A Model for Community Palliative Care in Gippsland

Part 2 - Framework
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Introduction

The Gippsland Regional Palliative Care Consortium (GRPCC) commissioned the development of this model to:

- Help community palliative care services meet the challenge of increasing demand; and
- Support capacity building.

The model is based on Palliative Care Australia’s *Standards for Providing Quality Palliative Care for all Australians* (2005) and is informed by the linked report. It also draws on the policies and procedures of Melbourne City Mission Palliative Care.

The model is intended to complement the policies and procedures of individual organisations.
Program logic

The program-logic links the components of community palliative care programs and demonstrates how they flow through to optimal palliative care in Gippsland.
### Glossary for Program Logic

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>DN</td>
<td>District Nurse</td>
</tr>
<tr>
<td>NP/C</td>
<td>Nurse Practitioner/Candidate</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>Funded beds</td>
<td>Designated beds for palliative care clients in Gippsland hospitals</td>
</tr>
<tr>
<td>PCCN</td>
<td>Palliative Care Clinical Network</td>
</tr>
<tr>
<td>GRPCC</td>
<td>Gippsland Regional Palliative Care Consortium</td>
</tr>
<tr>
<td>CPG</td>
<td>Clinical Practice Group</td>
</tr>
<tr>
<td>MDT</td>
<td>Multidisciplinary Team</td>
</tr>
<tr>
<td>Liaison Nurse</td>
<td>Nurse who liaises between the community and inpatient settings</td>
</tr>
<tr>
<td>Episodic care</td>
<td>Care that is provided during times of specific palliative care needs</td>
</tr>
<tr>
<td>Validated tools</td>
<td>Tools that have been developed scientifically, such as those of the Palliative Care Outcomes Collaboration (PCOC) e.g. Symptom Assessment Scale (SAS) covering difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain.</td>
</tr>
<tr>
<td>Reflective practice</td>
<td>Thinking critically and honestly about work experiences, practices and relationships, role boundaries and areas for development. This may be done individually or in groups and formally or informally. It may or may not be professionally facilitated.</td>
</tr>
<tr>
<td>Staff resilience</td>
<td>The ability of individuals and teams to manage the stresses of working with clients and families living with life threatening illness.</td>
</tr>
<tr>
<td>Holistic care</td>
<td>Care that encompasses physical, emotional, psychosocial, cultural and spiritual aspects of life.</td>
</tr>
<tr>
<td>Seamless care</td>
<td>Care that continues smoothly during transitions from one service to another, such as from hospital to home.</td>
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</table>
**Standard 1**

Care is based on respect for the uniqueness of the client, their carer/s and family. The needs and wishes of the client, carer/s and family are acknowledged and they guide decision-making and care planning.

**Standard 2**

The holistic needs of the client, carer/s and family are acknowledged in the assessment and care planning processes, and strategies are developed to meet those needs, in line with their wishes.

**Standard 3**

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the client, carer/s and family.

**Key Words:**

- Unique
- Client, Carer, Family
- Needs & Wishes
- Holistic
- Ongoing & Comprehensive
- Assessment
- Care Planning
| **Integrated multidisciplinary team** | **What?**  
An integrated multidisciplinary team (MDT) covering the physical, psychological, social, cultural and spiritual aspects of care  
**Why?**  
- Effective, seamless and holistic care  
- Understanding of each other’s roles  
- Mutual support  
**How?**  
- Acknowledgement of formal membership of the MDT and of disciplines who contribute when required  
- Intentional development of relationships at a senior level  
- Integration of progress notes and care plans for all disciplines, including the coordinator of volunteers  
- Formal referral mechanisms  
- District nurses attend visits with allied health (AH) practitioners or the coordinator of volunteers and introduce them as part of the palliative care team  
- Where possible, location of AH practitioners and the coordinator of volunteers in or near the DN office  
- Regular attendance of AH practitioners and the coordinator of volunteers at MDT meetings  
- An open invitation for AH practitioners and the coordinator of volunteers to attend daily handover  
- An open invitation to volunteers to attend the MDT meeting to liaise specifically about their client  

| **Linked with:** | **What?**  
An integrated multidisciplinary team (MDT) covering the physical, psychological, social, cultural and spiritual aspects of care  
**Why?**  
- Effective, seamless and holistic care  
- Understanding of each other’s roles  
- Mutual support  
**How?**  
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- District nurses  
- Nurse practitioner and/or  
- Nurse practitioner candidate  
- Palliative medicine specialist  
- Social worker  
- Loss & grief counselor  
- Pastoral/spiritual carer  
- Psychologist  
- Occupational therapist  
- Physiotherapist  
- Speech pathologist  
- Dietician  
- Coordinator of volunteers  
- Volunteers  

- General practitioner  
- Staff of funded palliative care beds
## Assessment, triage and management of referrals for palliative care

<table>
<thead>
<tr>
<th>What? Assessment of referrals</th>
</tr>
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<tbody>
<tr>
<td><strong>Why?</strong></td>
</tr>
<tr>
<td>• Appropriate use of resources</td>
</tr>
<tr>
<td>• Equitable and timely access</td>
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<table>
<thead>
<tr>
<th>How? Admission criteria: the person</th>
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<tbody>
<tr>
<td>• Lives in the catchment area</td>
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<tr>
<td>• Is aware and accepting of the referral</td>
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<tr>
<td>• Has a diagnosed life threatening illness: assess against <strong>Palliative Care Service Access and Management Flowchart for General Practitioners</strong>. If unsure, consult with the referrer, NP/C and/or palliative medicine specialist (specialist)</td>
</tr>
<tr>
<td>• Does not fit the criteria but admission for a designated period will enable a specific issue effecting quality of life to be addressed.</td>
</tr>
</tbody>
</table>

**Possible actions**

• Accept the referral
• Acknowledge uncertainty about the appropriateness of the referral and state the intention to the referrer, client and carer to assess over a period of time
• Suggest that a referral may more appropriately be directed to a different program or service
• Advise the referrer why the person does not meet the admission criteria.

<table>
<thead>
<tr>
<th>What? Triage of referrals</th>
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<tbody>
<tr>
<td><strong>Why?</strong> Rational determination of priority and allocation of appropriate team members to conduct the initial assessment. An AH team member may make the first visit if the client’s condition is stable and there are significant family issues.</td>
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<table>
<thead>
<tr>
<th>How? Urgent:</th>
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<tr>
<td>1. Late referral for a person in the community who:</td>
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<tr>
<td>• Wishes to be at home and is close to death and/or</td>
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<tr>
<td>• Is in symptomatic and/or psychosocial distress</td>
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<tr>
<td>• Has no carer</td>
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<tr>
<td>• Has a carer in distress.</td>
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</tbody>
</table>
2. Late referral from an inpatient setting of a person who is:
   • Close to death
   • Wants to die at home.

   **Routine:** the person and/or carer:
   • Is at home or is ready to be discharged home
   • Requires assistance with personal care and/or procedures
   • Requires assistance with symptom management
   • Requires assistance with psychosocial issues.

   **What? Planning the discharge** with the discharging unit

   **Why?** Care is effective and safe for client, carer and staff

   **How?** Ask questions:
   • What are the main issues?
   • What is the person’s functional capability?
   • Who is at home with the person?
   • Who is administering daily medications or injections?
   • If a hospital discharge, is the person going home with sufficient and appropriate medications and the means of administering them? If death is imminent, is the hospital sending the requisite anticipatory medications and orders?
   • Is the person currently having chemotherapy or radiotherapy? Where are they in their cycle? What might happen, what precautions should be taken and what plans should be in place? Who should be contacted?
   • Has an occupational therapy assessment been done?
   • Is an electric bed or other equipment required?
   • Is an interpreter required?
   • Has an Advance Care Plan been done?
   • Is there a Medical Power of Attorney?
### Initial assessment

**What?** A comprehensive and holistic assessment

**Why?**
- Identification of the needs, wishes and expectations of the client, carer and family
- Effective care planning
- Confirmation of eligibility for, and acceptance of, admission to palliative care

**How?** As for *Interpreters* and
- The key issues arising from the referral guide the allocation of disciplines to the initial assessment, e.g. a district nurse (DN) and social worker (SW)
- The key issues for the client, carer and family, and the client’s presentation and capacity, guide the content and duration of the assessment; it may extend over several visits

### Physical assessment

Tools of the Palliative Care Outcomes Collaborative (PCOC):
- Australia Modified Karnofsky Performance Scale
- Symptom Assessment Scale (SAS)
- Palliative Care Problem Severity Score
- Resource Utilisation Groups – Activities of Daily Living Scale (RUG-ADL)
- Phase of Care

Examples of other tools
- Initial Pain Assessment
- Abbey Pain Scale
- Distress Thermometer
- Carer Support Needs Assessment Tool
- Genogram
- Bereavement Risk Index

The following is a *guide to client and carer assessment*, to be used according to MDT members’ judgement:

---

1. Drawn from the policies and procedures of Melbourne City Mission Palliative Care
Insight: ‘What is your understanding of how things are going at the moment?’ ‘What is your understanding of palliative care?’ The client and carer/s should be aware of the limits of the service.

Client and carer’s wellbeing: ‘How is your mood at the moment? What sorts of things do you look forward to? What do you worry about most?’

Family communication: ‘Do you talk much as a family about X’s illness? Who are you most worried about?’ A genogram might be helpful in capturing close relationships, extended family and networks of support.

Social support: Friends, neighbours, links with community and faith organisations. ‘Would you consider a trained volunteer to provide practical support?’

Coping strategies and strengths: ‘You’ve faced challenges in your life before. What got you through those times?’

Spirituality and meaning: ‘What sustains your hopes and keeps your life meaningful?’ What’s most important to you right now?’ ‘Do you have a particular belief system?’

Culturally specific issues: ‘When did you migrate to Australia?’ ‘Is there anything we should know about your traditions that are important to you right now?’

Current concerns: ‘Would you like to talk about any problems now so that we can help you?’

Carer: Identify the primary carer/s, their desired level of involvement and ability to perform the role

Sites of care and death: Where does the client wish to be cared for? People’s wishes may change over time

Community services: ‘Are you receiving any assistance from your local council? Are you aware of financial support through Centrelink? Are you aware that as a live-in carer you are eligible to receive the Carer’s Allowance?’

Financial/Legal: ‘Have you finalised your will? Have you appointed a trusted person as your Power of Attorney?’

Advanced Care Plan (ACP): ‘Do you have an ACP in place? Would you be interested in knowing more about ACPs? If you were unable to make decisions about your health care, who would you ask to speak with your medical team on your behalf?’

Explanations, as appropriate, regarding after hours care and anticipatory medications
<table>
<thead>
<tr>
<th>Interpreters</th>
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</table>
| **What?** Preparation for infrequent occasions when a professional interpreter is needed:  
  - The client has no understanding or effective use of English  
  - The client is able to communicate in English but is more comfortable with their own language  
  - The client is under stress which may hinder their ability to communicate adequately in English  
  - When seeking important information, e.g. about prescribed drugs  
  - When providing information about entitlements, rights and responsibilities  
| **Why?**  
  - To ensure the needs and wishes of the client, carer and health professional are accurately conveyed and they understand each other  
  - Family members are not an appropriate substitute because:  
    - They should be given the opportunity to voice their own needs, concerns and feelings  
    - Health professionals cannot guarantee if and how family members interpret their questions and statements  
| **How?**  
  - To encourage the use of interpreters:  
    - ‘It is important to hear directly from [our client] about how they are feeling, then we can be confident that we’ve done our job’  
    - ‘We’d like to relieve you of the need to interpret so you can just be [the client’s] son or daughter’  
  - Have on hand literature from the provider, detailing:  
    - Arranging an interpreter  
    - Identifying the preferred language or dialect  
    - Identifying the preferred gender for reasons of culture or sensitivity  
    - Working with an interpreter face-to-face and by telephone |
### Culturally and linguistically diverse clients

<table>
<thead>
<tr>
<th>What?</th>
<th>Preparation for infrequent occasions when clients from culturally and linguistically diverse backgrounds are referred</th>
</tr>
</thead>
</table>
| Why?  | - To enable culturally appropriate palliative care  
        - To ensure the needs and wishes of the client, carer and health professional/s are accurately conveyed and they understand each other  
        - It is inappropriate to use an interpreter as a cultural adviser |
| How?  | - Refer to the Department of Health’s Cultural responsiveness framework, guidelines for Victorian health services |

### Children

<table>
<thead>
<tr>
<th>What?</th>
<th>Preparation for infrequent occasions when an infant, child or adolescent is referred for palliative care</th>
</tr>
</thead>
</table>
| Why?  | - To inform and support staff who are not accustomed to caring for infants, children or adolescents  
        - To ensure that the care offered and/or provided is appropriate to the infant and/or child and/or adolescent and their families |
        - Establish contact with the Victorian Paediatric Palliative Care Consultancy (VPPPCC) for advice, education and support  
        - Actively involve the MDT in all paediatric referrals  
        - Conduct a shared assessment e.g. DN and SW  
        - Acknowledge the skills of the parents/ legal guardians and their special knowledge of the child  
        - Where possible engage the child in decision-making  
        - The child or adolescent must be willing to engage in counselling |
## Care Plan – initial and ongoing

**What?** A tool used to record specific items of care and how they will be addressed

**Why?**
- To guide MDT members
- To facilitate continuity
- To reflect significant items for the client and mandatory items for palliative care
- To accommodate the evolving needs and preferences of the client, carer/s and family

**How?** As for Initial assessment and
The care plan is:
- A dynamic document
- Informed by the initial assessment, documenting significant issues and interventions as agreed with the client and carer
- Updated by all MDT members as new issues/needs arise and are discussed with the client and carer
- Reviewed after a designated period of time, e.g. 3 months, for currency and relevance

All items have **goals, actions and outcomes**

**Mandatory items** might include:
- Primary carer
- Distressing symptoms, e.g. identified from the Symptom Assessment Scale where scores are rated four and above, as well as issues derived from other tools
- Advance Care Planning (ACP): status
- Bereavement Risk Assessment
- End-of-Life Care Planning (EoLCP): client and carer education, decision-making, sites of care & death

**Additional items** might include:
- Referrals, when a team member has made an internal or external referral
- Communication, where issues have been identified
- Chemotherapy, and precautions to be taken

**Evaluation** can occur through audits, supervision, MDT meetings and case reviews
### Ongoing assessment and action

**What?**
Use of the five validated and standardised assessment tools of the Palliative Care Outcomes Collaborative (PCOC) for
- Accurate assessment of the quality of care across key palliative care domains
- Facilitation of action in response to physical, psychosocial and emotional symptoms common to people with life threatening illness
- Collection of information about client acuity and episodes of care

**Why?**
- Improves symptom management
- Provides a profile of symptoms and issues and a measure of interventions over time
- Facilitates consistent, formal documentation
- Involves clients in their own care
- Acknowledges the carer and family as part of the unit of care
- Facilitates holistic, safe and effective care

**How?** As for Care Plan – initial and Ongoing and
- Use PCOC tools at every visit
- Use additional tools recommended by the Palliative Care Clinical Network (PCCN) and GRPCC as required
- Use tools as part of a holistic approach: no tool is a complete assessment in itself
- Have formal channels for referral to appropriate MDT members

**Guide for PCOC tools:**

#### Symptom Assessment Scale (SAS)
- Introduce it to the client and carer at the first visit
- Score symptoms at every visit
- Use during phone calls when following up with client/carer after advice or an intervention
- If any physical, psychosocial or spiritual symptom is rated 4 or above, the symptom is added to the care plan with interventions; possible interventions include:
  - Additional assessment e.g. Initial Pain Assessment Tool or Distress Thermometer
  - Consultation with and/or referral to the GP, NP/C and/or specialist
  - Altered drug regimens and/or doses
  - Consultation with and/or referral to allied health (AH) colleagues or an external service
- Use as a guide to evaluate symptom management at daily handover, MDT and case conferences
Phase of Care

- A rating of ‘unstable’ may indicate the need for additional or different interventions; once a plan of management is established the phase of care becomes ‘stable’ or ‘deteriorating’
- The rating may determine the frequency of visits and day-to-day management e.g. clients who are 'stable' may be visited weekly or fortnightly, clients who are ‘unstable’ may receive a follow up phone call to assess the effect of an intervention

Australia Modified Karnofsky Performance Scale

- May be used as a trigger for assistance with personal care
- May be used as a trigger for the installation of an electric bed e.g. a rating of 40: in bed more than 50% of the time

Palliative Care Problem Severity Score

- A score of ‘moderate’ or ‘severe’: as for SAS

Resource Utilisation Groups – Activities of Daily Living Scale (RUG-ADL)

Other tools recommended by the PCCN and Clinical Practice Group include:

- Initial Pain Assessment
- Abbey Pain Scale
- Distress Thermometer
- Carer Support Needs Assessment Tool
- Genogram
- Bereavement Risk Index
<table>
<thead>
<tr>
<th>Progress notes</th>
<th><strong>What?</strong> A concise, integrated and systematically formatted record</th>
</tr>
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<tbody>
<tr>
<td></td>
<td><strong>Why?</strong></td>
</tr>
<tr>
<td></td>
<td>• Reflects integrated multidisciplinary care</td>
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<tr>
<td></td>
<td>• Promotes safe, effective and seamless care</td>
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<tr>
<td></td>
<td>• Informs and educates MDT members</td>
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<td></td>
<td>• Facilitates easy tracking and auditing</td>
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<tr>
<td></td>
<td><strong>How?</strong></td>
</tr>
<tr>
<td></td>
<td>• All MDT members share the same record</td>
</tr>
<tr>
<td></td>
<td>• Consistent formatting aligned with the goals of the care plan</td>
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</tbody>
</table>
### Advance Care Planning (ACP)

**What?** The process of planning for future health and personal care in the event that the client cannot make or communicate choices and decisions.

**Why?** To help the client receive care in the place of their choice and to minimise unwanted treatment.

**How?**

- There are different models but an ACP usually consists of one or all of:
  - Appointment of a suitable decision-maker and/or
  - Written record of client preferences/wishes at end-of-life and/or
  - Written advance directive/Refusal of Treatment Certificate

- In a consultative and ongoing way, identify the client’s values, beliefs and preferences
- Identify the most appropriate MDT team member to conduct ACP
- Clients who are more likely to be amenable to ACP are those who:
  - Are assessed as ‘stable’ or ‘deteriorating’
  - Have insight and understanding into their diagnosis and prognosis
  - Have indicated future preferences for care
  - Are likely to be discharged from palliative care
  - Have agreed to a ‘Not for Resuscitation’ order while in a hospital setting

- Collaborate across community and inpatient settings in the local area to implement ACP and promote seamless care
### Transferring or discharging clients from palliative care – episodic care

| **What?** Transferring or discharging clients from palliative care |
| **Why?** The client is no longer eligible for the palliative care service, and to: |
| • Preserve resources for clients and carers who are eligible |
| • Maintain equitable access and limit waiting times |
| • Promote high quality care, safety and client satisfaction |
| **How?** |
| **Criteria for transfer or discharge:** |
| • The client has been symptomatically stable for a prolonged period, e.g. 6-12 months, demonstrated through regular and consistent scoring with PCOC tools, e.g. Phase – stable, SAS scores below 4 |
| • Consultation with treating doctors, specialists, the NP/C and the GP regarding prognostic indicators confirms that the client’s stability is likely to continue |
| • Consultation with the MDT confirms there are no outstanding issues for the client, carer or family |
| • The client moves out of the catchment area |
| • The client requests discharge |
| • Delivery of care poses an unacceptable risk to the safety of staff |

**On admission**, unless the client’s condition renders it inappropriate, inform client and carer/s that:

• In the happy event of the client remaining stable from a palliative care perspective, the client is likely to be transferred or discharged

• Planning to transfer or discharge will occur over time and in consultation with the client and carer

• The palliative care service will welcome the client back if and when the need arises

• The palliative care service will fund equipment for three months

**Planning of transfer and discharge** may include:

• Consultation and planning with the client and carer/s

• Referral to a more appropriate care stream or service if required

• Staged transition to another care stream or service

• Provision of information related to ACP and Medical Power of Attorney, if not already attended to

**Review discharge** if client is readmitted within a short time, e.g. 2 months
Standard 4

Care is coordinated to minimise the burden on the client, carer/s and family.

Key Words:

Coordinated Care
<table>
<thead>
<tr>
<th>Working with GPs</th>
<th>What?</th>
<th>Effective working relationships between the MDT and GPs</th>
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<tbody>
<tr>
<td>Why?</td>
<td>The GP is the client’s primary doctor and an essential part of the palliative care team</td>
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<td></td>
<td>Seamless and holistic care</td>
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<td></td>
<td>Understanding of each other’s roles and mutual support</td>
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<tr>
<td>How?</td>
<td>Recognise that GP-client relationships are often long-established</td>
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<td></td>
<td>Streamline communication through standard letters to:</td>
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<td></td>
<td>Inform the GP of the admission of a client</td>
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<td>Update the GP when changes occur</td>
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<td>Request anticipatory medications</td>
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<td></td>
<td>Consult the GP or practice manager about the best way to communicate with them regarding non-urgent and urgent matters that require discussion, e.g. email or phone calls</td>
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<td></td>
<td>Formally review the relationship between the MDT and GP, e.g. annually</td>
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<td>Consult the GP before a specialist is approached and, if possible, include the GP in the discussion</td>
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<td></td>
<td>Maintain an open invitation for GPs to attend:</td>
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<td></td>
<td>MDT in person or by teleconference for discussion of specific clients</td>
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<td>Regular (e.g. fortnightly) lunch meetings at the GP clinic, attended by a specialist and/or NP/C and/or DNs</td>
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<td></td>
<td>Case reviews</td>
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<tr>
<td></td>
<td>Tele/videoconferences with the specialist and other MDT members</td>
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</table>
| Working with the holders of funded palliative care beds | What?  
|------------------------------------------------------|-----------------------------------------------|
|                                                      | • Effective working relationships between the MDT and staff of the inpatient unit holding designated palliative care beds  
|                                                      | • Fostering of a sense of team and mutual respect |
| Why?                                                 | • Shared approach to palliative care  
|                                                      | • Coordinated and seamless care |
| How?                                                 | Intentional approach at a senior level to develop relationships between both sets of staff by:  
|                                                      | • The inpatient unit and MDT working together to implement programs across both settings, e.g. ACP  
|                                                      | • The inpatient unit and DN and/or MDT sharing palliative care education  
|                                                      | • DN participation in inpatient discharge planning meetings  
|                                                      | • The DN team alerting the NUM to the potential need for a bed  
|                                                      | • The opportunity for nurses to experience each others’ work places |
### Agreed protocols with the holders of funded palliative care beds

#### What?
Agreed protocols with the local hospital about the management and review of shared palliative care clients

#### Why?
- Shared goals of care
- Effective communication
- Coordinated and seamless care

#### How?
- Consultation and agreement about:
  - Channels of communication
  - The palliative approach
  - Admission of clients to appropriate beds and wards
  - Direct admission to inpatient beds
  - Discharge planning
  - Carer respite
- A designated liaison nurse
- Shared case reviews, e.g. hospital staff, specialist, NP/C

---

### Referrals from the acute setting

#### What?
Consistent approach to referrals from acute settings

#### Why?
To achieve a successful discharge where care is effective and safe

#### How?
If possible, collaborate with other Gippsland community services and:
- See *Triage and management of referrals for palliative care*
- Reserve the right to refuse a referral until satisfied that appropriate preparation is in place
- Decide on what basis exceptions will be made
Standard 5

The primary carer/s is provided with information, support and guidance in their role according to their needs and wishes.

**Key Words:**

<table>
<thead>
<tr>
<th>Carer</th>
<th>information</th>
<th>Support</th>
<th>Guidance</th>
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<table>
<thead>
<tr>
<th>Supporting the carer</th>
<th>What?</th>
<th>Why?</th>
<th>How?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The carer is provided with information, support and guidance</td>
<td>To promote their wellbeing and safety</td>
<td>As for</td>
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<td></td>
<td></td>
<td></td>
<td>• Initial assessment</td>
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<td></td>
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<td></td>
<td>• Culturally and linguistically diverse clients</td>
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<td></td>
<td></td>
<td></td>
<td>• After hours care</td>
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<td></td>
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<td></td>
<td>• Anticipatory medications</td>
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<td></td>
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<td></td>
<td>• Preparation for End-of-Life</td>
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<td></td>
<td></td>
<td></td>
<td>• Bereavement and:</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Routine and ongoing assessment of carer burden</td>
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<td></td>
<td>• Involve appropriate MDT members: reiterate offers and/or visit with AH practitioners or coordinator of volunteers and introduce them as part of the palliative care team</td>
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<td>• Provide ongoing education and written instructions specific to individual symptoms</td>
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<td></td>
<td>• Without overwhelming the carer, make the carer aware of brochures and websites that may be helpful</td>
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</tbody>
</table>

Refer to:

- The resources of GRPCC and Palliative Care Victoria at [http://www.pallcarevic.asn.au/](http://www.pallcarevic.asn.au/)
- The Centre for Palliative Care’s *Clinical Practice Guideline for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Clients*
Anticipatory or 'breakthrough' medications

<table>
<thead>
<tr>
<th>What?</th>
<th>The provision of medications in the home for emergencies around the clock</th>
</tr>
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<tbody>
<tr>
<td>Why?</td>
<td>To enable rapid response to unexpected or exacerbated symptoms and appropriate end-of-life care when medical assistance is unavailable</td>
</tr>
</tbody>
</table>
| How?  | As for:  
|       | - Initial assessment  
|       | - Ongoing assessment and action  
|       | - Working with GPs  
|       | - Continuous subcutaneous infusions |

Guided by the GRPCC and Clinical Practice Group, the service decides:

- The triggers for arranging anticipatory medications, e.g.
  - On admission
  - When symptoms score 4 or more on the Symptom Assessment Scale
  - Client is taking regular opioids
  - Client is not tolerating or absorbing opioids
  - Client has entered the terminal phase

- Whether anticipatory medications will be arranged in a standard group, e.g. injectable morphine, injectable anti-emetic, clonazepam drops and injectable anticholinergic, or as specific medications

- Who will administer injectable medications?
  - Always DNs?
  - Carers who live in isolated areas?
  - Carers who are willing and able?

- If carer/s plan to administer injectable medications, who will draw them up?
  - Carer/s?
  - DNs?

- In the absence of evidence, the length of time drawn up medications should be kept in the fridge
<table>
<thead>
<tr>
<th>If DNs draw up injectable medications:</th>
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<tbody>
<tr>
<td>• Ensure drawn up syringes are clearly labelled (on the syringes themselves) with the medication’s name, dosage and date</td>
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<tr>
<td>• Place drawn up syringes back in their plastic covers</td>
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<tr>
<td>• Instruct client and carer to keep the drawn up medication in a safe place in the fridge and out of reach of children</td>
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</tbody>
</table>

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<thead>
<tr>
<th>If it is decided that carers will administer injectable medications:</th>
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</thead>
<tbody>
<tr>
<td>• Coach the carer and monitor results. Refer to Queensland Health’s Subcutaneous Medications and Palliative Care: A guide for caregivers</td>
<td></td>
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<tr>
<td>• Leave a written plan, e.g. ‘In response to pain, if the client does not feel much better after two doses of morphine given 30 minutes apart, phone the DN/after hours number ‘</td>
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<tr>
<td>• Evaluate the carer’s competence and confidence in managing the procedure</td>
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<tr>
<td>Continuous subcutaneous infusions (CSCI)</td>
<td>What? The delivery of subcutaneous medication via a portable battery operated pump</td>
</tr>
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<td></td>
<td>Why?</td>
</tr>
<tr>
<td></td>
<td>• The client cannot swallow</td>
</tr>
<tr>
<td></td>
<td>• Uncontrolled nausea and vomiting</td>
</tr>
<tr>
<td></td>
<td>• Client is not tolerating or absorbing oral medications</td>
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<tr>
<td></td>
<td>• Pain control is inadequate via the oral, transdermal or rectal route (the rectal route is not always acceptable)</td>
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<td></td>
<td>• Bowel obstruction</td>
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<td></td>
<td>• Severe weakness or decreased or fluctuating conscious state</td>
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<td></td>
<td>How? As for Anticipatory or ‘breakthrough’ medications and</td>
</tr>
<tr>
<td></td>
<td>• According to manufacturers’ instructions for the pump, subcutaneous needle and infusion set</td>
</tr>
<tr>
<td></td>
<td>• Through consultation with the GP, NP/C and/or specialist, and with consideration given to the DNs’ capacity to titrate the CSCI and breakthrough medications, obtain a dose range to enable timely responses to the client’s changing condition</td>
</tr>
</tbody>
</table>
### Respite

**What?** Giving carers a break

**Why?** To help them maintain their role as carer

**How?** As for *Agreed protocols with the holders of funded palliative care beds* and:

- Referral for volunteer support
- Via the Aged Care Assessment Service and admission to a Residential Aged Care Facility (clients aged 65 years and over)
- Admission to an inpatient palliative care unit in Melbourne
- Collaboration with other community services in Gippsland to devise alternative options, e.g. personal care attendants in the home

### After hours support

**What?** Support outside the normal working hours of the DN service

**Why?**
- To provide continuity of care, advice, comfort and support
- To help clients remain at home if that is their wish
- To reduce travel and admissions to emergency departments

**How?**
- According to the service’s policy and procedure
- Refer to the GRPCC’s project: After – Hours
| Installation of electric beds | **What?**  
The timely and appropriate installation of an electric bed with adjustable height in the client’s home |
|-----------------------------|------------------------------------------------|
|                             | **Why?**  
• To minimise the risks of manual handling for staff, carer/s and family  
• To help staff work in a manner that is not harmful to their own health and safety or the health and safety of others  
• To ensure practice is consistent and not left to the discretion of DNs |
|                             | **How?**  
At the initial assessment inform the client and carer/s that:  
• Their home is your work place  
• You are obligated to work in a way that does not put you or your colleagues at risk  
• Over time some equipment may have to be installed |
|                             | Use the Karnofsky Performance Scale as a guide:  
• A score of **50** (client requires considerable assistance and frequent medical care) **triggers discussion** with client and carer/s about the introduction of an electric bed  
• A score of **40** (the client is in bed more than 50% of the time) **triggers installation of an electric bed** |
|                             | If the client or carer/s decline an electric bed:  
• Let them know that staff will be unable to give some hands-on care, such as personal care, owing to occupational health and safety regulations  
• Document the issue in the care plan under ‘Risk Management’ |
Standard 6
The unique needs of dying clients are considered, their comfort maximised and their dignity preserved.

Key Words:
Dying Comfort Dignity
### End-of-Life Care

**What?** Care of the client, carer/s and family when death is imminent

**Why?**
- Carer/s and family are aware and prepared
- Comfort is maximised and dignity is preserved

**How?** As for:
- Care Plan – initial and ongoing
- Ongoing assessment and action
- Supporting the carer
- Anticipatory or ‘breakthrough’ medications
- Continuous subcutaneous infusions
- Agreed protocols with the holders of funded palliative care beds
- Culturally and linguistically diverse clients

**Additional measures** include:
- Provision of clear information and education about what to expect, at a time that is acceptable for client, carer/s and family, using written materials such as Palliative Care Victoria’s brochure *The Process of Dying*
- Provision of information about funeral directors and procedures to follow after death
- Re-assessment of the needs of carer/s and family
- Clarification of the goals of care
- Clarification of the preferred site death, being prepared to transfer the client to an inpatient unit if the carer is exhausted or the needs of the client are overwhelming
- Notification of other disciplines and health professionals that death seems imminent

**Pathway for Improving Care of the Dying (PICD)** is the end-of-life care pathway implemented in some settings in Gippsland, as advocated by the GRPCC. Collaboration across community and inpatient settings in local areas to implement the PICD would:
- Guide end-of-life care through a series of prompts, guidelines and medication algorithms
- Promote consistency across community services and inpatient settings
Review the death, e.g. at the next MDT meeting, to evaluate:
- The nature of the death
- Symptom management
- The quality of care provided to the client and family
- Reasons for not meeting the client’s wishes regarding site of death

To assist evaluation, refer to Guideline 20 of the Centre for Palliative Care’s Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients.
Standard 7

The service has an appropriate philosophy, values, culture and structure for the provision of competent and compassionate care.

Key Words:

Competent  Compassionate  Philosophy  Values  Culture  Structure
### Philosophy and values of palliative care

**What?** The World Health Organisation’s definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

**Why?** This definition and articulation of values underpin palliative care

**How?**
- The service commits to the philosophy and values of palliative care in writing
- The philosophy and values of palliative care are embedded in all relevant documents
- This model informs the culture and structure of the palliative care service
Standard 8

Formal mechanisms are in place to ensure that the client, carer/s and family have access to bereavement counselling, information and support services.

Key Words:

Mechanisms  Bereavement  Counselling  Information  Support
### Bereavement

**What?** All carers and families are offered appropriate support and interventions in a timely and sensitive manner.

**Why?**
- Bereaved people have access to support that is appropriate to their needs and level of risk.
- Grief is a normal response to death and the evidence does not support routine interventions for all bereaved people.
- Poor bereavement outcomes are associated with identified risk factors.

**How?**
- **Initial assessment**
- **Supporting the carer**
- **End-of-Life Care**
- **Care Plan – Initial and ongoing** and

- Screen all carers and families for bereavement risk on admission, documenting issues related to loss and grief in the care plan.
- Add new and relevant issues during the course of the episode of care.
- Use a screening tool, e.g. Bereavement Risk Index (note there is no validated tool for this purpose).
- Explore risk and strength/resilience factors as outlined in Bereavement support standards for specialist palliative care services.
- Initiate a discussion with the MDT member responsible for bereavement prior to the client’s death if significant issues are identified.
- As soon as practicable after the client’s death, the most appropriate member of the MDT contacts the carer/s and family to offer condolences and respond to queries; document any new and relevant issues.
- Assess the need for a home visit.
- Review the death at a regular and appropriate meeting, e.g. the MDT meeting, and review the bereavement risk.
**Universal bereavement supports** may include:
- Bereavement call and/or visit
- Condolence card
- Written material about loss and grief
- Anniversary card

Best practice bereavement support for most people:
- Identifies and reinforces their coping and positive achievements
- Avoids interfering with their innate capacity for recovery
- Avoids undermining or replacing their family and community as sources of social support

**Specialist bereavement supports** for carers identified as ‘medium’ risk may include:
- Follow up from a volunteer trained in bereavement
- Invitations to service-specific bereavement groups
- Invitations to local bereavement groups

**Specialist bereavement supports** for carers identified as ‘high’ risk may include:
- Follow up from a member of the MDT responsible for bereavement
- Referral to other agencies such as:
  - Private loss and grief practitioners via the GP
  - Australian Centre for Grief and Bereavement Counselling
  - CALD specific agencies

Refer to:
- Department of Health’s Bereavement support standards for specialist palliative care services
- Centre for Palliative Care’s Clinical Practice Guidelines for the Psychosocial and Bereavement support of Family Caregivers of Palliative Care Patients
- Palliative Care Victoria at [http://www.pallcarevic.asn.au/](http://www.pallcarevic.asn.au/)
**Standard 9**

Community capacity to respond to the needs of people who have a life limiting illness and their carer and family is built through collaboration and partnerships.

**Key Words:**

Community  Capacity  Collaboration  Partnerships

<table>
<thead>
<tr>
<th>Growing community capacity</th>
<th>What?</th>
<th>Why? To build positive and open discussion in the community and:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>• Knowledge and understanding of death, dying and bereavement</td>
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<td></td>
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<td>• Awareness of the palliative approach</td>
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<td></td>
<td></td>
<td>• Resilience</td>
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<td></td>
<td>• Resources</td>
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<th>How?</th>
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<td></td>
<td>• Give clients, carers and families opportunities to feed back to the service, both informally and formally, e.g. satisfaction surveys</td>
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<td>• Maintain a strong group of palliative care volunteers</td>
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<td>• Forge links with groups such as Rotary</td>
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<td>• Give the annual Palliative Care week a local profile</td>
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<td></td>
<td>• Establish links with other service providers, e.g. residential aged care facilities and Victorian Aboriginal Community Controlled Health Organisation (VACCHO)</td>
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<tr>
<td>Collaborative innovation and expertise</td>
<td>What?</td>
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<tr>
<td>----------------------------------------</td>
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<td></td>
<td>The service contributes to a central, accessible and compact repository of innovations and developing expertise in community palliative care in Gippsland.</td>
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</tbody>
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<thead>
<tr>
<th>Why? To:</th>
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<tr>
<td>• Give other services ideas</td>
</tr>
<tr>
<td>• Help other services embark on similar projects</td>
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<td>• Save other services from wasting resources and repeating others’ mistakes</td>
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<tr>
<td>• Provide opportunities for collaboration</td>
</tr>
<tr>
<td>• Provide a resource where other services have little experience</td>
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<tr>
<td>• Promote pride in significant achievement</td>
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<th>How?</th>
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<tr>
<td>• For example, a page maintained on the GRPCC website</td>
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<tr>
<td>• Participation in the Clinical Practice Group</td>
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</tbody>
</table>
Standard 10

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Key Words:

Access   Clinical   Need
| Access to specialist clinical MDT members | **What?** Criteria for referral to Palliative Medicine Specialists and Nurse Practitioner/Candidates (NP/Cs)  
**Why?**  
• Appropriate use of resources  
• Equitable and timely access  
• To enable NP/Cs to address other aspects of their role  
**How?** As for:  
• Integrated multidisciplinary team  
• Assessment, triage and management of referrals for palliative care  
• Culturally and linguistically diverse clients  
• Children and:  

**Palliative Medicine Specialist**  
• According to service-specific arrangements  

**Nurse Practitioner Candidates**  
• Refer to Gippsland Region Palliative Care Consortium (2014) *Framework for the Nurse Practitioner Candidacy Program* and  
• Referral criteria:  

In general, triggers for referral to the NP/C indicate instability and/or complexity of clinical and/or psychosocial issues. They include:  
• Phase of care: unstable and/or deteriorating or terminal  
• Frequent presentations to acute care  
• Frequent inpatient palliative care admissions  
• Refractory symptoms  
• Client/caregiver/family distress  
• Psychosocial/spiritual issues  
• Challenging family dynamics  
• Request for death at home  
• Facilitation of end-of-life care, choices and decision-making  
• Anticipated loss and grief issues  
• Opportunities to educate and support other staff |
Standard 11

The service is committed to quality improvement and research in clinical and management practices.

Key Words:

Quality Improvement Research

<table>
<thead>
<tr>
<th>Quality improvement and research</th>
<th>What?</th>
<th>Why?</th>
<th>How?</th>
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<tbody>
<tr>
<td></td>
<td>• The integration of clinical expertise with the best available evidence</td>
<td>Continuous quality improvement</td>
<td>• As for <em>Ongoing assessment and action</em>, using the Palliative Care Clinical Outcomes Collaborative (PCOC) to support regular and systematic measurement, analysis, evaluation and benchmarking</td>
</tr>
<tr>
<td></td>
<td>• Critical evaluation of practice</td>
<td></td>
<td>• Integration of recommendations from PCOC and the Clinical Practice Group</td>
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<td>• Reflection on formal and informal feedback from clients, carers, families and health professionals with appropriate alteration of practice</td>
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<td>• Formal review of all deaths and unsuccessful discharges, e.g. at MDT meetings</td>
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<td>• Regular audits of care plans and progress notes</td>
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<td>• Formal review of all incidents related to palliative care</td>
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<td>• Staff attendance at study days and conferences and reports back to the team</td>
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<td>• Participation in the National Standards Assessment Program, enabling self assessment against the national standards, action plan development, implementation and peer mentorship</td>
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<td></td>
<td>• Participation in external accreditation</td>
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<td>• Participation in research, even at a junior level, to foster understanding and insight</td>
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Standard 12

Health professionals and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

**Key Words:**

**Health Professionals**  **Appropriately Qualified**

<table>
<thead>
<tr>
<th>Qualifications of health professionals and volunteers</th>
<th>What?</th>
<th>Why?</th>
<th>How?</th>
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</thead>
<tbody>
<tr>
<td>All members of the MDT and volunteers are appropriately qualified for their roles in palliative care</td>
<td>All members of the MDT and volunteers are competent and confident in addressing the physical, psychological, social, cultural and spiritual needs of clients, carers and families</td>
<td>The MDT and volunteers are competent and confident in addressing the physical, psychological, social, cultural and spiritual needs of clients, carers and families</td>
<td>Where possible, all members of the MDT have experience in palliative care or oncology</td>
</tr>
<tr>
<td></td>
<td>Members of the team have specialist expertise</td>
<td>Members of the team have specialist expertise</td>
<td>All members of the MDT are educated in the palliative approach</td>
</tr>
<tr>
<td></td>
<td>Practice is based on evidence</td>
<td>Practice is based on evidence</td>
<td>All MDTs include a palliative medicine specialist</td>
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<td></td>
<td>All DN teams include two DNs with post graduate qualifications in palliative care, which may include a nurse practitioner or nurse practitioner candidate</td>
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<td></td>
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<td></td>
<td>Post graduate qualifications underpin the appointment of DNs to senior positions in palliative care</td>
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<td>An appropriately educated and experienced team member coordinates and supervises volunteers</td>
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<td></td>
<td>All MDT members are encouraged and supported to undertake professional development in palliative care</td>
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</tbody>
</table>
Standard 13

Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

Key Words:

Staff    Volunteers    Reflective Practice    Self-Care
### Care of staff and volunteers

**What?**
- A culture and environment conducive to the management of stressors inherent in palliative care
- Opportunities to express and reflect on feelings related to interaction with clients, carers and families

**Why?** To:
- Maintain sustainable practice and services
- Mitigate stress
- Promote:
  - Personal growth
  - Resilience
  - Safety and wellbeing
  - Job satisfaction
  - Retention of staff

**How?**
- Recognition that staff and volunteers:
  - Can experience a client’s death with sorrow, loss, fear and regret
  - Have a responsibility to care for themselves
- A range of protective and supportive strategies available routinely rather than in response to crises:
  - Control over workload with procedures regulating admission and discharge
  - A shared culture of care and team that creates the opportunity for supportive relationships and the storytelling that helps make meaning out of experiences such as the death of a client
  - Ongoing education
  - Relationships and trust between the DN and AH teams, providing avenues of peer support and mentorship
  - Professional supervision, a practice of mentoring that develops the ability to reflect critically and honestly on work practices, role boundaries and areas for development. It may be in a group or peer format or conducted externally for individuals
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