The Gippsland Region Palliative Care Consortium acknowledges Bass Coast Health collaborative approach in facilitating reproduction of their recently developed policies and procedures to be made available for health organisations across the Gippsland Region.
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Background

The Gippsland Region Palliative Care Consortium (GRPCC) commissioned the development of a model for community palliative care to help community services meet current and future demands and to facilitate care that is evidence-based holistic and cost effective. The main objectives of this model are to assist health services in the region to:

- meet the challenges of increasing demand;
- support capacity building;
- complement the policies and procedures for individual organisations;
- be adapted for local environments and contexts of clinical practice; and
- promote consistency and continuity of palliative care delivery across the subregions.

The model was based on Palliative Care Australia’s Standards for Providing Quality Palliative Care for all Australians (2005). The model of care report findings resulted in the following 9 recommendations:

**Recommendation 1** Actively develop relationships among all disciplines of the MDT, and with GPs and local hospitals, to promote holistic and seamless care as well as mutual support and education.

**Recommendation 2** To enable accurate representation of multidisciplinary activity, ensure robust collection and reporting of data.

**Recommendation 3** To facilitate collaboration, enable all disciplines to share and contribute to integrated progress notes and care plans.

**Recommendation 4** Consider the appointment of a DN in each team to the role of Liaison Nurse to enhance relationships and promote safe, seamless and effective transitions between inpatient and community settings.

**Recommendation 5** To promote equitable access and appropriate use of resources, each organisation will have policies and procedures to guide admissions to, and discharges from, palliative care.

**Recommendation 6** To increase specialist capacity, consider supporting two DNs per team to achieve palliative care post-graduate qualifications. DNs with such qualifications include NP/Cs.

**Recommendation 7** Build evidence-based practice with comprehensive implementation.

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1 A Model for Community Palliative Care, Gippsland Region Palliative Care Consortium 2014
of PCOC and NSAP, supported by appropriate information systems. Over time, consider the introduction of additional tools as recommended by the PCCN and GRPCC.

**Recommendation 8** To promote resilience and mitigate stress and burnout, enhance the range of options available to palliative care staff for professional and emotional support.

**Recommendation 9** To promote collaboration across services and to conserve resources, develop a central location for the publication of areas of innovation and expertise.

In June 2015, Bass Coast Health, through the implementation of this model of palliative care delivery, conducted a review of new policies and procedures to address:

- Capacity building and sustainability;
- Clinical governance;
- Streamlining of professional activities; and
- Consistency and continuity of care delivery

This work resulted in the development of a suite of policies and procedures in line with the GRPCC Model for Community Palliative Care **Recommendation 5** 'to promote equitable access and appropriate use of resources, each organisation will have policies and procedures to guide admissions to, and discharges from, palliative care'.

The importance of implementation of clinical care protocols, policies, tools and guidelines is recognised in the Department of Health’s *Strengthening Palliative Care: Policy and Strategic Directions 2011-2015* "There is evidence that implementing clinical guidelines, protocols and tools facilitates improvements in client care…".

The clinical protocols and procedures included in this document have been predominantly based on the Bass Coast Health’s work.

**Purpose of these guidelines**

These guidelines provide an efficient structure to:

- inform health services in the development of their own policies and procedures regarding a model for a palliative care service delivery.
- reduce unwanted variations in care in the delivery of palliative care
- identify and incorporate the needs, current symptoms and preferences of the individual into an active plan of care that promotes effective care

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3 Implementing a Best Practice Model for Bass Coast Health Palliative Care Service- Catherine Duck Consulting June 2015
4 Department of Health, 2011, Strengthening Palliative Care: Policy and Strategic Directions 2011-2015 (page 56)
• effective care coordination;
• succinct and concrete communication among nursing and multidisciplinary team (MDT) members;
• seamless dissemination and documentation of the most important aspects of client’s care to team members, other health professionals and relevant health stakeholders across the settings from initial assessment to separation.
• Involves assisting the client to make decisions appropriately in line with the most important issues, wishes, values and circumstances as they see it;
• It includes an OH &S plan client/caregivers and nursing staff, particularly when care is delivered in the home setting; and
• Is responsive and sensitive to the cultural requirements of the client/caregiver.

**Palliative Care Standards**

These policies and procedures are informed by some of main *Standards for Providing Quality Palliative Care for all Australians*:

**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.

**Standard 5**

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

**Standard 6**

The unique needs of dying clients are considered, their comfort maximised and their dignity preserved.

**Standard 8**

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

**Summary**

Referrals for palliative care in Gippsland are increasing. The GRPCC commissioned the Model for Community Palliative Care to assist community services meet current and future demand and to facilitate care that is evidence-based, holistic, safe and effective.

The model **Recommendation 5** to promote equitable access and appropriate use of resources each organization will have policies and procedures to guide admissions to and discharges from palliative care.

These policies and procedures are intended to complement the general policies and procedures of individual organisations in the Gippsland Region.

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7 A Model for Community Palliative Care, Gippsland Region Palliative Care Consortium 2014
Figure 1. Integrated Policies and Procedures

- Holistic
- Multidisciplinary
- Comprehensive
- INDIVIDUAL
- Integrated
- CARE PLAN
- PCOC
- PAIN ASSESSMENT
- BEREAVEMENT ASSESSMENT
- CSNAT
- PROGRESS NOTES

PCOC
PAIN ASSESSMENT
BEREAVEMENT ASSESSMENT
CSNAT
G1. Initial Assessment: Guideline and procedure

1.0 Suggested POLICY STATEMENT

On admission to palliative care, a comprehensive and holistic assessment is undertaken to:
• Identify the needs, wishes and expectations of the client and carer,
• Facilitate effective care planning, and
• Confirm eligibility for, and acceptance of, admission to palliative care.

This guideline aligns with:

PROCEDURES
• Multidisciplinary Team (MDT)
• Working with General Practitioners (GPs)
• Working with Interpreters
• Working with Culturally and Linguistically Diverse Communities
• Symptom Assessment (PCOC)
• Electric Beds and Lifting Machines
• Carer Support
• Site Assessment
• After Hours Support
• Discharge Planning

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>All team members</th>
<th>Build on information obtained at initial assessment to avoid repetition and duplication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Unit Manager</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- SCTT
- GP Liaison
- Functional Assessment
- Site Assessment
- Genogram
- Care Plan
- Progress notes
- Palliative Care Handover

4.0 GUIDELINE

• Introduce yourself and explain your role
• Confirm the reason for your visit
• Outline the content of the visit and the approximate duration (and keep to that estimate).

Introduction to Service (XXXX) and Palliative Care
• Outline the philosophy of multidisciplinary care
• Assess the client and carer’s understanding of palliative care and the reason for the referral
• Discuss the xxxx (XXXX) discharge policy

**Client Consent**
• It is a medico-legal requirement that consent is received before services can be provided
• Discuss the consent form with the client/carer
• Complete the consent if the client/carer agree. XXXX is unable to provide a service if the consent form is not signed.

**Introduction of the Home Folder**
Introduce the home folder to the client/carer, including

• It is the property of xxxx and must be returned at the end of the episode of care
• After hours service
• Rights and responsibilities
• Complaints process
• Information privacy
• Advance Care Planning
• Carer Allowance.

**Confirmation of Client and Carer Details**
Confirm:
• Name, address phone number/s, date of birth, Medicare number
• Carer’s name, address and phone number
• GP and specialist details
• Ascertain or confirm the following Minimum Data Set requirements:
  - Indigenous status
  - Country of birth
  - Carer availability and address, i.e. do they live with the client?
  - Carer’s relationship to the client
  - Who does the client live with?

• Identify the client’s preferred language and ongoing need for an interpreter
• Identify the client’s source of income, e.g. pension or Department of Veterans’ Affairs

**History of Illness**
Refer to Appendix: Guide to Assessment

**Symptom Assessment**
• Assess physical and psychosocial symptoms and functional status supported by Tools of the Palliative Care Outcomes Collaborative (PCOC):
  - Phase of Care
  - Resource Utilisation Groups – Activities of Daily Living Scale (RUG – ADL)
  - Palliative Care Problem Severity Score
  - Australian Modified Karnofsky Performance Scale (AKPS)
  - Symptom Assessment Scale (SAS)

• If pain is rated 1 or more an Initial Pain Assessment Tool is completed. This comprehensive pain assessment elicits concise and meaningful information for the treating doctors.

• If any physical, psychosocial or spiritual symptom is rated 4 or moderate or more it is entered into the care plan.

**Psychosocial and Spiritual Assessment**
Guide to Assessment
Risk Assessment
- Refer to Site Assessment
- Discuss solutions with the client/carer, e.g. equipment

Care Planning
- Ensure a shared understanding of current issues, symptoms and goals of care for inclusion in the care plan
- Discuss the proposed frequency of ongoing visits
- Advise the client/carer to phone the office if an earlier visit is needed or to cancel a scheduled visit – preferably the day before

Processing the Assessment
Complete documentation including:
- PCOC tools, CSNAT and Initial Pain Assessment (if required)
- Progress notes (according to guidelines), linked with
- Care plan
- Referrals to MDT colleagues if required.

Liaison with the GP
- According to Working with GPs.

4.1 Equipment Required
- Tools of the Palliative Care Outcomes Collaborative (PCOC):
  - Phase of Care
  - Resource Utilisation Groups – Activities of Daily Living Scale (RUG – ADL)
  - Palliative Care Problem Severity Score
  - Australian Modified Karnofsky Performance Scale (AKPS)
  - Symptom Assessment Scale (SAS)
- Carer Support Needs Assessment Tool (CSNAT)
- Initial Pain Assessment Tool

4.2 Key Nursing Considerations
- Key issues within the referral guide the allocation of disciplines to the initial assessment, e.g. district nurse and social worker
- Include all aspects of a general health assessment but focus on the palliative care philosophy of care
- Management of symptom distress or psychosocial issues may take precedence at this visit
- Key issues for the client and carer, as well as well as the client’s presentation and capacity, guide the content and duration of the assessment; it may extend over more than one visit
  - The initial assessment should conform to the basic structure, with the health professional gently returning the discussion to topic when needed, e.g. ‘We’ll come back to that in a moment, but I need to hear more about …… ’
  - Use a checklist to ensure all areas are covered but maintain a degree of flexibility. Beware of closed questions, e.g. ‘You said that you are going to have more chemo – tell me about that’ rather than a question requiring a ‘yes’ or ‘no’ response
• Be alert to important words or phrases that may indicate underlying worries, e.g. ‘You mentioned that you’ve been taking lots of pills – are you worried about that?’ or ‘What do you mean by that?’

• If you have not covered everything in the first visit, acknowledge this and let the client and carer know you will discuss those items next time. Check that you have addressed what is most important to them: ‘Have we covered the issues that are most important for you?’

5.0 REFERENCES

• A Model for Community Palliative Care in Gippsland, Part 2 – Framework, Gippsland Regional Palliative Care Consortium, 2014

• Bostanci, A, Hudson, P, Philip J 2012, ‘Clinical tools to assist with specialist palliative care provision’, Centre for Palliative Care c/o St Vincent’s and The University of Melbourne, Australia

• Melbourne City Mission Palliative Care procedures and guidelines

### History of Illness

‘Would you like to tell me about your current illness? What treatments have you had? Do you have any other medical conditions e.g. diabetes?’

### 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.

### Medications

‘Can you show me the medications you are taking at the moment?’ ‘Can you show me any that you have taken in the recent past but are not taking right now?’

### Allergies

‘Do you have any allergies?’ If yes, ‘What happens when you take that medication?’ Note the difference between allergy and sensitivity, e.g. nausea when taking an opioid is an expected side effect and can be managed.

### Client Assessment

ESAS (symptoms), PCPSS (pain, other symptoms, psychological/spiritual), Braden Scale, RUG-ADL & Karnofsky (level of function).

### Carer Assessment

Identify the primary carer/s, their desired level of involvement and ability to perform the role. CSNAT and PCPSS – family/carer.

### Client and Carer Wellbeing

‘How is your mood at the moment? What sorts of things do you look forward to? What are your immediate concerns? What things 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 may 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 Strengths and Strategies

‘You’ve faced challenges in your life before. What got you through those times?’
<table>
<thead>
<tr>
<th>Community Services</th>
<th>‘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?’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spirituality and Meaning</td>
<td>‘What sustains your hopes and keeps your life meaningful?’ ‘What’s most important to you right now?’ ‘Do you have a particular belief system?’</td>
</tr>
<tr>
<td>Culturally Specific Issues</td>
<td>‘When did you migrate to Australia’? ‘Is there anything we should know about your traditions that are important to you right now?’</td>
</tr>
<tr>
<td>Environment Assessment</td>
<td>Discuss any manual handling or safety issues for inclusion on the Site Assessment, e.g. smoking, animals. Raise potential need for equipment as per Electric Beds and Lifting Machines.</td>
</tr>
<tr>
<td>After Hours</td>
<td>Explain the process as per After Hours Support.</td>
</tr>
<tr>
<td>Anticipatory Medications</td>
<td>‘In community palliative care we plan the management of symptoms and try to prevent unplanned admissions to hospital. This often includes having injectable forms of some medications in a safe place in your home for use by the nurses, in and out of hours. Would you be happy for me to speak with your GP about this? Would you have any concerns if these medications were stored in your home?’</td>
</tr>
<tr>
<td>Advanced Care Plan</td>
<td>‘Do you have an ACP? Would you be interested in knowing more about ACPs? If you were unable to make decisions about your health care, who would you want to speak with the medical team on your behalf?’</td>
</tr>
<tr>
<td>Financial/Legal</td>
<td>‘Do you have a will? Have you appointed a trusted person as your Enduring Power of Attorney and Medical Power of Attorney?’</td>
</tr>
<tr>
<td>End of Life</td>
<td>Where does the client wish to be cared for now and if they become less well? People’s wishes may change over time as they encounter new circumstances.</td>
</tr>
</tbody>
</table>
G2. Symptom Assessment (PCOC): Policy and procedure

1.0 SUGGESTED POLICY STATEMENT

XXXX uses the validated and standardised assessment tools of the Palliative Care Outcomes Collaborative (PCOC) to:

- Improve symptom management
- Provide a profile of symptoms and issues and a measure of interventions over time
- Facilitate consistent and formal documentation
- Involve clients in their own care
- Acknowledge the carer and family as part of the unit of care
- Facilitate holistic, safe and effective care.

N.B. PCOC is just one part of holistic assessment.

This guideline aligns with:

PROCEDURES
- Initial Assessment
- Care Planning – Initial and Ongoing
- Multidisciplinary Team (MDT)
- Working with General Practitioners (GPs)
- Carer Support

2.0 RESPONSIBILITY

| Palliative Care District Nurses | Use the PCOC tools at every visit |
| Nurse Unit Manager |

3.0 RECORDS & DOCUMENTATION

- PCOC
- Care Plan
- Initial Pain Assessment
- Carer Support Needs Assessment Tool (CSNAT)

4.0 GUIDELINE

Use each of the five tools at every visit.
PCOC recommends assessment using all five tools at each contact (face-to-face and by telephone) for clients in the community. It may not always be practical to use all of them in telephone contacts.

Symptom Assessment Scale (SAS)

- SAS is designed to involve clients in rating their distress caused by individual symptoms. Some may be unable to participate or choose not to participate. In such cases, the carer or staff member estimates the score.
- SAS describes the level of client distress relating to seven symptoms most commonly experienced by palliative care clients: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain.
• Introduce the SAS to the client and carer at the first visit. Provide them with the SAS - Information for patients and Form for completion by patients.

• Score symptoms from 0 – 10 on a numerical scale: 0 means the symptom is absent, 1 means the symptom or problem is causing minimal distress and 10 means the symptom is the worst possible distress.

• Use during phone calls when following up with the client/carer after advice or an intervention.

• If **pain is scored 1 or more** an Initial Pain Assessment Tool is completed.
  - This comprehensive pain assessment elicits concise and meaningful information.
  - Any new pain or exacerbation of pain requires another Initial Pain Assessment Tool to be completed.

• If any other physical, psychosocial or spiritual symptom is scored 4 or above, the symptom is added to the care plan with interventions; possible interventions include:
  - Consultation with and/or referral to the GP and/or specialist,
  - Altered drug regimens and/or doses, and
  - 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 meetings and case conferences.

**Palliative Care Problem Severity Score (PCPSS)**

• Is rated by the clinician and facilitates the global assessment of four palliative care domains: pain, psychological/spiritual, other symptoms and family/carer. The family/carer domain measures problems associated with the client’s condition or palliative care needs.

• Each domain is rated on a 4-point scale: 0 = absent, 1 = mild, 2 = moderate and 3 = severe.

• A score of ‘moderate’ or ‘severe’: as for a SAS score over 4.
Phase of Care

- Describes the client’s phase of illness: Stable, Unstable, Deteriorating, Terminal and Bereaved (post death support).

- The unstable phase indicates a need for urgent changes or interventions. Clients who are assessed as unstable may require intense review for a period of time. 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.
  - a client who is ‘stable’ may be visited weekly or fortnightly, and
  - a client who is ‘unstable’ and changed to ‘deteriorating’ when an intervention is instigated may receive a follow up phone call to assess the effect of that intervention.

Australia Modified Karnofsky Performance Scale (AKPS)

- Measures the client’s performance across the dimensions of activity, work and self-care. It is a single score between 10 and 100 assigned by the clinician.

- May be used as a trigger for assistance with personal care, and

- 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.

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

- Assesses the client’s level of functional dependence and the degree of assistance required based on what the person actually does rather than what they are capable of doing.

- Ask ‘Do you …?’ rather than ‘Can you …?’

4.1 Equipment Required

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

- Carer Support Needs Assessment Tool (CSNAT)

- Initial Pain Assessment Tool

4.2 Equipment Location

- Symptom Assessment Scale – Information for patients
- Symptom Assessment Scale – Form for completion by patients

4.3 Instructions

- The CSNAT is used in addition to the PCOC tools.
- Find Education for clinical assessments used in PCOC at www.pcoc.org.au
4.4 **Key Nursing Considerations**

- The AKPS and RUG-ADL scores should be in alignment.
- The *Initial Pain Assessment Tool* provides succinct, specific and credible information when communicating with GPs about a client’s pain, and therefore contributes to:
  - Facilitation of better pain management, and
  - Development of mutually respectful relationships.

5.0 **REFERENCES**

- *A Model for Community Palliative Care in Gippsland, Part 2 – Framework*, Gippsland Regional Palliative Care Consortium, 2014
- Melbourne City Mission Palliative Care procedures and guidelines
G3. CARE PLAN: Guideline and Procedure

1.0 Suggested POLICY STATEMENT

A care plan is initiated on admission of the client. It records specific items of care and how they will be addressed. The care plan:

- Guides multidisciplinary team members
- Facilitates continuity
- Reflects significant and evolving issues for the client and carer as well as mandatory items that ensure holistic palliative care.

This guideline aligns with:

PROCEDURES
- Initial Assessment
- Symptom Assessment (PCOC)
- Multidisciplinary Team (MDT)
- Progress Notes (Palliative Care)
- Working with General Practitioners (GPs)
- Carer Support
- Bereavement

2.0 RESPONSIBILITY

| All nursing Staff and MDT members | Initiate and update the care plan so that it reflects issues relevant to the client and carer |
| Nurse Unit Manager, Nurse Practitioner and Candidate | Ensure all clinical staff adhere to care plan requirements |

3.0 RECORDS

- Palliative Care Outcomes Collaborative (PCOC)
- Initial Pain Assessment
- Carer Support Needs Assessment Tool (CSNAT)
- Braden Scale
- Care Plan
- Progress Notes

4.0 PROCEDURE

- The care plan records significant issues and interventions as agreed with the client and carer. It is:
  - Dynamic
  - Informed by the initial and ongoing assessment
  - Initiated as near as possible to the assessment or second visit,
  - Updated by all MDT members as new issues/needs arise
  - Reviewed monthly for currency and relevance.

- The care plan contains:
  - Issues – Mandatory and as required (selected from the standardised issues below)
  - Actions
  - Goals
  - Outcomes

- The care plan is aligned with the progress notes (see Appendix for an example):
Outcomes of discussions and decision-making are recorded in the care plan. Succinct narratives, if required, are recorded in the progress notes under the heading corresponding with the care plan item.

**TIPS for integrating the care plan with the progress notes**

- In general, the care plan contains bullet points while the progress notes contain succinct and concrete narrative.
- After a visit, update the care plan first and then write what is needed in the progress notes.
- The care plan is updated after each visit, if this required. Reasons for which the care plan is updated:
  - Phase of illness change
  - There is exacerbation of a known symptom or new/modified management of the same symptom
  - A new symptom issue emerges that rates 1 if pain or 4 if another symptom.
- In general the progress notes will contain more narrative on assessment (setting the scene) and when changing circumstances are complex.
- On assessment you may write briefly in the progress notes about items that are not problems to indicate that you have addressed them: e.g. bowels functioning well and good oral health. Do not add them to the care plan.
- When writing in the care plan, ask ‘What value do these words add?’
- It may be helpful to write the outcome and ‘see progress notes 23/5/15’
- Including PCOC scores in the care plan can help demonstrate the effectiveness of interventions succinctly.

- **Care plan items that should be mandatory:**
  - Primary carer and/or decision-maker (they may not be the same person) including their relationship to the client and potential impediments to fulfilling the role
  - Skin Integrity (Braden Scale)
  - Advance Care Planning (ACP): include presence, absence or progress of a will and Enduring and Medical Power of Attorney
  - End-of-Life Care: include preferred site of care and funeral arrangements
  - Bereavement Risk

- **Standardised care plan items, as required:**
  - As for the Symptom Assessment Scale, when pain is rated 1 and over and other symptoms are rated 4 and over:
    - Pain
    - Tiredness
    - Nausea/Vomiting
    - Depression
    - Anxiety
    - Drowsiness
    - Appetite
    - Wellbeing,
    - Shortness of breath
    - Constipation
  - As for the Palliative Care Problem Severity Score (PCPSS) where items are scored 2 (moderate) or 3 (severe):
    - Psychological/Spiritual
    - Family/Carer burden: associated with the client’s condition or palliative care needs
  - Anticipatory Medications
  - Delirium
- Insomnia
- Pruritus
- Risk Alert, i.e. security risk for staff
- Risk of Palliative Care Emergency, e.g. Risk of Spinal Cord Compression, including possible signs and symptoms and planned action
- Communication, including the need for an interpreter
- Cultural requirements
- Respite
- Chemotherapy, including details of trials with the name of the coordinator or key contact
- Falls Risk
- Safety (Equipment)
- Oral hygiene
- Nutrition
- Wound care
- Urinary problems: retention, infection
- Device, e.g. Device: Stoma or Device: PICC
- Other, e.g. xxxx

- **Review of the** care plan:
  - Occurs every month to ensure currency and accuracy, and
  - Issues are ongoing, resolved or achieved.

- **Evaluation** occurs through supervision, MDT meetings, case reviews and audits.

### 5.0 REFERENCES

- A Model for Community Palliative Care in Gippsland, Part 2 – Framework, Gippsland Regional Palliative Care Consortium, 2014
- Bostanci, A, Hudson, P, Philip J 2012, ‘Clinical tools to assist with specialist palliative care provision’, Centre for Palliative Care c/o St Vincent’s and The University of Melbourne, Australia
- Melbourne City Mission Palliative Care procedures and guidelines
Example of care plan linked with PCOC and progress notes

<table>
<thead>
<tr>
<th>DATE</th>
<th>MANDATORY ISSUE</th>
<th>ACTION/PLAN</th>
<th>GOAL</th>
<th>OUTCOME Ongoing/Achieved/Resolved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>17/6/15</td>
<td>Primary carer and decision maker</td>
<td>☐ Wife Barb is the primary carer. She is fit and well.</td>
<td>The primary carer and decision maker are identified.</td>
<td>Ongoing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Eldest son Steve is the decision-maker.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
G4. Progress Notes: Guideline and procedure

1.0 SUGGESTED POLICY STATEMENT

The progress notes for palliative care clients are concise and systematically formatted to:

- Reflect integrated multidisciplinary care
- Promote safe, effective and seamless care
- Inform and educate multidisciplinary team members
- Facilitate tracking and auditing.

**This guideline aligns with:**

**PROCEDURES**
- Documentation – Medical Record
- Initial Assessment
- Care Planning – Initial and Ongoing
- Symptom Assessment (PCOC)
- Progress Notes (Palliative Care)
- Carer Support
- Multidisciplinary Team (MDT)
- Bereavement

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>Multidisciplinary Team</th>
<th>Use a single, consistently formatted client record.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Unit Manager</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- Palliative Care Outcomes Collaborative (PCOC)
- Initial Pain Assessment
- Carer Support Needs Assessment Tool (CSNAT)
- Braden Scale
- Care Plan
- Progress Notes

4.0 GUIDELINES

- Progress notes are aligned with the care plan (see Appendix for an example)
- Outcomes of discussions and decision-making are recorded in the care plan
- Succinct summaries of the content of discussions are recorded in the progress notes under the heading corresponding with the care plan item.

**TIPS for integrating care plan with the progress notes**

- In general, the **care plan contains bullet points** while the **progress notes contain succinct narrative**
- After a visit, update the care plan first and then write what is needed in the progress notes
- In general the progress notes will contain longer narrative on assessment (setting the scene) and when changing circumstances are complex
- On assessment you may write briefly in the progress notes about items that are not problems to indicate that you have addressed them: e.g. bowels functioning well and good oral health. Do not add them to the care plan.
- When writing in the care plan, ask ‘What value do these words add?’
- It may be helpful to write the outcome and ‘see progress notes 23/5/15’

4.1 Instructions

This procedure is underpinned by the principles of Documentation – Medical Record

5.0 GUIDELINES related to Medical Records compliance and legislative requirements
Example of progress notes linked with PCOC and care plan

17/6/15

ADMISSION: Jim is a retired farmer diagnosed with metastatic small cell lung cancer in March 2015. Metastases in his 4th, 5th and 6th thoracic vertebrae were diagnosed in May (note risk of spinal cord compression). Jim and Barb are open about Jim’s diagnosis and prognosis. Active treatment ceased late May.

PRIMARY CARER: Barb is fit and seems to be managing Jim’s care well. Their son Steve, who lives nearby with his young family, visits every day and two other adult children (Anna and John) visit from Melbourne frequently. While Jim is clear that he would like to remain at home and be kept comfortable, he and Barb tend to defer to Steve.

SKIN INTEGRITY: See care plan. Jim and Barb are reluctant for Jim to be in a separate bed but they recognise the coming need.

PAIN: See care plan.

DYSPNOEA: See care plan.

INSOMNIA: See care plan.

CONSTIPATION: See care plan.

APPETITE: Jim’s appetite is poor but he and Barb understand that this is an expected part of his disease. He is drinking reasonably well. SAS 3, PCPSC: mild.

PLAN: Follow up call tomorrow.

18/6/15

Follow up call:

PAIN: Jim has taken prn hydromorphone 5mg at 1500 and 2200 yesterday with good effect and again at 1000 this morning. SAS reduced to 4. Physio will see Jim tomorrow.

DYSPNOEA: As for PAIN. SAS 3.

INSOMNIA: Slept better with improvement in pain and dyspnoea. SAS 4.

CONSTIPATION: bowels opened well today. SAS 0.

PLAN: Follow up call tomorrow to check pain and insomnia scores and schedule next visit.

19/6/15

Follow up call:

PAIN: Seen by the physio this morning. Jim and Barb think her suggestions about moving in ways that minimise pain have been helpful. IR hydromorphone 5mg required once only today. SAS 3.

DYSPNOEA: SAS 2.

INSOMNIA: Sleep improving. SAS 3.
G5. Continuous Subcutaneous Infusions CSCI (Syringe Drivers) Guidelines

1.0 Suggested POLICY STATEMENT

A continuous subcutaneous infusion (CSCI) via a NIKI T34 Pump is used to administer medications when the client:
- Cannot swallow
- Has uncontrolled nausea and vomiting
- Is not tolerating or absorbing oral medications
- Has pain that is inadequately controlled via the usual (oral or transdermal) routes
- Has a bowel obstruction
- Is very weak or has decreased or fluctuating conscious state.

This guideline aligns with:

PROCEDURES
- Anticipatory (breakthrough) Medications
- Medication Management
- Working with General Practitioners (GP)
- Infection Control/Hand Hygiene
- Mandatory Training

DOCUMENTS
- Niki T34 Syringe Pump Instruction Manual
- Opioid Conversion Guidelines (Gippsland Region Palliative Care Consortium Clinical Practice Group)
- Subcutaneous Drug Infusion Compatibility Guideline (Gippsland Region Palliative Care Consortium Clinical Practice Group)
- How to give a subcutaneous injection in Carer's Safety & Information Kit (Gippsland Region Palliative Care Consortium Clinical Practice Group)
- McKinley T34 Syringe Pump Patient Reference Guide (McKinley Medical)

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>All palliative care district nurses commencing and caring for a client with a CSCI</th>
<th>Nurse Unit Manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>Successfully complete the NIKI T34 Pump orientation and an annual competency</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- Syringe Driver & Breakthrough Medications
- Niki T34 Equipment Log-In
- Annual Calibration
- Niki T34 check list
4.0 GUIDELINES

4.0.1 Education of client and carer
Provide simple and concise information to the client and carer about:
- The purpose of the CSCI
- Care of the syringe driver, e.g. keeping it away from water
- What to do if problems occur – provide the McKinley T34 Syringe Pump Patient Reference Guide

4.0.2 Sites of insertion for the Saf-T-Intima™
Possible sites of insertion include:
- Upper anterior chest wall, away from the axilla
- Anterior thigh
- Abdomen (preferable in a cachectic client)
- Outer aspect of upper arm.

NB. Areas of oedema are not suitable as drug absorption may be affected.

Check the insertion site each visit for:
- Inflammation
- Induration
- Bleeding
- Leaking
- Pain.

The overall integrity and patency of the SaF-T-Intima™ catheter will vary from client to client. The recommendation from the manufacturer is that it should be replaced weekly but the site should be changed if any of the above symptoms are present.

4.0.3 Care of extension tubing
Change the extension tubing every 7 days unless contamination is suspected. Indicate the date of line change on the Syringe Driver Record.

4.0.4 Procedure for set up
The NIKI T34 has been pre-programmed to a fixed duration of 24 hours and has the lock function turned on.

Fitting the battery
1. Slide the compartment cover at the back of the pump. Place the battery into the compartment.
2. Ensure the battery terminals are aligned as per the diagram inside the compartment.
Battery Test
1. Always check there is enough charge to set up the infusion (>30%).
2. Switch the pump on.
3. Press the INFO key.
4. Select BATTERY LIFE from the menu and press YES to confirm.
5. Verify that sufficient battery charge is available to complete the current programme.
   If not, change the battery (usually every 2-3 days).

Loading the syringe
1. Perform hand hygiene.
2. Draw up prescribed medication and diluent. Check compatibility if more than one medication is ordered (see GRPCC Subcutaneous Drug Infusion Compatibility Guideline). No more than 3 medications should be used in an infusion as precipitation may occur. In most cases the diluent should be sodium chloride 0.9% as it is closest to physiological tonicity and causes less irritation. The main exception to this is cyclizine. Cyclizine must be diluted with water for injection.
3. Complete the Subcutaneous Drug Additive Label and place it on the syringe driver. (Do not label the syringe or apply anything that changes its external diameter at the point where the barrel clamp is applied as incorrect syringe recognition may result and/or obstruct the movement of the syringe).
4. Connect the extension line to the Y connector of the Saf-T-Intima™ catheter.
5. Connect the other end of the extension line to the Luer-Lok ® syringe.
6. Manually prime the extension line to the Luer-Lok ® syringe.
7. Press and hold the ON/OFF button until it beeps.
8. The version of the software will flash on the screen. The screen will then flash PRELOADING. Wait for the pump to pre-load. It calibrates itself during this process.
9. Measure the drawn up syringe against the NIKI T34 and press either FF or BACK to align the actuator with the plunger. The actuator can be moved only in this way. Do not force or move the actuator manually as this could damage the pump.
10. The pump will state LOAD SYRINGE.
11. Raise the barrel clamp arm, position the syringe and lower the clamp. The screen will flash if the position of the syringe is incorrect. Check the 3 sensors:
   - Barrel Clamp Arm
   - Syringe ear/collar – ensure secure positioning of the syringe collar.
   - Plunger Sensor
12. Once the syringe is correctly loaded, the screen will ask for identification of the brand of syringe.
13. Use the ▲▼ to select the brand of syringe.
14. Check the data on the screen – Volume, Duration, Rate, e.g. 8.7ml, 0.36ml/hr. If the volume of the syringe differs significantly from the volume shown on the screen, remove the syringe, turn off the pump and start the process of switching on the pump again. If this reoccurs, do not use the pump and have it inspected.
15. To confirm press YES.

4.0.5 Commencing the infusion
1. The pump will ask START INFUSION? To confirm press YES.
2. Activate the keypad lock: with the pump infusing, press and hold the INFO key until a chart is displayed showing a bar moving from left to right. Hold the key until the bar
has moved completely across the screen and you hear a beep that confirms the lock has been activated.

3. During the infusion the rate will always be displayed in the middle of the screen.
4. At the bottom of the screen will show the brand and size of the syringe.
5. A green light will flash intermittently above the ON/OFF key.
6. Complete the Subcutaneous Drug Additive Label label and place on pump under the syringe.
7. Place the pump in the box, lock it and place it in the protective pouch.
8. Perform hand hygiene.

4.0.6 Breakthrough medications
1. Insert another Saf-T-Intima™ catheter.
2. See the procedure for Anticipatory (Breakthrough) Medications
3. In the absence of a range for a specific medication orders, manage breakthrough symptoms with prn medications until you are able to liaise with the GP.

4.0.7 Day 2, 3 etc
1. Perform hand hygiene.
2. Prepare medication as per prescription in the relevant syringe.
3. Press the NO/STOP button.
4. Perform hand hygiene.
5. Remove the old syringe and attach the new syringe to the infusion line.
6. Perform hand hygiene.
7. Measure drawn up syringe against the NIKI T34 and press either FF or BACK to align the actuator with the plunger.
8. Raise the arm clamp and position the syringe in the pump.
9. Close the arm clamp
10.Select the correct brand of syringe.
11.Select NO for a new syringe.
12.Check the data on the screen – Volume, Duration, Rate.
13.To confirm press YES,
14.When START INFUSION? is displayed, press YES.

4.0.8 Discontinuation of the NIKI T34
1. Explain to the client and carer why the pump is to be discontinued.
2. Explain the procedure.
3. Perform hand hygiene.
4. Press and hold the INFO key to unlock the keypad.
5. Press the NO/STOP button.
6. Extend the arm clamp and remove the syringe from the pump.
7. Press and hold the ON/OFF button until the screen turns off.
8. Remove the battery from the pump.
9. Perform hand hygiene and don gloves.
10. Remove the extension set from the SaF-T-Intima™.
11. Remove the SaF-T-Intima™ catheter, clean the site apply a dressing as required.
12. Remove gloves and perform hand hygiene.
13. Do not bring any medications back to the office – check the box and instruct the carer to return them to the pharmacy.
14. Dispose of any unused medications in the syringe and document.

4.1 Equipment Required

- A current (less than 12 months) legible medical order
- Prescribed medications
- Sharps bin
- Alcohol based hand rub
- Gloves
- NIKI T34 Pump (a portable battery operated pump) with its rigid locked box and carry pouch
- A checklist of contents showing when the box was cleaned and restocked. Contents:
  - SAF-T-Intima™ Catheters (access devices used to administer subcutaneous medications) – they reduce local site reactions, reduce needle stick injuries and increase longevity
  - 70% isopropyl alcohol cleansing swab
  - Diluent
  - Syringes:
    - Luer-Loc® to prevent disconnection
  - 20ml to reduce the risk of incompatibility, adverse site reactions and to minimize the effect of priming the line.
  - Subcutaneous Drug Additive, Line/Catheter and Medicine Labels
  - Luer-Loc® extension tubing (minimum 140cm in length)
  - 10cm x 10cm sterile transparent dressing
  - 9 volt battery (ensure a spare battery is in the syringe driver box) – do NOT use non-alkaline or rechargeable batteries.

4.2 Equipment Location

- The NIKI T34 Pump is stored at the District Nursing & Palliative Care office
- SAF-T-Intima™ Catheters are stored in the sterile stock room
- Sign the NIKI T34 in and out of the NIKI T34 Equipment Log-In

4.3 Instructions applicable to the individual organisation

4.4 Key Nursing Considerations

1. Advantages of a CSCI include:
   - Steady plasma concentrations without peaks and troughs
   - The management of multiple symptoms using a combination of medications via the one route.

2. The nurse has the right to request a quiet and tidy environment when preparing and administering medicines in the home. A distracting, noisy
environment may decrease the ability to concentrate and increase the likelihood of errors.

### 5.0 REFERENCES

- A Model for Community Palliative Care in Gippsland, Part 2 – Framework, Gippsland Regional Palliative Care Consortium, 2014


- Drugs Poisons and Controlled Substances Regulations 2006 (SR No 57 of 2006)

- Melbourne City Mission Palliative Care procedures and guidelines

G6. Anticipatory (Breakthrough) Medications: Guidelines and procedure

1.0 Suggested POLICY STATEMENT

XXXX seeks to:
- Facilitate prompt symptom relief at whatever time the client develops distressing symptoms
- Prevent crises and unplanned admissions to hospital
- Promote dying at home for those clients and carers whose choice this is.

This guideline aligns with:

PROCEDURES
- Initial Assessment
- Working with General Practitioners (GPs)
- Medication Management
- Infection Control/Hand Hygiene
- Continuous Subcutaneous Infusions (CSCI)
- Carer support (including Respite)

DOCUMENTS
- Palliative Care Anticipatory Prescribing Guidelines - Gippsland Region Palliative Care Consortium (GRPCC)
- Subcutaneous Drug Infusion Compatibility Guideline (GRPCC)
- TOOLS TO ASSIST AFTER-HOURS TELEPHONE TRIAGE of Community Palliative Care Clients (GRPCC)

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>Palliative Care District Nurses</th>
<th>Anticipate and prepare for breakthrough symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client and carer</td>
<td>Arrange collection and transport of prescriptions and medications.</td>
</tr>
<tr>
<td>Nurse Unit Manager (NUM)</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

Nurse administered:

Client/carer administered:

4.0 PROCEDURE guideline itself

4.0.1 Obtain Anticipatory Medications

- Establish the name and contact details of the client’s GP prior to or at the assessment
- If the patient is being discharged home from hospital, try to have the necessary orders and medications arranged for discharge
- Contact the GP within 24 hours of the initial assessment and as part of your discussion:
- Establish the need for anticipatory medications (or that the discharging hospital has provided same)
- Discuss/refer to the GP letter and the fax-back template for standard Anticipatory Prescribing Orders.

- If the GP agrees, fax the letter and template with the expectation that the GP will:
  - Fax the completed and signed form back
  - Provide the prescriptions for the necessary medications.
  - Document in the care plan and/or progress notes:
    - Letter and template have been sent to the GP
    - Requested medications
    - Progress of obtaining anticipatory medications or the reason progress has stalled.

- Discuss any difficulties in obtaining anticipatory medications with the NUM.

- Repeat this process as new symptoms develop or the client moves into the terminal phase.

- On receipt of the signed orders:
  - Contact the client/carer to ensure they have obtained the prescriptions from the GP
  - Place the signed orders in the home folder
  - At the next home visit, place the anticipatory medications with the Breakthrough Medication Kit and advise the client/carer of safe storage.

4.0.2 Reasons why anticipatory opioids may not be obtained include:

- Client is opioid naïve (but may still require other anticipatory medications, e.g. subcutaneous (sc) metoclopramide)
- Client has no carer
- There is a history of drug abuse in the home (consider a locked box)
- Client or carer refuses anticipatory injectable medications.

4.0.3 Insertion of Saf-T-Intima™ catheter

- Insert a Saf-T-Intima™ catheter when the client is beginning to need subcutaneous (sc) anticipatory medications
- Saf-T-Intima™ catheters reduce the number of intermittent injections, needle stick injuries and local site reactions.

4.0.4 Possible sites of insertion include:

- Upper anterior chest wall, away from the axilla
- Anterior thigh
- Abdomen (preferable in a cachectic client)
- Outer aspect of upper arm.

NB. Areas of oedema are not suitable as drug absorption may be affected.

4.0.5 Check the insertion site each visit for:

- Inflammation
- Induration
- Bleeding
- Leaking
- Pain.
The overall integrity and patency of the SAF-T-Intima™ catheter will vary from client to client. The recommendation from the manufacturer is that it should be replaced weekly but the site should be changed if any of the above symptoms are present.

### 4.0.6 Preparation, storage and administration of anticipatory medications

Anticipatory medications may be:
- Drawn up and administered by the nurse or GP, or
- Drawn up by the nurse and left for the client/carer to administer.

In exceptional circumstances the client/carer may be educated to draw up medications. This must be discussed with the NUM.

If the client/carer are administering sc anticipatory medications:
- Refer the carer to How to Give a Subcutaneous injection via a Cannula Using No Needle Technique and
- Document that the client/carer have been educated about and are confident in the administration of drawn up anticipatory medications.

If not immediately used, each pre-prepared syringe is:
- Diluted with sodium chloride 0.9% to a minimum of 1ml. The main exception to this is cyclizine. Cyclizine should always be diluted with Water for Injection
- Individually labelled with the date and time of preparation, the name of the medication, the dose and the nurse’s initials
- Capped with a Carefusion ‘red bung’
- Stored in a cool and place, in a separate and labelled container and away from children
- Checked each visit
- Discarded after 72 hours.

### 4.0.7 Guidelines for administration of oral and sc breakthrough medications

In general,
- Ensure the client is taking regular medications as prescribed, e.g. MS Contin 12 hourly and metoclopramide tds or qid
- Clients with breakthrough pain or dyspnoea should have up to three doses of oral prn medications, 30-45 minutes apart (as prescribed) before considering sc breakthrough medication
- Clients with breakthrough nausea should have one dose of ‘as necessary’ (prn) oral medication (as prescribed) before considering sc prn medication.

The responses to specific questions and clinical judgement may indicate that sc medications are immediately appropriate, e.g. if the patient is unable to swallow or unable to keep oral medications down.

### 4.1 Equipment Required

- GP letter and template of orders for anticipatory medications
- Breakthrough Medication Kit (SAF-T-Intima™ catheters, needles, syringes and alcohol swabs)
- How to Give a Subcutaneous injection via a Cannula Using No Needle Technique (Brisbane South Palliative Care Collaborative)

### 4.2 Equipment Location
4.3 Instructions

- Nurses may not collect and transport Schedule 8 drugs.
- In exceptional circumstances, two nurses may transport Schedule 8 medications to the pharmacy for destruction. This must be documented and countersigned.
- Registered and Endorsed Enrolled Nurses should only administer medicines from the container in which they were originally dispensed from the pharmacy.

5.0 REFERENCES


- Drugs Poisons and Controlled Substances Regulations 2006 (SR No 57 of 2006)


- Gippsland Regional Palliative Care Consortium (2014) A Model for Community Palliative Care in Gippsland, Part 2 – Framework

- Gippsland Regional Palliative Care Consortium (2015) TOOLS TO ASSIST AFTER-HOURS TELEPHONE TRIAGE of Community Palliative Care Clients

- Melbourne City Mission Palliative Care procedures and guidelines

- Therapeutic Guidelines Limited. Therapeutic Guidelines: Palliative Care 2010 Version 3
G7. After Hours Support: Guidelines and procedure

1.0 Suggested POLICY STATEMENT

XXXXX provides clients and carers with after-hours service to:

- Enable new or exacerbated issues of concern to be addressed as they arise
- Provide continuity of care, advice, comfort and support
- Help clients remain at home if that is their wish
- Avoid unnecessary travel and admissions to emergency departments.

This guideline aligns with:

PROCEDURES
- Anticipatory (Breakthrough) Medications
- Work Related Driving and Mobile Phones

DOCUMENTS
- TOOLS TO ASSIST AFTER-HOURS TELEPHONE TRIAGE of Community Palliative Care Clients (Gippsland Region Palliative Care Consortium)

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>District Nurses</th>
<th>Nurse Unit Manager</th>
</tr>
</thead>
</table>

3.0 RECORDS & DOCUMENTATION

- Client Summary Palliative Care (GRPCC)

4.0 PROCEDURE guideline itself

1. The purpose of the after-hours service is explained to the client and carer on admission:

- The service is primarily one of phone support and advice
- The nurse will ask questions about what is happening and to help establish the best course of action
- A nursing visit will be provided if it is clinically appropriate and there is a nurse available.

2. The procedure is explained to the client and carer: this procedure has to apply to the individual organisation: XXXX to complete.

- Explain:
  - The district nurse may be attending to another client or driving and therefore unable to answer the phone immediately.
  - If the call is not answered within 5 minutes, call again.
  - If the call remains unanswered, call again after 5 minutes.
  - If this feels too long to wait, call the Health Service Coordinator at XXXXXXXXXXX phone number:
4.1 Equipment Required


4.2 Key Nursing Considerations

- There is no legal requirement for the funeral industry to obtain written verification of death before moving the body. However, funeral directors may require verbal reassurance that death has occurred.
- There is no limit on how long someone who has died can stay at home.

5.0 REFERENCES

- A Model for Community Palliative Care in Gippsland, Part 2 – Framework, Gippsland Regional Palliative Care Consortium, 2014
- Guidance Note for the “Verification of Death” Department of Human Services Victoria. April 2009
- Verification and Certification of Death, Gippsland Region Palliative Care Consortium, 2015

1.0 SUGGESTED POLICY STATEMENT

The carer is provided with information, guidance and support specific to their needs.

This guideline aligns with:

- Procedures
  - Initial Assessment
  - Care Plan – Initial and Ongoing
  - Culturally and Linguistically Diverse Clients
  - Anticipatory Medications
  - Preparation for End-of-Life
  - Bereavement

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>Multidisciplinary Team</th>
<th>Identify opportunities to enhance the carer’s resilience through initial and ongoing assessment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Unit Manager</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- Document in the care plan under Carer Support

4.0 PROCEDURE Guideline itself

4.0.1 INITIAL ASSESSMENT

If it is clear from the referral that the carer is struggling, involve another discipline from the multidisciplinary team (MDT) in the initial assessment, e.g. social worker or coordinator of volunteers. They may be present for the whole visit or join you towards the end.

Tools
Palliative Care Problem Severity Score (PCPSS) for Family/Carer
- Score on admission and at each visit

Carer Support Needs Assessment Tool (CSNAT)
- Use it to open up a conversation with the carer, to see what their support needs are and what is most important to them.

Triggers for referral to relevant team member/s and inclusion in the care plan include:
- PCPSS for Family/Care = 3
- CSNAT scores of ‘Quite a bit more’ and ‘Very much more’.

Care plan
Identify Carer Support on the care plan.

4.0.2 INTERVENTIONS/OPTIONS
Help carers to help themselves
- It is normal to feel distress when caring for someone with a life-threatening illness. A supportive listener may be all the carer needs.
- Explore what the carer normally does to help them cope with difficulties, e.g. talking to friends, listening to music or having higher levels of practical support.
- Encourage carers to contact the relevant bodies below if:
  - PCPSS is 1 (mild) or 2 (moderate)
  - CSNAT score is ‘A little more’ or ‘Quite a bit more’
- Refer to appropriate MDT members or organisations yourself if you think it is appropriate.

Multidisciplinary Team
Explain to the carer why you think referral to another team member might be helpful if:
- PCPSS is 3 (severe)
- CSNAT is ‘Very much more’
- The PCPSS and CSNAT scores are lower but in your judgement referral is appropriate.

If the carer agrees, refer as appropriate. This may include referring for counselling support via the general practitioner (GP). Note that this option may take time. If immediate attention is required, liaise with the social worker.

If the carer refuses involvement from another discipline, seek advice from the relevant MDT member about how to proceed.

Ongoing education and written instructions specific to individual symptoms
For example, the management of shortness of breath

Consider:
- GRPCC’s Carer’s Safety & Information Kit
- Palliative Care Victoria’s information for families:
  http://www.pallcarevic.asn.au/

Palliative Care Victoria and Cancer Council brochures, as appropriate – it may be helpful to let the carer know you have placed a particular brochure in the Communication Folder for them to read when they are ready, e.g. Process of Dying.

Financial Assistance
- Carer Allowance – income supplement, not means tested and paid in addition to wages, Carer Payment or other Centrelink payment
- Carer Benefit – financial support for people who are unable to work in substantial employment because they provide full time daily care
- How to lodge a claim - see Palliative Care Victoria, Carers Allowance and Carers Payment – Ways to lodge an intent to claim
Cancer Council Victoria (see website)
Legal and financial advice and assistance (means tested)

XXXX Shire Council (see website)
- Service in the Home (cleaning and maintenance)
- Carers’ Retreats
- Transport
- Veterans’ Home Care

Respite – in home
Consider referral to:
- Coordinator of Volunteers
- Veterans’ Home Care (see website)
- XXXX Shire Council
- Commonwealth Respite and Carelink Centre (see brochure and website).
  Limited funding for short-term episodes – assessed case by case.

Respite - inpatient
- Discuss the need for respite and the options with the client’s GP.
- Consider a specialist palliative care facility when there are acute issues requiring
  specialist input, e.g. uncontrolled symptoms, psychosocial issues.

Options:
- XXXX Hospital (0900 – 1700 - ring the Health Service Coordinator
  (5671 3384) about availability of the palliative care bed or other
- An aged care facility (ACF) if the patient is eligible (aged over 65 or a younger
  person with a disability and assessed by the Aged Care Assessment Service).
  - The health professional or carer can make a verbal or written referral to the
    Commonwealth Respite and Carelink Centre who will pay 50% of costs (see
    brochure and website).
  - The carer is responsible for finding an available bed in an ACF.
- Public metropolitan inpatient units
  - Peninsula Health Palliative Care Unit, Frankston - 9784 8600
  - Southern Health - Casey Hospital, Berwick – 8768 1699
  - Southern Health - McCulloch House, Clayton – 9594 5320
  - St Vincent’s - Caritas Christi Hospice, Kew – 9854 1621
  - St Vincent’s – Caritas Christi Hospice, Fitzroy – 9288 4697
  - Calvary Health Care Bethlehem, Caulfield South (especially for clients with
    motor neurone disease) – 9596 2853
- Private metropolitan palliative care unit
  - Cabrini Acute Palliative Care Unit, Prahran, (provides ‘relief of carer burden’
    rather than ‘respite’) – 9508 5027

Urgent respite
- Annecto- 41- 43 Ringwood Street, Ringwood- T: (03) 9876 0122
  http://www.annecto.org.au/contact-us

4.1 Written Information that may be Required

- Are you a carer? (brochure – Latrobe Community Health & Commonwealth Respite
  and Carelink Centre)
- Carers Allowance and Carers Payment – Ways to lodge an intent to claim (Palliative
  Care Victoria)
4.2 Location of Written Information

- Carer’s Safety & Information Kit (GRPCC)
- Carers Allowance and Carers Payment – Ways to lodge an intent to claim (Palliative Care Victoria)
- Are you a carer? (brochure)

4.3 Instructions

- Palliative Care Victoria [http://www.pallcarevic.asn.au/](http://www.pallcarevic.asn.au/)

4.4 Key Nursing Considerations

- Visiting a client and carer with a colleague from another discipline demonstrates that you work as a team.

5.0 REFERENCES

- A Model for Community Palliative Care in Gippsland, Part 2 – Framework, Gippsland Regional Palliative Care Consortium, 2014
G9. Electric Beds and Lifting Machines: Guidelines and Procedure

1.0 Suggested POLICY STATEMENT

XXXX encourages the timely and appropriate installation of an electric bed with adjustable height and/or a lifting machine (lifter) in the client’s home to:

- Minimise the risks of manual handling for the carer and staff
- Help staff work in a manner that is not harmful to their own health and safety and the health and safety of others
- Ensure practice is consistent.

This guideline aligns with:

PROCEDURES
- Manual Handling
- Occupational Health & Safety

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>District Nurses</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapist (OT)</td>
<td></td>
</tr>
<tr>
<td>Nurse Unit Manager (NUM)</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- Site Assessment
- Care plan under Risk Management
- Contract for acknowledging refusal of recommended equipment and the implications for care.

4.0 PROCEDURE guideline itself

1. As part of the client admission, inform the client and carer that:
   - Their home is your workplace
   - You are obligated to work in a way that does not put you or your colleagues at risk
   - Over time equipment, such as an electric bed or lifter, may be required
   - Such equipment is also important to maintain the health and safety of the carer.

2. Use the Karnofsky Performance Scale as a guide to installing an electric bed:
   - A score of 50 (client requires considerable assistance and frequent medical care) triggers discussion with the client and carer about the coming need for an electric bed
   - A score of 40 (the client is in bed more than 50% of the time) triggers installation of an electric bed
   - The recommendation of the occupational therapist (OT) triggers installation of an electric bed and/or lifter.

3. Lifters must be prescribed and trialled by a XXXX OT. If the lifter is already in the home, staff must not use it unless the XXXX OT has assessed it as suitable and safe.
4. Inform the client and carer of the cost of the bed and/or lifter. If they cannot afford it, consider these options:
   - Liaise with the NUM. XXXX will fund a bed, at the NUM’s discretion, for one month.
   - If the client has motor neurone disease (MND), the OT will liaise with the MND Association.
   - If the client has a long-term prognosis, the OT will refer to the Statewide Equipment Program (SWEP).

5. The client or carer may decline the installation of an electric bed and/or lifter. If so,
   - 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.
   - Express your concern for the health and safety of the carer.
   - Discuss with the NUM and arrange for client/carer to sign a contract that acknowledges refusal of recommended equipment and implications for care.
   - Document the issue in the care plan under Risk Management.

4.1 Equipment Required

As per OT assessment

4.2 Equipment Location

Coastal Independence

4.3 Instructions

Arrange installation of beds through Coastal Independence (0421 162 530).

4.4 Key Nursing Considerations

Your unsafe practice while alone with a client exposes your colleagues to risk. They will be under pressure to practise in the same unsafe way when they visit.

5.0 REFERENCES

- A Model for Community Palliative Care in Gippsland, Part 2 – Framework, Gippsland Regional Palliative Care Consortium, 2014

- Australian Commission on Safety and Quality in Health Care Safety and Quality Improvement Guide Standard 1: Governance for Safety and Quality in Health Service Organisations (October 2012) Sydney
G10. End-Of Life Care: Guidelines and Procedure

1.0 SUGGESTED POLICY STATEMENT

As the client approaches end-of-life, XXXX endeavours to:

- Meet the client’s stated and changing wishes,
- Prepare the carer and family, and
- Maximise comfort and preserve dignity.

This guideline aligns with:

- Initial Assessment
- Care Plan – Initial and Ongoing
- Ongoing Assessment and Action (PCOC)
- Supporting the Carer
- Anticipatory (Breakthrough) Medications
- Continuous Subcutaneous Infusions
- Advance Care Planning
- Bereavement

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>Multidisciplinary team MDT</th>
<th>Prepare the client, carer and family for end-of-life and support them during the terminal phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Unit Manager</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- Care Plan

4.0 PROCEDURE *guideline itself*

PLANNING FOR THE TERMINAL PHASE

- Revisit and clarify goals of care as circumstances change
- Provide information and education about what to expect at a time that is acceptable for the client and carer. This may be late in the episode of care.

Site of Care

- Clarify the preferred site for end-of-life care and death
- Let the client and carer know that:
  - XXXX will do all it can to support the client’s wishes
  - It is OK to revise the plan if care becomes too challenging at home, e.g. carers may promise to keep the client at home before fully understanding what that might mean.

Psychosocial, Spiritual and Cultural Needs

As appropriate, clarify

- Cultural and/or religious traditions around dying and death which may influence the carer’s expectations of care
- Hopes, fears and perceptions the client and/or carer have around death and dying
- Client and/or carer’s wishes regarding the involvement of children in the impending death
- Need for information about funeral directors
- Need for information about what to do following the death
- Implications of the client’s advance care planning.

**Death certificate**

Establish who will write the death certificate (within 24 hours of death).

**TERMINAL PHASE - ASSESSMENT**

Recognition of the terminal phase can be difficult and clients may live longer than expected and vice versa.

In progressive disease such as cancer it is likely that the client has a prognosis of a few days when they become:
- Profoundly weak
- Bed bound
- Semi-comatose
- Unable to take tablets or having great difficulty swallowing them
- Unable to take more than sips of fluids.

In consultation with the general practitioner, clarify:
- Carer’s perception of the client’s condition
- Priorities of interventions to achieve maximum comfort.

If the carer seems not to realise that the client is in the terminal phase, you could:
- Say ‘what do you think might be happening here?’ or ‘are you seeing what I’m seeing?’
- Ask them to describe what they are seeing and hearing
- Respond with your own observations
- Gently lead them to the probability that the client is most likely dying.

Be alert to:
- Potentially reversible conditions, e.g. hypoglycaemia, and
- Improvement in the client’s condition (which will lead to a change in care planning).

**NUTRITION and FLUIDS**

Carers may express anxiety that starvation or dehydration will cause death. Explain that:

- Loss of interest in food and fluid, and the inability to eat or drink, are part of the process of dying
- Attempting to feed a client who is unable to swallow may cause distress
- Frequent mouth care and crushed ice will promote comfort and relieve thirst.

Use of subcutaneous (sc) fluids in these circumstances is controversial. They may contribute to urinary output, oedema and chest secretions yet provide comfort for the client and/or carer. Discuss all requests for sc fluids with the MDT, including the GP.

**CESSATION of ORAL MEDICATIONS**

The value of medications previously considered necessary should be reevaluated with the GP and negotiated with the carer:
- Hypoglycaemics, antihypertensives and anticoagulants may be ceased.
- Consider other routes of administration, e.g. subcutaneous for medications needed for the client’s comfort, e.g. opioids, anticonvulsants and anti-emetics.

**NOISY BREATHING**
The inability to cough effectively or to clear secretions from the oropharynx or trachea causes a repetitive gurgle. This symptom is often more distressing and unpleasant to carers:
- Repositioning the client on one side may allow drainage from the mouth
- Administration of occasional or repeated doses of an anticholinergic may help reduce secretions, but
- It is unlikely that anticholinergics will be effective in the presence of active pneumonia.

**URINARY RETENTION**
- Urinary output is likely to decrease as death approaches
- Retention of urine may occur
- The decision to insert an indwelling catheter will be guided by the client’s mobility, levels of discomfort and the carer’s ability to manage the situation.

**DYSPNOEA**
- Regular breathing patterns may change in the last hours, with periods of several minutes where no breathing occurs. This indicates a decrease in blood circulation and a build-up of waste products.
- Offer symptomatic relief with opioids and benzodiazepines.

**TERMINAL RESTLESSNESS**
Restlessness occurs commonly at end-of-life and can often be attributed to multiple causes. It is characterised by an inability to relax, picking at the bedclothes or trying to climb out of bed.
- Consider constipation and urinary retention and manage appropriately. (Note that opioids can contribute to urinary retention.)
- Ensure all regular analgesia, anti-emetics and sedation have been administered as prescribed. Consider prn doses of same.
- Encourage the carer and family to:
  - Speak in a quiet and natural way
  - Read or play music softly
  - Have familiar people in the room
  - Light the room according to the time of day, e.g. night light
  - Give a tepid sponge if appropriate.

**COMMUNICATION with the DYING PERSON**
The dying client may try to communicate things that the carer and family may not understand, e.g. about travel or seeing someone who is not there. Encourage the family to:
- Respond with calm acceptance and reassurance
- Listen for the meaning but not to worry if this is not clear
- Resolve underlying issues if possible.

Note that the senses, as well as hunger, tend to be lost in an orderly fashion: hunger, thirst, speech, vision, hearing and then touch.

**FAMILY CONCERNS about ANALGESIA and SEDATION**
Families and carers may express concern that death is being accelerated with medication, particularly opioids:
- Acknowledge that this is a common concern which is not based on medical evidence
- Explain that it often necessary to combine sedation with analgesia to manage restlessness, confusion or myoclonus
• Explain that appropriate analgesic relief is aimed at promoting comfort and preventing avoidable suffering.

**POST DEATH**

• Attend to verification if required
• Arrange certification if required
• Update the bereavement risk assessment
• Remind family of options for bereavement support
• The appropriate team member contacts the carer.

### 4.1 Equipment Required

Palliative Care Victoria brochures:
- About Planning a Funeral Ahead of Need
- About The Process of Dying
- About What to do When Someone Dies

### 5.0 REFERENCES

Department of Human Services, What to do following a death

Gippsland Region Palliative Care Consortium, Tools to Assist After-Hours Telephone Triage of Community Palliative Care Clients

Melbourne City Mission Palliative Care procedures and guidelines

Palliative Care Victoria (brochures)
[https://www.pcvlibrary.asn.au/display/pcv/Brochures](https://www.pcvlibrary.asn.au/display/pcv/Brochures)
G11. Bereavement Support: guidelines and procedure

1.0 Suggested POLICY STATEMENT

XXXX recognises that grief is a normal response to grief and that most people are resilient and supported in their grief by family and community. A minority of people will require specialist interventions.

XXXX seeks to ensure that:
- Issues related to loss and grief are assessed and documented from the time of admission, and
- Appropriate supports are offered in a timely and sensitive manner.

This guideline aligns with:
- Initial Assessment
- Care Plan – Initial and Ongoing
- Carer Support

2.0 RESPONSIBILITY

<table>
<thead>
<tr>
<th>All multidisciplinary team members (MDT) involved in client care</th>
<th>Identifying and documenting bereavement risk as issues arise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Unit Manager</td>
<td></td>
</tr>
</tbody>
</table>

3.0 RECORDS & DOCUMENTATION

- Care Plan
- End-of-Life Care
- Progress Notes

4.0 PROCEDURE guideline itself

4.01 Be familiar with factors that enhance resilience in bereavement
- Drawing upon past losses – i.e. how I survived
- Connecting with family and community
- Drawing on spiritual/religious beliefs and practices
- Identifying internal and external strengths and resources
- Reconstructing meaning and identity after loss
- Drawing on the experience and support of other bereaved people
- Higher levels of practical support
- Holding a belief in a just world and acceptance of death
- Gaining comfort from talking or thinking about the deceased.

4.02 Bereavement support – during the episode of care and at time of death
- As appropriate, discuss with the carer the factors that enhance resilience in grief
- Identify and reinforce the carer’s coping and positive achievements
- Reinforce the importance of family and community as sources of support
- Build on strengths and encourage the carer’s innate capacity to recover and cope with grief
- Intervention should be minimal.
4.03 Screening and Assessment – Initial and Ongoing

In the absence of a validated tool, consider the following factors in relation to the main carer:

<table>
<thead>
<tr>
<th>Characteristics of bereaved carer</th>
<th>Bereaved carer’s history of loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Under 18</td>
<td>• Cumulative multiple losses</td>
</tr>
<tr>
<td>• Was a twin</td>
<td>• Previous mental health issues</td>
</tr>
<tr>
<td>• Young spouse</td>
<td>• Current mental health issues</td>
</tr>
<tr>
<td>• Elderly spouse</td>
<td>• Other significant health issues</td>
</tr>
<tr>
<td>• Isolated</td>
<td>• Migrant/refugee</td>
</tr>
<tr>
<td>• Lacks meaningful social support</td>
<td></td>
</tr>
<tr>
<td>• Dissatisfied with help available</td>
<td></td>
</tr>
<tr>
<td>• during illness</td>
<td></td>
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<tr>
<td>• New to financial independence</td>
<td></td>
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<tr>
<td>• New to decision making</td>
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<td>• Migrant/refugee</td>
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<table>
<thead>
<tr>
<th>Illness of deceased</th>
<th>Relationship with deceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Inherited disorder</td>
<td>• Profound lifelong partner</td>
</tr>
<tr>
<td>• Stigmatised disease in the</td>
<td>• Highly dependent</td>
</tr>
<tr>
<td>family/community</td>
<td>• Antagonistic</td>
</tr>
<tr>
<td>• Lengthy and burdensome</td>
<td>• Ambivalent</td>
</tr>
<tr>
<td></td>
<td>• Deeply connected</td>
</tr>
<tr>
<td></td>
<td>• Culturally defined, e.g. marital</td>
</tr>
<tr>
<td></td>
<td>status or the father dies</td>
</tr>
<tr>
<td></td>
<td>leaving his son as the eldest</td>
</tr>
<tr>
<td></td>
<td>male</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify any relevant issues in the care plan</td>
</tr>
</tbody>
</table>

- On initial assessment, note the presence of any of the listed factors in the care plan under Bereavement Risk. If needed, make succinct notes in the progress notes under the same heading.
- Add to the care plan and progress notes as issues come to light throughout the episode of care.
- If you identify a carer is at medium – high risk of complicated bereavement or you are concerned, discuss with the appropriate MDT member and at the MDT meeting.
- Remember that protective factors and resilience may outweigh apparent risk factors.

4.04 After the bereavement phone call or visit

- Record the contact in the progress notes, noting potential risks.
- Complete the Bereavement Risk Assessment.
- Assign a risk level:

  **Low risk**
  - No further follow up.
  - Routine practice – Card? Letter? Brochure? e.g. Palliative Care Victoria’s About Grief or the resources of the Australian Centre for Grief and Bereavement at [http://www.grief.org.au/](http://www.grief.org.au/)

  **Medium – high risk**
• Refer to social worker? Refer to GP for counselling referral? (using the Bereavement Risk Assessment and your own assessment)

4.1 Key Nursing Considerations

Typical Grief
Each person’s grief trajectory will be unique. For the majority, grief will involve intense yearning, intrusive thoughts and images and emotional responses such as anxiety, unhappiness or uneasiness. These symptoms will not persist longer than a few months and eventually they will be able to integrate the loss into their lives and regain interest and engagement with life. (Shear K, Shair H 2005, ‘Attachment, loss and complicated grief’. Developmental Psychobiology, vol. 47, no.3, pp253-267)

Complicated Grief

Low Bereavement Risk
No risks of complicated grief identified by CBRAT

Medium Bereavement Risk
Minimal risk of complicated risk identified by CBRAT

High Bereavement Risk
Multiple risks of complicated grief identified by CBRAT.

5.0 REFERENCES

• Hall C, Hudson P, Boughey A 2012 Bereavement support standards for specialist palliative care services, Department of Health, State Government of Victoria, Melbourne

• Melbourne City Mission Palliative Care - procedures and guidelines

• Bereavement Risk Screening and Management Guidelines 5th draft Gippsland Region Palliative Care Consortium- Clinical Practice Group