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Advance Care Planning in Residential Aged Care

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Abstract

Advance Care Planning (ACP) is encouraged for people, with decision making capacity, in anticipation of a future when the individual may not have decision making capacity in relation to medical treatment decisions. However, many residents in residential aged care will not have engaged in any form of ACP when they had decision making capacity and yet are now at a stage of life where significant medical decisions may need to be made.

- How can the preferences and values of these residents be elicited and given effect to?
- How can family members give voice to the preferences and values of the resident?
- What role is there for guardians to enable processes to ensure that the rights, will and preferences of residents are given effect to?
- What educative role can Public Advocates have in ensuring that health practitioners, residential aged care facilities, and the general community understand a decision making paradigm based on rights, will and preferences?

These are the issues that the Victorian Public Advocate has spent much time in contemplating how to progress. We will explain the resources that we have been developing to address these issues.

What obligations are there upon residential aged care facilities (RACF) to promote and coordinate Advance Care Planning (ACP)

Current Aged Care Quality Standards

- Residential Aged Care Facilities (RACF) must comply with the **Aged Care Quality Standards**
- There is no specific quality standard that refers to Advance Care Planning (ACP) processes but it flows from standard 2 which relates to **health and personal care**
  - care recipients' physical and mental health will be promoted and achieved at the optimum level in partnership between each care recipient (or his or her representative) and the health care team.

Current Aged Care Quality Standards

- Regulatory compliance: The organisation's management has systems in place to identify and ensure compliance with **all relevant legislation**, regulatory requirements, professional standards, and guidelines, about health and personal care.

- Relevant legislation (in Victoria)
  - *Aged Care Act* 1997 (Cth)
  - *Medical Treatment Planning and Decisions Act* 2016 (Vic) (**MTPDA**)

New Aged Care Quality Standards

- *Quality of Care Amendment (Single Quality Framework) Principles* 2018 (made under the Aged Care Act) – contains the new (8) standards (from **1/7/19**)
- Standard 2: ongoing assessment and planning with consumers
  - assessment and planning identifies and addresses the consumer's current needs, goals and preferences, including advance care planning and end of life planning **if the consumer wishes**
- Standard 3: personal and clinical care
  - the organisation delivers … clinical care … in accordance with the consumer's … **preferences**
  - information about the consumer's … **preferences** … is documented

User Rights Principles

- The Aged Care Act, Schedule 1: User Rights Principles
- Care recipients have a number of rights, including:
  - to full and effective use of his or her personal, civil, legal and consumer **rights**
  - to **full information** about his or her own state of health and about available treatments
  - to be treated and accepted as an **individual**, and to have his or her individual **preferences** taken into account and treated with **respect**
  - to maintain **control** over, and to continue making decisions about, the personal aspects of his or her daily life, financial affairs and possession.

What is Advance Care Planning (ACP)?

Definition of ACP

- ACP is a **process of planning** for future medical treatment, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions

- ACP is an **expression of autonomy**, involving:
  - making and communicating medical treatment decisions for oneself
  - expressing preferences and values to inform medical treatment decisions by a medical treatment decision maker.

Definition of ACP

- ACP does not have a *legislative* definition but States/Territories have legislation which regulate some forms of ACP. In Victoria, the MTPDA regulates:
  - appointing a medical treatment decision maker
  - appointing a support person
  - making an advance care directive (instructional directive and/or values directive).
- There are other forms of ACP
  - documenting one's preferences and values in a format other than an advance care directive
  - discussing one's preferences and values with family members and health practitioners.

This information assists a medical treatment decision maker to make a decision consistent with the person's preferences and values.

Why OPA is an unique voice in the ACP discourse

OPA – unique voice in ACP discourse

- OPA has a legislative mandate to minimise the restrictions on the rights for people of disabilities and to disseminate information about legislation dealing with or affecting persons with a disability
- OPA has a wholistic approach to dealing with the diversity of issues relating to disability and mental illness and all relevant legislation. Consequently, OPA is well placed to deal with difficulties created by an incomplete legislative narrative
- OPA engages with diverse stakeholders – government departments, health networks, disability advocacy organisations, the supported residential and aged care sectors, and the legal profession as well as the general community. OPA is aware that ACP requires a collaborative health/legal paradigm and given our multi sector engagement is well placed to promote this

OPA – unique voice in ACP discourse

- OPA has been involved in working towards reduction of abuse against people with disability and elder abuse and is cognisant of the need to ensure that decision making for people lacking decision making capacity is not abusive but reflective of the person's autonomy
- OPA is committed to supported decision making. Supported decision making should form part of the ACP discourse
- OPA has a role in making medical treatment decisions
- OPA has significant expertise about Enduring Powers of Attorney, medical treatment decision making, and VCAT Guardianship List processes
- The first edition of *Take Control* was published in **1993** and is currently in its **fourteenth edition**.

ACP is about human rights – human rights are UNIVERSAL

Every human is an individual – ACP is UNIQUE to individuals

ACP – human rights

- ACP is sourced in human rights, most particularly the right not to be “subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent.”
  - *Charter of Human Rights and Responsibilities Act*, 2006 (Vic)
- “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages.”
  - Justice Cardoza in Schloendorff v. Society of New York Hospital, **1914**

ACP is a creative process

- Given every individual is **unique**, ACP for any particular individual should reflect that. Although there are forms to assist people to document their preferences and values, the purpose of ACP is not rote form filling
- A form should be the **outcome** of a decision making process, the elements of which may include:
  - the person engaging in personal reflection; it is not always immediately obvious to any individual what their preferences and values are
  - the person engaging in discussions with trusted family members and friends and relevant professionals
  - the person researching health issues they have particular concerns about and discussing these with relevant health practitioners.
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What ACP is NOT

What ACP should **NOT** be

- ACP should not be for the convenience or benefit of other individuals or organisations
- ACP should not be an administrative, bureaucratised, form filling function of health and residential service providers
- ACP should not be a condition of accessing health and residential services.

OPA’s experience of ACP in RACF

OPA's experience: ACP in RACF

- OPA's Advocate/Guardians are often asked by RACF to sign documentation relating to end of life decision making, particularly resuscitation, at the time of admission of the resident. Usually, the expectation is that documentation is signed but no information is provided about how the completed form will be used and there is no meeting organised with anyone at the RACF, or with the resident's GP
- In the past these forms were usually called 'terminal care wishes' forms but are now likely to be called ACP forms
- It can be assumed that what is expected of a care recipient's guardian is otherwise usually expected of the care recipient, or a family member.

OPA's concern: ACP in RACF

- On occasions, OPA has been concerned that forms developed by some RACF have not been consistent with Victorian law. In particular, OPA has been concerned that some forms purport to invest a person with decision making authority in relation to a resident they do not have, or cannot have, under Victorian law
- In Victoria it is not possible for anyone but the person him or herself, to make a medical treatment decision in an **advance care directive** – that is, to make a medical treatment decision in anticipation of medical treatment being offered.
  - Prior to 12/3/18 it was possible for a guardian or medical agent to complete a Refusal of Treatment Certificate for an incompetent person.

OPA's concern: ACP in RACF

- **If** the person, *correctly* described as the medical treatment decision maker, is asked to make a medical treatment decision then the health practitioner would need to explain
  - the likely effects and consequences of the medical treatment, including the likely effectiveness of the medical treatment, and
  - whether are any alternatives.

- Given family members (and guardians) are usually asked to complete forms without any discussion about the proposed speculative treatment (for example, to consent to or refuse resuscitation) then it means:
  - they are being asked to make decisions they cannot lawfully make; and
  - they are being asked to make decisions without the information they require in order to make a decision lawfully (if in fact it is a decision they lawfully could make)

Example of RACF form

MEDICAL INTERVENTIONS (if there is a pulse and/or breaths)

☐**Comfort Measures** (Allow Natural Death) – relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Transfer to hospital for **comfort needs** (should needs not be able to be met in current location).
Treatment plan: **maximise comfort through symptom management**

☐**Limited Additional Interventions** – in addition to the care described in Comfort Measures, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. Use less invasive airway support (eg. CPAP, BiPAP) as indicated. **Transfer to hospital** if indicated.
Treatment plan: **provide basic medical treatments**

☐**Full Treatment** – in addition to the care described in Comfort Measures and Limited Additional Interventions, use intubation, advanced airway interventions and mechanical ventilation as indicated. **Transfer to hospital and/or intensive care unit** if indicated.
Treatment plan: **full treatment including life support measures in the intensive care unit**

OPA's concern: ACP in RACF

- This form requires signature by the resident or their 'representative'
- It may be treated at a future point as a decision (to consent to, or to refuse) medical treatment
- Some of this treatment would occur in the context of an emergency (and not require the consent of the medical treatment decision maker)
- The 'representative' may nor may not be the medical treatment decision maker (the representative is most likely to be the family member organising admission)
- The representative is being asked to make various and unknown decisions (antibiotics for …..) possibly without being provided any information about risks, benefits, alternatives, etc.

OPA's policy position

- Advocate/Guardians at OPA are instructed not to sign any RACF documentation which purports to be a pre-emptive medical treatment decision (such as 'Not for Resuscitation') as this is beyond the individual's legal authority. A position statement will be posted on our website shortly
- Our advice to family members similarly is not to sign documentation which purports to give them a legal authority they do not have.

What can be done in RACF to ensure that ACP programs promote each residents' wishes, preferences and rights?

OPA’s recommendation for ACP in RACF

The processes depend upon whether:

- The resident has decision making capacity (for …)
- The resident does not have decision making capacity (for …).

Note: the question must always be asked what specific decision is the person being asked to make or wishing to make – as there cannot be a global assessment of decision making capacity.

Decision Making Capacity

- An adult is presumed to have decision making capacity unless there is evidence to the contrary. This presumption includes residents of RACF. However, clearly in the case of many residents this presumption will be rebutted by evidence to the contrary
- According to Dementia Australia, 52% of RACF residents have dementia. However, a diagnosis of dementia does not in itself mean that the person lacks decision making capacity for any specific decision.

Timing for ACP discussions with resident

- The point in time when a resident is admitted to a RACF will ordinarily be a stressful time for them and may follow some crisis in the community or discharge from hospital
- It is therefore possible that for some residents their decision making capacity may be more impaired at this time than at some short point in time in the future when they settle into their new accommodation and lifestyle
- It may therefore be wise to wait a while before attempting to engage a person in ACP discussions to maximise their capacity for decision making.

Practicable and appropriate support

A person has decision making capacity to make a decision if they are given practicable and appropriate support. This may mean:

- waiting until the person has settled in or their precipitating medical condition has stabilised allowing enough time for discussions, including allowing for several separate discussions
- ensuring that a person who may not previously have thought they needed an interpreter nonetheless has an interpreter given the possible complexity of the discussion (noting that it is common for people for whom English is a second language to lose some second language capacity associated with dementing processes)
- creating a calm non-conflictual space
- choosing the time of the day when the person is most cognitively alert

Practicable and appropriate support

- Respect privacy
- Reassure fears about death and dying
- Reassure concerns about upsetting others
- Ensure collaboration between family members
- Respect choices.

Expression of preferences and values

- Even if a resident lacks decision making capacity to make particular decisions
  - make a medical treatment decision
  - appoint a medical treatment decision maker
  - appoint a support person
  - make an advance care directive (instructional directive and/or values directive).

it does not mean they cannot express their preferences and values for current or future medical treatment decisions, that will be made for them by a medical treatment decision maker, and they should be supported and encouraged to do so.

What is the role of clinicians?

Planning by clinicians

- GPs who attend upon residents in RACF, like all health practitioners, should know the law as it relates to topics such as consent to treatment, decision making capacity, substitute consent
  - OPA has a fact sheet for health practitioners identifying their obligations under the MTPDA
  - AMA position statement on end of life care and advance care planning

- GPs can complete a Goals of Care form. This form was developed by a working group led by Dr Barbara Hayes, Clinical Lead of ACP at Northern Health. It is available on Northern Health's website and there is a link to it from OPA's website

End of life law for clinicians

10 free online training modules on end of life law, and 22 training workshops across Australia. Workshops will be held from February 2019 – June 2020

https://palliativecareeducation.com.au/course/index.php?categoryid=5

1. The role of law in end of life care
2. Capacity and consent to medical treatment
3. Withholding and withdrawing life-sustaining medical treatment
4. Advance Care Planning and Advance Care Directives
5. Substitute decision-making for medical treatment
6. Providing palliative medication
7. Children and end of life decision-making
8. Futile or non-beneficial treatment
9. Emergency treatment for adults
10. Managing conflict.

What is the role of family members?

What is the role of OPA guardians?

Planning by family members

- Family members can
  - speak with the resident and record what the resident is communicating to be their preferences and values; and
  - also reflect upon what they understand to be the resident's preferences and values; and
  - consult with any person that they reasonably think that the resident would want them to consult; and then
  - record what they understand to be the person's preferences and values.

Form: ***'What I understand to be the person's preferences and values'***

‘What I **understand** to be the person’s preferences and values’

This form was developed by a working group led by Dr Barbara Hayes, Clinical Lead of ACP at Northern Health. It is available on Northern Health’s website and there is a link to it from OPA’s website

The form is for family members/others concerned to ensure that the preferences and values of the resident are given effect to by a future medical treatment decision maker

Role of OPA Guardians

- OPA Advocate/Guardians (A/G) often make decisions that it is the best interests of the represented person to be admitted to permanent residential aged care.
- The A/G may during the course of this decision making have learnt something about the preferences and values of the represented person relevant to any future medical treatment decision making, whether or not it is expected that it would be the A/G who would make any medical treatment decisions. If so, the A/G can complete the form *What I understand to be the person's preferences and values*
- Otherwise, the A/G can direct the RACF or family members to relevant resources.

Types of medical treatment decisions for residents in RACF

Planning for likely medical treatment

Residents will need to make (or have made for them) medical treatment decisions that:

- anyone at any stage of life might need to make
  - dental treatment, influenza vaccination
- are common for people who have reached the life stage of needing residential care
  - podiatry, scans and diagnostic tests, medication to manage high blood pressure, cholesterol, etc.
- are common for people who have psychological and behavioural symptoms of dementia
  - psychotropic medication
- are likely end of life scenarios
  - cardiac/respiratory arrest (resuscitation?)
  - pneumonia (antibiotics?)
  - ‘putting down the spoon’ (PEG feeding?)

Planning for likely medical treatment

It would be useful if GPs and RACF provided information to residents and their family members about:

- likely types of medical treatment decisions
  - medication
- likely reasons for transfer to hospital
  - falls
- palliative care
  - describing what palliative care is, and
  - noting that a medical treatment decision cannot refuse palliative care
- most likely causes of death
  - ***Cause of death patterns and people's use of aged care: a Pathways in Aged Care analysis of 2012–14 death statistics*** **(Australian Institute of Health and Welfare):** Almost 245,000 older people died in Australia in the 2 years to 30 June 2014. The majority of people (80%) had used an aged care program before their death, and the leading causes of death were coronary heart disease, dementia and cerebrovascular disease.

Collaboration

Collaboration

- One of the principles of the *Medical Treatment Planning and Decisions Act* 2016 is that a partnership between a person and the person's family and carers and health practitioners is important to achieve the best possible outcomes
- A collaborative approach is highly recommended to ensure clarity of communication between the health practitioner (who has clinical expertise), the person (to the extent they can express their preferences and values) and their family and carers (who are concerned about the person and also have knowledge about their preferences and values).

Collaboration

- It is important that there are relationships between all the following:
  - the resident
  - the health practitioners
  - the RACF
  - family members and friends
  - the medical treatment decision maker
    - this may be an OPA guardian (but increasingly in Victoria it is less likely that VCAT will appoint the Public Advocate to make medical treatment decisions, as by default if the person does not have a medical treatment decision maker then the Public Advocate is empowered to make significant medical treatment decisions)

3 great life fears

Great Life Fear #1: Admission to RACF

Fears of residents

- loss of independence
- loss of identity – no longer being treated as an unique individual
- loss of decision making capacity
- loss of decision making control – respect for, and implementation, of one's preferences
- 'God's waiting room' – physical/cognitive decline

Fears of the residents' families

- not being able to advocate effectively for the resident's rights, preferences and values
- that the resident will have a difficult, painful dying process

Great Life Fear #2: Death

Residents may routinely die in RACF but the death of someone you love will always be one of life's most significant moments

"How people die remains in the memory of those who live on"

Dame Cicely Saunders, founder of the hospice movement

Informed and effective ACP may assist with ensuring that the memory is that the person's preferences and values were respected and implemented.

Great Life Fear #3: Public Speaking

Phew, just about done

Resources

OPA Resources available online

These 2 guides were developed by a working group led by Dr Barbara Hayes, Clinical Lead of ACP at Northern Health, and published by OPA

- ‘Medical decision making and the person who lacks capacity: for clinicians
- Medical decision making and the person who lacks capacity: for medical treatment decision makers

- There is a link to Northern Health website to these 2 forms :
  - ‘What I understand to be the person’s preferences and values’
  - Goals of Care

OPA Resources available online

- **Publications**
  - Take Control: a self-help guide to appointing a medical treatment decision maker, making an advance care directive, making an enduring power of attorney
  - Side by Side: A guide for people wanting support to make decisions
  - Supported decision making in Victoria: A guide for families and carers
  - Securing Their Future: a resource for parents, relatives and significant others caring for people with a decision-making disability
  - Medical consent flow chart (and app)
- **Practice Guideline: *Medical Treatment Planning and Medical Treatment Decision Making***

OPA Resources available online

Fact sheets (on OPA website)

- Obligations for health practitioners under the *Medical Treatment Planning and Decisions Act* 2016
- Advance care planning and mental illness
- Do I need the consent of the Office of the Public Advocate (OPA) for urgent medical treatment?
- Palliative care when the person does not have decision making capacity
- Treatment for mental illness: transitioning from the *Mental Health Act* 2014 to *Medical Treatment Planning and Decisions Act* 2016 for treatment for mental illness
- End of life decision making when there is no medical treatment decisions maker
- Advance Care Planning and substitute medical treatment decision making

OPA Resources in development

- Advance Care Planning and residential aged care
- Advance Care Planning and dementia
- Children, Medical Treatment and OPA
- Relationship Between Guardianship and Decision Making Capacity for Medical Treatment Decisions

These will be uploaded soon to the OPA website

OPA Resources in development

Overarching ACP resources

1. Publications and other resources
2. What is Advance Care Planning, who should do Advance Care Planning, when should Advance Care Planning be done?
3. OPA's Role in Relation to Future Planning (Including Advance Care Planning) and Medical Treatment Decision Making
4. Terminology of Advance Care Planning and Medical Treatment Decision Making
5. Advance Care Planning Options
6. Advance Care Planning is a Creative Process
7. Supported Decision Making
8. Relationship between substitute decision making and Advance Care Planning
9. Planning for people lacking decision making capacity
10. Clinical decision making
11. Advance Care Planning and Palliative Care

OPA Resources in development

Overarching ACP resources

12. Advance Care Planning and Treatment for Mental Illness
13. Advance Care Planning and Persons Aged Under 18 Years
14. Advance Care Planning and Residential Aged Care Facilities
15. Advance Care Planning and People Living with Dementia
16. Advance Care Planning and people with intellectual disability
17. Advance Care Planning and Indigenous Australians
18. Advance Care Planning and Culturally and Linguistically Diverse Communities
19. Advance Care Planning and LGBTI Communities
20. Advance Care Planning and Jehovah's Witnesses
21. Who can help you in doing Advance Care Planning?
22. Who can help you in making medical treatment decisions for another person?

Northern Health

- ‘What I understand to be the person’s preferences and values’
  - document is for family members/others concerned to ensure that the preferences and values of the resident are given effect to
- Goals of Care
  - document is for doctors

There is a link from OPA’s website

Advance Care Planning Australia

Advance care planning in aged care: A guide to support implementation in community and residential settings

https://www.advancecareplanning.org.au