral Carers
     - Senior nursing staff e.g. Clinical Manager, Clinical Nurse
   - Note: Facility Manager or RN can be substituted as per site requirement
   - **Community:**
     - Pastoral Carers
     - Community Program Coordinators

2. The staff member/s undertaking the ACP Education Program will:
   - Be recognised as an ACP Facilitator and be able to conduct ACP conversations with individuals at their facility / service.
   - Employ a ‘train the trainer’ model to educate staff at their facility / service.
   - Be responsible for assignment of ACP elearning modules, coordination and delivery of the ACP face to face workshop at service level or as delegated by Facility/Service Manager.

3. HR / Clinical Learning and Development are responsible for:
   - Updating the content of the ACP Education Program in consultation with the ACP Facilitators.
   - Providing education support for ACP Facilitators at facility / service level as requested.
   - Central orientation workshop:
     - Scheduled as per the SVCS Residential Aged Care Education Calendar 2013 – 2015 in May and October every year.
     - Assignment, coordination and delivery of the central orientation ACP program.
     - Places will be allocated to new staff as a priority and then opened to the services (maximum of 12 participants per session).

4. Each site should have a minimum of 2 formally recognised ACP Facilitators – it is recognised there may be only 1 ACP Facilitator available while recruitment is occurring.

5. Records of conversations around Advance Care Planning will be audited as a part of the continuous quality improvement program.
**Document Management System (DMS) Data Field Summary**

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Community Care Standards: 2.2, 2.3, 2.4, 2.5, 3.1 |
| **Act:** | Aged Care Act 1997; Powers of Attorney Act 1998; Guardianship and Administration Act 2000 |
| **Australian standard:** | Australian National Safety and Quality in Health Care Standards – Standard 1 & Standard 9  
Palliative Care Australia –Standards of Care |
| **Guideline:** | Department Of Health and Ageing: Guideline to a Palliative Care - Approach to Care in Residential Settings |
| **Code of practice:** | Catholic Health Australia: “Code of Ethical Standards for Catholic Health and Aged Care Services in Australia”, 2001 |
| **Reference documents:** | 1. Catholic Health Australia, (2009) Provision of Palliative Care in Catholic Health and Aged Care Services, Advice for Staff, p.10  


6. Catholic Health Australia, (2009), Provision of Palliative Care in Catholic Health and Aged Care Services, p.54


9. Catholic Health Australia, A guide for health care professionals implementing a future health care plan, Catholic Health Australia, Canberra

10. Catholic Health Australia, (2009) Provision of Palliative Care in Catholic Health and Aged Care Services Advice for Staff, p.12, Catholic Health Australia, Canberra


15. Catholic Health Australia, A guide to people considering their future health care, Catholic Health Australia, Canberra


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