Advance Care Planning Guidelines
January 2019

Gippsland Region Palliative Care Consortium
Clinical Practice Group

Title
Advance Care Planning Guidelines

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Person-centred, decision making, end of life, conversations planning, and clients’ outcomes.

Ratified
GRPCC Clinical Practice Group

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Purpose
The intent of this document is to assist health services and clinical staff across the Gippsland region to facilitate End of Life Care discussions and development of an Advance Care Planning for clients nearing end of life.

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Disclaimer
The intent of the GRPCC Clinical Practice Group endorsed clinical guidelines is to make them available to health services and clinical staff across the Gippsland region to promote evidence-based practice in delivering palliative care.

Clinical guidelines are intended to provide general advice to the medical, nursing, and allied health staff working with clients with a life limiting illness. These endorsed clinical guidelines are not a substitute to comprehensive assessment and critical thinking relevant to the particular patient’s individual clinical circumstances and degree of symptom burden. There may also be strong clinical evidence for choosing a therapeutic intervention that may be different to what is recommended in these guidelines. Timely consultation and advice from the palliative care service is always recommended, if appropriate, when using these guidelines.

When developing clinical guidelines, the GRPCC ensures the guidelines content is accurate and based on evidence. The GRPCC takes no responsibility for new clinical evidence or information that become available or be published following guideline distribution or nominated review date.

The GRPCC guidelines may be used by providers to develop similar protocols and procedures that can be customised according to the organising clinical context and requirements. Health organisations must also ensure that utilisation of these guidelines complement their organisational governance structure including health professional palliative care delivery scope of practice.
1. **Background**

Death is part of life and living, but the “management of death and dying” has had a direct impact on the way in which society communicates, or avoids communicating about, end of life care\(^1\). People need to be supported to develop an advance care plan that will guide medical treatment and care if they become unable to communicate their wishes, values, beliefs and preferences or participate in decision making. The Medical Treatment Planning and Decision Act 2016 was enacted in Victoria in March 2018\(^2\). An Advance Care Directive is the only legally recognised document that a person can record their medical treatment preferences in. However, should a person lose decision making capacity, any written record of their values or medical preferences must be considered by their medical treatment decision maker.\(^3\)

2. **Purpose of these guidelines**

The purpose of advance care planning guidelines is to support clinical staff to “have the conversation” with clients and caregivers about end of life decision making, engage clients and their families in decisions about their care and help them to undertake advance care planning. These guidelines aim in assisting health services in the Gippsland region to:

- develop and structure their own policies and procedures regarding introduction and progression of advance care planning;
- adapt and customise these guidelines to cater for their individual clinical needs and context of practice; and
- ensure effective initiation of advance care planning process and conversations that promotes clients and caregivers informed decision-making.

3. **Context of practice and target population**

This guideline applies to all interdisciplinary clinical staff, including general practitioners, who deliver palliative care in any of the subregional health services, including residential aged care facilities, in Gippsland.

4. **The objectives of these guidelines are to:**

- encourage clinical staff to engage in advance care planning conversations with clients when the client is stable and thinking clearly;
- facilitate a process of planning for the future health, treatment and care whereby a person’s values, beliefs and preferences are made known; and guide clinical decision
- making at future time when that person cannot make or communicate their decisions due to lack of capacity.\(^4\)
4.1 Intended benefits of these guidelines

The advance care planning process can involve writing an advance care plan that contains the client’s clearly expressed values and preferences. An advance care plan can also be used by clinical staff and doctors to inform decision making when the client becomes too unwell to participate directly.

Advance care planning places the client at the center of care, involving them, their medical treatment decision maker, their family (if appropriate), carers and their doctors in medical and personal care decisions.\(^3\)

Advance care planning is relevant to everyone but is particularly important for key groups. The advance care planning; have the conversation: A strategy for Victorian Health Services 2014-2018 focuses on priority groups of people who would benefit from support to articulate their wishes for future treatment and care. These include:

- aged or older people who are frail;
- people of any age with chronic progressive and life-limiting conditions;
- people approaching end of life;
- people with multiple comorbidities and/or at risk of conditions such as stroke or heart failure; and
- people with early onset of cognitive impairment
- people who are isolated and vulnerable.\(^5\)

5. The importance of advance care planning for health services

The introduction of advance care planning as part of usual clinical practice is important because health services are responding to a range of changing needs and demands that include:

- delivering person-centered care; and
- caring for an ageing population.

The advance care planning process can take place at any stage of an adult person’s life and can result in:

- expression of values and preferences for treatment and care;
- completion of Refusal of Treatment Certificate; and
- appointment of a medical treatment decision maker.

Some suggested times to talk to clients about advance care planning, particularly in the palliative setting, are:

- when a client is making a will that may include Medical Treatment Decision Maker;
- when the client’s illness enters a new advancing phase;
- when the client is isolated and/or vulnerable; and
- when a client has differing opinions, values or beliefs to their carer and/or family members.
6. Summary

Advance care planning has benefits for the person and their family, the health professional and the broader health system. These include:

- supporting better client outcomes;
- assisting clinicians to provide person-centred care; and
- optimising the use of health resources.

It would be unreasonable to expect people to understand the full implications of a medical decision, even those with an advancing and progressive illness, under all potential and possible scenarios. Advance care planning that contains clearly articulated values and life philosophies will help clinicians to avoid ambiguity and medical treatment decision makers to make decisions based on the person's values and preferences.
Appendix 1: Guideline: Advance Care Planning

1.0 POLICY STATEMENT

All clients at XXX Palliative Care Service are offered support and guidance to complete an ACP during the admission process and through the episode of care. This clinical approach is supported by an evidence-based and quality framework to accurately reflect clients' values and expressed wishes about future health care and medical decisions.

STRATEGIC DIRECTION

Victorian Government’s “end of life and palliative care framework 2016”, 6
Priority 1 Person-centred services
“People have opportunities to develop their advance care plan”

This policy and procedure is to be read in conjunction with:

GRPCC Advance Care Planning Guidelines
XXXX Palliative Care Service care planning;
Use of interpreters; and
Guidelines for Deactivation of Implantable Cardioverter Defibrillators at End of Life.

This policy and procedure contains:

ACP Procedure
ACP Medical Treatment Decision Maker (MTDM) Hierarchy

2.0 EXPECTED OUTCOMES

- Clients and carers are supported to complete an advance care plan that clearly documents their wishes and preferences in relation to future medical treatment.
- XXXX has an effective ACP system and process in place to enable ACP planning documentation.
- ACP planning and development:
  - is conducted in partnership with clients, families and carers;
  - is timely documented and updated by XXXX clinical staff in the client’s electronic clinical record; and
  - is incorporated into the client’s care plan followed by appropriate filing of ACP hard copies record.
- When a client is identified as lacking capacity for medical decision making, it is the clinician’s responsibility to ensure this is clearly documented in the client’s ACP notes together with the name of the MTDM.
- Clinical staff understands the legal implications of each component of the client’s ACP.
Advance Care Directive (ACD) is a way of formally recording an advance care plan. ACD is a written plan recognised by law that is completed and signed by a competent adult, and witnessed by a medical practitioner. In Victoria, the options are to make an instructional directive, or a values directive. An ACD records the person’s values and preferences for future care and appoints a medical treatment decision maker to make decisions about health care.

Adult Patient is a person 18 years or older

Medical Treatment Decision Maker (MTDM) is a legal appointment of another person to make decisions about a person’s medical treatment. The appointment begins if and when the person is unable to make decisions about their medical treatment. The MTDM should be someone who has a close and continuing relationship with the person, and will objectively follow the decisions the client has made about their treatment. If a person does not appoint a MTDM, there is a hierarchy for determining

Support Person is a role to help a person who has decision making capacity to make their own decisions. The role will vary depending on the type of support required.

Not for Resuscitation are orders designed to prevent the use of cardiopulmonary resuscitation (CPR) in situations when it is deemed futile or unwanted. The term CPR refers to a range of resuscitative efforts, including basic and advanced cardiac life support to reverse a cardiac pulmonary arrest.

Definition of family

• The closest to the person in knowledge, care and affection. This may include the immediate biological family, the family of acquisition (related by marriage/domestic partnership), and the family of choice and friends (not related biologically or by marriage/domestic partnership).

In Aboriginal and Torres Strait Islander communities, kinship connections extend beyond family to community and carry specific roles and responsibilities.

Definition of decision making capacity

The Medical Treatment Planning and Decision Act 2016, provides a four part test to determine if a person has decision making capacity. To have decision making capacity, a person must be able to:

• Understand the information relevant to the decision and the effect of the decision.
• Retain the information to the extent necessary to make the decision
• Use of weigh that information as part of the process of making the decision; and
• Communicate the decision and the person’s view and needs as to the decision in some way, including by speech, gestures, and other means

An adult is presumed to have decision-making capacity unless there is evidence to the contrary. If a health practitioner cannot determine whether or not a person has capacity to make decisions, a referral for relevant specialist assessment is advised. If a person is
deemed to not have decision making capacity, they can seek a second opinion. They may also apply to VCAT to challenge a finding related to decision-making capacity.

If a person does not have decision making capacity, the health practitioner has not obtained informed consent. Providing medical treatment (significant treatment) without consent may constitute unprofessional conduct.

**Consent**

A health practitioner must obtain informed consent before providing medical treatment. If a person has decision making capacity, consent is obtained from the person. If a person does not have decision making capacity, and a medical treatment is proposed or required, the health practitioner must make reasonable efforts in the circumstances to locate an ACD and a MTDM.

**Primary attributes of ACP**

- Is person directed
- Provides opportunities to inform and educate patients, caregivers and family about their illness/es, including prognosis and likely outcomes of alternative care and treatment plans
- Define the key priorities in end-of-life care and offers an structure to capture and address these priorities and associated concerns
- Informs future clinical care to fit the client’s preferences and values.

**Potential Benefits of ACP**

- Help clients find hope and meaning; and
- Strengthen relationships with loved ones.

**General Information**

- A culturally appropriate ACP recognises the physical, social, emotional, cultural and spiritual matters important to the individual
- All clients over the age of 18 are eligible to participate in ACP processes and are provided with the relevant ACP information
- ACP is only applicable to medical treatment and only comes into effect if and when a person is unable to make decisions for themselves
- When Clinical staff identify a client wishes to complete an ACP, they must timely refer to the Practice Leader- Psychosocial
- XXX staff are not permitted to witness or sign any sections of the ACP
- Aboriginal and Torres Strait Islander clients who do not have an ACP should be provided with the cultural resource ‘Taking control of your Health Journey’.
4.0 RESPONSIBILITY

| Who, where, when and how: nurses, doctors, allied health members of the MDT (context of practice: community, inpatient RACF) | Clinical staff awareness and adherence to the guideline  
Capacity building requirements |
| Relevance stakeholders Organization, NP, NPCs, senior clinical staff, nursing and allied health | Incorporation of guideline into each organisation End of Life Care clinical governance framework |

5.0 RECORDS & DOCUMENTATION

- Initial Assessment
- Care plan
- End of Life Care module
- Progress notes

6.0 PROCEDURE *guideline itself*

This ACP procedure guides members of the interdisciplinary team in supporting and facilitating clients and families to develop an ACP.

The ACP procedure:
- Reflects integrated interdisciplinary (IDT) clinical practice systems and processes;
- Promotes safe, responsive, effective and seamless care;
- Informs and educates IDT members; and
- Facilitates ACP consistent documentation, tracking and auditing.

Scope
This procedure applies to all IDT members

Roles and responsibilities
The responsibility for ensuring that this procedure is understood and followed lies with the XXX Clinical Operational Manager.

It is the responsibility of all clinical staff working at XXX to:

- open up ACP discussions from admission;
- adhere to the XXX ACP policy and procedure; and
- seek support and coaching when having difficulties in starting and/or progressing the “difficult conversations”.
Many clients may expect their health care team to initiate such discussions. It is therefore essential that health care professionals are:

- sensitive to circumstances and cues when it may be an appropriate time to offer ACP; and
- able to identify when clients might be indicating their readiness to discuss.

It is important to note, there is no recommended time frame to initiate or to progress ACP discussions. These may be ongoing and can take place over several visits.

**Intake nurse**

*Title of designated organisational role*

When a referral is received, the intake nurse:

- Checks referral documents and/or SCTT for evidence of an ACP. If an ACP has **been provided with the referral information**, the intake nurse reviews available ACP information prior clinical staff conducting initial assessment;
- Contacts referrer to enquire whether an ACP exists or whether there is any information available related to advance care planning;
- Requests a certified copy, if an ACP exists, with the referral information, if appropriate attach ACP information to client’s record, **hard copy or electronic** and opens the end of life plan item/module;
- Highlights any notification relevant to ACP for the staff member conducting the assessment; and
- Ensures any ACP information is then followed through at initial client’s assessment.

**ACP Process**

**On admission**

- If the client already has an ACP clinical staff conducting assessment discuss client’s choices and preferences, updates information and documents ACP components on the client’s record
- If an ACP exists but has not been provided as part of the referral process; the assessor requests a certified signed copy of the ACP (either by the client or by a person who has authority to sign statutory declarations). This copy can be obtained at initial face-to-face contact during the assessment process (or as soon as is appropriate and practicable).

**When capacity is identified**

- The client is asked whether she/he has an ACP or a MTDM
  - If a MTDM already exists, provide a copy of this document (signed by a person responsible for statutory declarations) for scanning on to the client’s medical record. Arrangements made prior to the implementation of the Medical Treatment Planning and Decision Act in March 2018, for a medical enduring power of attorney, will remain valid.
- Discussion is initiated about development of ACP. Development of this discussion is assisted by **XXX ACP Client Information Kit** that includes:
• ACP information sheet; and

- The staff member facilitating ACP discussions arranges a time with the client and the nominated MTDM to continue discussions aimed at completing ACP documentation
- Clinical staff liaise with the XXX departmental managers and /or clinical leaders for assistance and/ or coaching on ACP communication skills
- Each team member is expected to follow up/build on introductory and/or previous ACP discussions at the next scheduled visit to determine whether the client wishes to proceed with ACP
- If the client wishes to proceed with ACP development; the staff member promptly completes a referral to clinical leader- psychosocial as soon as this is practicable
- It is recommended that the GP is encouraged to be an active part of the ACP discussion. The GP is required to review and sign all the relevant documents completed by the patient.
- When the ACP is signed by the GP or treating medical specialist (and witnessed), update the end of life module on the client’s clinical record and attach the document
- When appropriate refer the client to their general practitioner for discussion and witnessing of the ACP.
- Once all ACP documents are completed the client is encouraged to forward a copy to their treating hospital and medical team
- If the client does not wish to proceed with ACP discussions. The clinical staff member documents the decision in the end- of- life module in the client’s electronic record
- End of life care components such as client preferred place for end of life care and site of death must also be documented.

Timing for opening up ACP discussions

- At a minimum, ACP should be considered whenever the health care provider asks himself/herself the surprise question: “would I be surprised if this patient were to die within the next 12 months?”

- Whilst the discussion on ACP must be considered for all clients, there are those clients who are most likely to benefit from opening of the discussion these may include:
  - Clients identified as being stable or in the deteriorating phase of their illness
  - Clients who raise concerns about the future
  - Clients who state future preferences for healthcare
  - Clients with no-one or socially isolated
  - Clients with complex family structure and dynamics
Clients who are likely to be discharged from the service

Clients who may benefit from ACP discussions can also be identified at team meetings and handover activities

Clients with a life limiting or progressive illness known to have agreed to an NFR order during their last hospital admission\(^\text{10}\).

- Clients who are competent can consent to, or refuse, treatment for themselves, or appoint a:
  - MTDM to consent or to refuse future treatment
  - Person responsible in writing to consent to treatment

- Clients identified lacking temporary or permanent capacity should still be invited to participate in ACP discussion and medical decision-making to the extent that they are capable.

- If the client is unable to provide ACP information and/or to engage in ACP discussion because of temporary or permanent capacity, information should then be sought from the client’s appointed MTDM or family/carer/other health professionals involved in the client’s care.

**When unable to assess capacity - it must be noted that:** a person is presumed to have decision making capacity unless there is evidence to the contrary\(^\text{11}\)

- Refer the client to the general practitioner or treating specialist for confirmation of capacity
- If it is determined that the client does not have capacity:
  - Introduce, if appropriate, the ACP process to the family and caregiver to determine whether they wish to document a statement of choices for a non-competent patient
  - If family/caregiver agree, organise a meeting to discuss and complete the client’s non competent statement of choices.
- Document the outcomes of the assessment in the client’s clinical notes in their clinical record.

**Documentation**

- XXX recognises the following forms as valid client’s documentation:
  - ACP forms: MEPOA (if current)/Appointing a MTDM, ACD forms or any other ACP related documents from health services, the Office of the Public Advocate and/or solicitors.

- XXX staff ensures to follow up on any ACP documentation (including certified copies) not already provided at referral processes. Once these are provided, documents are uploaded onto the client’s electronic record followed by timely documentation in the client’s record.
• ACP becomes a mandatory item in the client’s care plan under the ACP heading that evidences:
  
  o Completed ACP documentation—either through initial assessment and/or through client’s stay in the XXX PC program—are scanned into the client’s record
  o The client and/or their agent retain original ACP documents

Please note

ACP documents can be revoked by the client, either verbally or in writing, while they remain competent. Revoked documents must be noted in the client’s progress notes ACP/EOL module XXX clinical record. Completed revoked documents must be scanned and attached to the client’s XXX clinical record.

Staff education

XXX is committed to support clinical staff develop and strengthen their ACP communication skills.

When opening up ACP discussion clinical staff are expected to:

• Display impeccable professional and ethical behaviour and exhibit knowledge of:
  
  o Assessment of a person’s capacity to make medical treatment decisions;
  o Medical Treatment Planning and Decision Act 2016;
  o VCAT Guardianship Orders;
  o The ‘MTDM’ as distinctive from ‘Next of Kin’ or ‘Contact Person’;
  o Written ACD;
  o ACP timely documentation; and
  o How to access ACP information and brochures for clients and caregivers.

Key Clinical Staff Considerations

Facilitating ACP discussions and communication skills

Communication skills are central to holding effective ACP and end-of-life discussions13

• Take the lead in starting the discussion. Many clients are reluctant to initiate an ACP discussion; physicians, counsellors and nurses can “open the door” to such discussions by asking:
  
  o How do you feel things are going?
  o Have you given any thought to how you wish to be cared for should your illness worsen?
Who would make medical decisions for you if you were too ill to do this for yourself? And

How would they know what you want?  

**Explain the reasons for developing an ACP.** Clients identify ACP as an important part of medical care if they have a good understanding of how the process will benefit them:

- What are you most hoping for? If that doesn’t work out, what else would you be hoping for?
- I’d like to spend some time talking to you about the future course of your illness so that I have a clear understanding of your wishes and preferences.

**Use effective communication skills.** Do not use medical jargon (e.g. ‘ventilator’): language should be clear and succinct. Use empathetic and active listening skills:

- be mindful of your posture;
- make eye contact if culturally appropriate;
- touch can be used if desire to respectfully convey a supportive and compassionate gesture, particularly if the person becomes anxious and/or visibly upset;
- endeavour to build trust; and
- ensure privacy and allow sufficient time for discussion. If there is no sufficient time make an appointment to continue the discussion as soon as practicable.

**Identify a MTDM**

- Clients should be encouraged and assisted to:
  - identify a MTDM; and
  - discuss/clarify their wishes with this appointed person.

- The value of ACP discussions is in the sharing of the information between the client, caregiver, MTDM, other family members and the health care team.
- The MTDM is presumed to have the greatest knowledge of the client’s preferences and values.
- If appropriate and agreed with the client, schedule a meeting to progress discussions and facilitate understanding between the client, their MTDM and other family members as nominated by the client.

**Cautionary notes**

- The ACP process must be sensitive to disease, gender, age, social and cultural contexts.
• Not everyone will be willing or ready to discuss ACP or end-of-life components. Clinical staff, however, must always endeavour to provide opportunities to open up and to facilitate ACP conversations.

• ACP is an evolving process that may require a series of discussions until its value is demonstrated. Debilitated clients often have challenges in processing information and require time to reflect on the information provided and its impact on their lives.

Special considerations

If the client is deteriorating rapidly or in the terminal phase of their illness there may be insufficient time to introduce ACP discussion and or process. However, it is still important to identify and capture the goals of care and the client’s preferences for end of life care including place of death.

7.0 LEGISLATION

Medical Treatment Planning and Decision Act, 2016

Victorian Government ‘end of life and palliative care framework 2016’.


8.0 STANDARDS


Palliative Care Australia (2018). National Palliative Care Standards 5.15-5.20

9.0 MEDICAL TREATMENT DECISION MAKER HIERARCHY

At any one time, a person will only ever have one medical treatment decision maker. This ensures it is clear who is responsible for making the medical treatment decisions. There is a hierarchy for determining the person’s medical treatment decision maker, and the first available and willing person from the list below will be the medical treatment decision maker.

• an appointed medical treatment decision maker;
• a guardian appointed by VCAT;
• the first of the following with a close and continuing relationship with the person:
  o the spouse or domestic partner;
  o the primary carer of the person;
  o the oldest adult child of the person;
  o the oldest parent of the person;
  o the oldest adult sibling of the person.
If a medical treatment decision maker consents to treatment, a health practitioner may proceed with that treatment. If the medical treatment decision maker refuses treatment, a health practitioner cannot provide that treatment.

10.0 REFERENCES

1. Advanced care planning: have the conversation: A resource for doctors. Department of Health Victoria 2014


5. ibid.


10. Advance Care Planning in 3–Steps- Dr Barbara Hayes Palliative Care Physician & Clinical Leader- Northern Health ACP Program Wonthaggi 2015

