

Rural Palliative Care Resource Kit



End of Life Clinical Pathways in Residential Aged Care Facilities

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Purpose

Over a decade of clinical practice and evaluation of End of Life (EOL) Clinical Pathways³ has demonstrated their value in supporting quality end of life care since their first application in palliative care in the UK in the mid 1990's.¹ Locally and more recently, many Residential Aged Care Facility (RACF) healthcare workers in Australia are becoming aware of the benefits of EOL Clinical Pathways and are interested in applying them in their facility.

This document provides information on the basic steps to planning, implementing, and evaluating the efficacy of such a model of care. The document is in two parts:

1. information to assist you determine if this model of care is likely to be beneficial in your Residential Aged Care Facility (RACF)
2. information offered to assist with the practicalities of how it will be implemented. The process of implementation requires adequate resources and access to quality supports.

The document's intended audience includes RACF workers and management, GPs and Divisions of General Practice (DGP) who have an interest in exploring this model of care planning. Rural and remote GPs and RACF staff are the focus audience for the additional information that relates to enhancing access to emergency medications after hours to facilitate the provision of best practice terminal phase care.

Background

Clinical pathways have been used in many areas of medicine since their introduction in the USA in the 1980s.¹³ When applied in palliative care for terminal phase or EOL care, they can be a supportive clinical tool at what is a difficult and challenging time for the patient, their family and the medical and health care workers.

The RACF is the final home for many in our community with approximately 6 per cent of people aged over 65 years being aged care facility residents.¹⁴ Their morbidity on admission is higher, with the RACF often filling the role of 'de facto hospices'.¹⁴

The diagnosis at death for RACF residents is more likely to be related to end stage organ failure than cancer (Partington).

The cause of morbidity can have implications for RACF staff in determining the appropriate time to commence the End of Life Clinical Pathway. With organ failure, the trajectory towards death⁷ is often gradual and fluctuating, making prognostication about the terminal phase particularly challenging for nursing and medical staff.

The Australian Government Department of Health and Ageing funded the development of the *Guidelines to the palliative approach in residential aged care*⁷. The guidelines emphasise the diversity and individuality of this terminal phase experience for all involved. The clinical pathway is not a definitive plan or process; rather it acts as a clinical tool, supporting the health care worker to focus their care on:

- the psycho social aspects of palliative care

- the preferred spiritual and cultural practices of a person and their family
- the appropriate symptom assessment and management for the terminal phase
- ensuring GPs are notified of patients deterioration in a timely manner
- completing adequate documentation of palliative care delivered
- the importance of communicating with the family about the pending death, to assist families to prepare emotionally and practically for it.

All these aspects of care are in accordance with the standards for aged care facilities.¹² The role of EOL Clinical Pathways are to inform and assist the clinical decision makers to ensure that comprehensive terminal phase care is offered to the resident and their family.

The implementation of an EOL Clinical Pathway can be both a way of enhancing current clinical practice as well as delivering a quality improvement activity.

Determining need

It is essential to determine if the RACF has the capacity to undertake implementation of an EOL Clinical Pathway before commencing planning. The key factors of this capacity include adequate resources and sufficient interest to 'drive' the change in clinical practice process.

All change management requires support from the RACF management as well as enthusiastic 'champions' who will act as motivators and resource people for the quality activity.¹⁴ Several points to consider include:

- is their adequate interest in this quality improvement (QI) activity or does your facility have other QI priorities?
- who will be available to drive the process of implementation?
- are the key stakeholders (the GPs, Nursing Staff, RACF management) willing to meet regularly to discuss planning and implementation of an EOL Clinical Pathway?
- is it feasible and viable to do this activity in conjunction with another site to help share the burden of organisation and co-ordination?

Possible barriers

There are many issues that could prevent or impact the implementation of an EOL clinical pathway, including:

- no staff member is available to take on extra duties of implementing an EOL Clinical Pathway
- RACF management's reluctance to provide resources such as education venues, payment of staff to attend education (back filling staff)
- difficulty engaging GPs in the process of consultation and EOL Clinical Pathway form development.

Possible resolutions to barriers

There are very few issues that cannot be overcome with careful strategic planning. Solutions to identified barriers include:

- impressing upon RACF management the benefits to quality palliative care delivery for residents in the terminal phase by implementing an EOL Clinical Pathway, and how this

quality improvement helps to address standards for RACF accreditation as well as meeting Standard 11 of the *Standards for Providing Quality Palliative Care for all Australians*⁵

- once staff are familiar with using the clinical pathway, the ongoing utilisation of EOL Clinical Pathway should be self sustaining
- encourage GPs to investigate incentive funding programs such as Aged Care GP Panels program funding through Department of Health and Ageing (Appendix 1, Useful Tools, tool 5).

Getting started

Once your facility has decided to implement an EOL Clinical Pathway, there are several activities that should be undertaken.

1. Form a group of interested healthcare workers. The ideal palliative care consultative committee would include all or a mix of the following:
 - a representative from the nursing management of the RACF(s)
 - a GP
 - a healthcare worker who may be pastoral care worker, physiotherapist, registered nurse, assistant in nursing
 - community pharmacist.
2. As a consultative group, define what the desired outcomes of this implementation process are going to be. This may be concerned with:
 - improving documentation of palliative care during the End of Life phase
 - enhancing the communication with families when death is imminent
 - improving the assessment and management of terminal dyspnoea
 - more general outcomes such as improving terminal phase symptom assessment and treatment
 - when setting outcomes remember that the more specific the outcome, the easier it will be to evaluate or measure later on.
3. Undertake a clinical audit of current medical records to determine if there are any specific issues that the EOL Clinical Pathway can address (Appendix 2). This is an opportunity to determine a baseline of existing documentation practice, which can later be reviewed to evaluate some of the impacts of the EOL Clinical Pathway.
4. Select existing models of EOL Clinical Pathways for the group to review. Formulate (if necessary) a customised local EOL Clinical Pathway form that meets the needs of your facility. Specific areas may include meeting the spiritual and cultural needs of a diverse ethnic community, determining the preferred medications for inclusion on the initial medical review sheet or selecting criteria for commencement on the EOL Clinical Pathway.
5. Develop a plan for implementation that includes pre-implementation education activities, regular ongoing education activities and feedback to staff about progress of the implementation. In large facilities or when working across several facilities, you may wish to consider 'staggered'.

6. All necessary resources should be collated and centrally located so that all staff can have access when needed. Items for inclusion in this Palliative Care Kit may include:
 - *Palliative Care Therapeutic Guidelines (version 2)*
 - current *mims*
 - opioid conversion charts (Appendix 1),
 - list of contact numbers for local ministers fraternal
 - contract numbers for GPs and local hospital, contact numbers for after hours support lines for palliative care (if available in your area) and spare palliative care symptom assessment charts.
7. Education calendar. Prior to commencing the pathway, it is vital that all staff understand the role of EOL Clinical Pathway and what implementation of an EOL Clinical Pathway aims to achieve in your facility. There are a variety of education packages, as well as locally developed resources that are specific to your facility. A number of DGP across Australia have developed and collated education programs via the RPCP and Aged Care General Practice Panels Initiative (AGGPPI), it is worth checking with your local DGP.

Education

The role of education in the process of successful implementation can not be over emphasised. It is perhaps the most important aspect of the implementation process. Aspects of educational activity include:

- raising awareness of the benefits of EOL Clinical Pathways
- raising capacity of RACF staff to identify the terminal phase
- raising capacity of RACF staff to assess terminal phase symptoms and understand the appropriate time to commence treatment on the pro re nata medication ordered
- increasing awareness of the importance of the psycho social aspects of preparing the family and resident for death
- providing education for GPs around current innovations in palliative care and what clinical support services are available for them to use if required.

The education calendar needs to accommodate all the RACF staff's differing requirements, including enrolled and registered nurses and nurse aides. It is important to ensure the education offered to staff is appropriate to their level of training and position responsibility. Assistants in nurse training through local Technical and Further Education (TAFE) centres are increasing the component of palliative care education within their training modules.

The key to avoiding staff merely complying to a series of tick boxes¹⁶ in the provision of end of life care, is providing comprehensive, holistic palliative care education. The topics in the education sessions must include not only terminal phase symptom assessment and management, but the vitally important psycho social aspects of dying. A holistic approach to the dying resident includes acknowledging the physical, spiritual and emotional needs of both the resident and their family.

A useful resource has been developed as part of the *Guidelines for a Palliative Approach in Residential Aged Care* (Appendix 1, Useful Tools, tool 6). It offers a comprehensive range of PowerPoint presentations as well as trainer resources.

Where possible, using a palliation physician, a Palliative Care Clinical Nurse Consultant or a palliation pharmacist for some education activities is an ideal way to enhance participation and credibility in these events.

Completion of an evaluation form following these events is useful. They highlight the value to attendees, as well as eliciting any areas where staff would like further education (Appendix 5).

Medication access issues

For some RACFs in regional and remotes areas, the matter of after hours access to medications has been identified as a significant area of concern. Intermittently, specific medications for terminal phase symptoms cannot be delivered for several days due to the distance of these rural facilities from the suppliers. This time lag may contribute to the resident not being able to access the required medications in a timely manner - sometimes dying before they become available and consequently without the best pain management possible.

RACF access to emergency medications through an imprest system may overcome after hours access issues for certain restricted medications. It is best to approach the relevant state or territory regulatory body (addressing drugs and poisons) before implementing this system.

States and territories have differing legislative provisions for the access, storage and handling of medications. RACFs should enquire how access to emergency medications could be achieved within the relevant regulatory provisions. (Appendix 4 provides for contact details and the relevant legislation for each Australian state and territory).

Evaluating the implementation process

In order to determine if the outcomes of the implementation are being met, it is important to periodically review them. The evaluation may involve a further clinical audit. Another effective way of determining if the EOL Clinical Pathway is meeting outcomes is to hold a focus group discussion with stakeholders to assess their attitudes to the clinical pathway.

It is important to feedback to staff how the implementation is going, and to also respond to any concerns or issues around implementation as they arise. Like all quality improvement activities, the continual cycle of Plan, Do, Assess, Act is part of the ongoing evaluation of the implementation of an EOL Clinical Pathway. The key drivers of the implementation should make themselves available to staff for education, discussion and debriefing/supervision (if required).

The Eurobodalla pilot experience

Following are some details from the Eurobodalla pilot experience of "EOL Clinical Pathways in rural aged care facilities". In 2006, two RACFs in south eastern NSW piloted the implementation of EOL Clinical Pathway. Prior to the implementation, both facilities had been delivering quality palliative care. However, nursing management were mindful that improvements could be made in the areas of documentation and more rapid response in managing terminal phase symptoms. Anecdotal case studies provide important information and are powerful tools for providing strategic direction.

For the Eurobodalla a key motivating activity occurred approximately six months prior to the commencement of the introduction of the clinical pathway. The division held an education and information session conducted by a physician and clinical nurse consultant with experience in implementing an EOL Clinical Pathway in a hospital. The attendees at the session included local GPs, a community pharmacist, RACF senior nurses and RNs.

A catalyst for the introduction of the EOL Clinical Pathway pilot was exploring ways to overcome issues of after hours access to certain medications to control terminal agitation (Midazolam) and terminal respiratory secretions (Hyoscine Hydrobromide).

The Aged Care GP Panel (a government funded initiative) met every three months to discuss the formatting of the clinical pathway as well as acting as a forum for education from the visiting palliation physician. These GP panel meetings were vital in maintaining GP interest for the project and enabled GPs to contribute to the forms development.

Several of the staff were overseas trained RNs who had not had any prior experience in formal palliative care. This promoted the provision of a general palliative care education activity held as weekly sessions for 90 minutes over five weeks covering the basics in palliative care symptom assessment and management. This education was instructive for the overseas trained staff and was a good opportunity for many of the other RNs to update their palliative care knowledge.

A major issue was determining the appropriate time to commence the EOL Clinical Pathway. As stated earlier, end stage organ failure is the most common cause of death in RACF. The *Criteria to be considered before commencement of the pathway* (page 1, Appendix 3) were sometimes an inadequate indication of the terminal phase due to the high morbidity of the frail aged residents. Extensive discussion and consultation with the GP Panel Group resulted in the inclusion of '*change in baseline behaviour for dementia patients*' and '*marked deterioration in condition in recent days*'. Ultimately, the decision to commence an EOL Life Clinical Pathway is determined by the GP. It is based upon their clinical assessment of the patient. The criteria act as a guide only. Any change in medical condition is firstly reviewed for reversible causes and treatment. The terminal phase is clinically declared once it is determined that the dying process has commenced as indicated by the criteria.

The EOL Clinical Pathway form adopted by the group for the pilot was modified nine times following feedback on inclusions.

The GPs suggested the inclusion of the *Current Condition and Duration* (page 2, Appendix 3). When a GP called out to the RACF after hours to complete a death certificate for a resident they did not personally treat, this information completed by the resident's usual GP, was most helpful.

Communication between staff and the pilot coordinator was encouraged. The options included direct phone access during office hours, emailing and using a communication book stored in the palliative care resource box. The most commonly used communication method was phone calls which occurred intermittently as issues arose.

Certain staff raised concerns about perceptions that the implementation of the EOL Clinical Pathway would 'hasten death'. These concerns needed to be discussed in a non judgmental way, with the emphasis being on the necessity to control symptoms so that resident's comfort would be maintained in compliance with standard 6 of the *Standards for providing Quality Palliative Care for all Australians*.⁵ The clinical indications for analgesia or sedation were determined through the assessment of pain or agitation.

The feedback from families was that they appreciated being supported in the terminal phase. Whilst quality palliative care was being delivered prior to the implementation of the clinical pathway, the pathway did foster a greater emphasis on explaining the dying process to the family and reassuring families. It would also act as a prompt to notify family members from out of area (an issue for many in rural RACF).

The local GP community, who are all aged over 50, had received minimal palliative care education in their medical training. As it is a newer area of medical speciality, the multiple education sessions with the palliation physician allowed GPs to enhance their clinical skills with updates on innovations in palliative care treatment options.

The original list of medications that were requested to be put on the imprest list has been reduced. After the 12 months trial, certain medications had not been used or were felt to be unnecessary.¹⁵ These included *clonazepam* (not required in terminal care as most residents were no longer ambulant in this phase), *Buscopan* (all GPs and senior nurses felt that there was very little indication of terminal phase hiccups developing) and Loperimide (no incidence of terminal phase diarrhoea during pilot).

Conclusion and key messages

The introduction of an End of Life Clinical Pathway to Residential Aged Care Facilities is a tool that can support staff in the delivery of quality end of life care.

For the implementation of an End of Life Clinical Pathway to be successful the key features are:

- gather a group of motivated people to act as a consultative and resource group; the process will need to have the support of the attending GPs and senior management
- ensure that all the staff are aware of why the clinical pathway is being introduced and what the gains can be for the residents, the families and the healthcare providers
- develop a comprehensive education calendar that raises awareness of the importance of the psycho-social aspects of preparing the resident and their family for death and increases the capacity of all workers to assess and manage terminal phase symptom
- encourage a consultative approach. Supportive lines of communication with staff, residents and family are vital at this time when issues of care are often highly emotive.

References

Ellershaw, J., Wilkinson, S. (2003). *Care of the Dying- A Pathway to Excellence*. Oxford, UK: Oxford University Press.

Eurobodalla Shire Council (2006). *Eurobodalla Shire Social Plan 2005-2009*. Eurobodalla Shire Council

Marr, K., Cleasby, P., Jacques, J. (2005). *Central Coast Collaborative Pathway Project - An Introduction and Step by Step Guide*. NSW: Central Coast Palliative Care Service.

Mirando, S. (2005). 'Introducing an integrated care pathway for the last days of life' *Palliative Medicine* 19 2005: 33-39

Mid North Coast Area Health Service (2005) *Palliative Care Integrated Clinical Pathway for End of Life Care Form*.

Palliative Care Australia (2005). *Standards for Providing Quality Palliative Care for all Australians*. Deakin, ACT: Palliative Care Australia.

Palliative Care Australia (2005). *A Guide to Palliative Care Service Development- A Population Based Approach*. Deakin, ACT: Palliative Care Australia.

Palliative Care Australia (2006). *Guidelines for a Palliative Approach in Residential Aged Care- Enhanced version, May 2006*. Deakin, ACT: Palliative Care Australia.

Reynard, L., Charles, M., Isreal, F., Read, T., Teston, P. (2005). 'A Strategy to increase the palliative care capacity of rural primary health care providers' *Australian Journal of Rural Health* 13: 156-161.

Reynard, L., Mitchell, G., McGrath, B., Welsh, D. (2004). *Research into the Educational, Training and Support needs of General Practice in Palliative Care*. Report commissioned by Palliative Care Australia, Mt Olivet Health Services.

Sydney West Area Health Service (2005). *Clinical Pathway-Integrated End of Life Care Form*.

Therapeutic Guidelines 2005, Palliative Care 2005 Version 2. North Melbourne: Therapeutic Guidelines Limited.

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-standard-facility-sacfindx.htm>

Overill, S. (2003). 'The Development, role and integration of integrated care pathways in modern healthcare', in Ellershaw, J., Wilkinson, S.(eds), *Care of the Dying- A Pathway to Excellence*. Oxford, UK: Oxford University Press.

Phillips, J., et al (2006). 'Residential aged care: The last frontier for palliative care' *Journal of Advanced Nursing* 55 (4) 416-424

Griffin J (2006). *Pharmacological Evaluation of a pilot of an End of Life Clinical Pathway in a Rural Aged Care Facility*. South East NSW Division of General Practice Ltd.

Partington, L. (2006). 'The Challenges in adopting care pathways for the dying for use in care homes' in *Practice Development: End of Life issues In Long Term Care Settings*. London: Blackwell Publishing.

Useful Kit Tools

1. Guidelines for a Palliative Approach in Residential Aged Care, Enhanced Version - May 2006 The National Palliative Care Program, funded by the Department of Health and Ageing.

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-workf-guide.htm>

A key document that provides details on what is required in the delivery of a palliative approach and excellent resources.

2. Medical Care of Older Persons in Residential Aged Care Facilities (4th ed) ('The Silver Book') Prepared by the Royal College of General Practitioners, funded by Department of Health and Ageing.

<http://www.racgp.org.au/silverbookonline/index.asp>

A valuable resource for GPs aiming to provide information on:

- Common clinical conditions
- Organisational aspects of medical care
- Assessments tools appendix.

3. Chan, V. McConigley, R. (2006). Outline of Palliative Medicine (4th ed) Dr Victor Chan, Sydney.

Practical guide to palliative symptom assessment and management with input from medical and nursing perspective.

4. Therapeutic Guidelines 2005, (Palliative Care 2005 Version 2). North Melbourne: Therapeutic Guidelines Limited.

5. The website for information about Aged Care GP panels:

<http://www.adgp.com.au/site/index.cfm?display=2343>

6. Guidelines for a Palliative Approach in Residential Aged Care – Educational package.

<http://www.agedcare.pallcare.org.au/Default.aspx?tabid=825>

Symptom Management: These resources will assist staff to provide care for nausea and vomiting, bowel care, nutrition and hydration.

Pain Assessment and Management: Pain has been identified as significant symptom which is under-treated in many clinical settings leading to distress and a reduced quality of life. The key principles of management of any symptom are early identification, comprehensive assessment and appropriate treatment. This package focuses on the assessment and management of pain.

End of life Care: Care of a resident at the end of life is a distinct and important part of residential and community care. The modules of this resource are designed to support you in the delivery of optimal end of life care. They cover many of the central aspects of end of life care including recognising the end of life phase, planning for the end of life, managing end of life care – a pathway approach, providing end of life care physical symptom relief, providing comfort care at the end of life, non physical elements of end of life care, post death care, ethical dilemmas in end of life care and quality issues in end of life care.

Grief and Bereavement Support: This resource is about supporting residents and carers in residential aged care facilities (RACF) who are affected by the death of another resident. This resource is divided into modules include defining loss, grief and bereavement, grief reactions, support needs of the aged care team, impact of loss and grief on other residents and their family and grief reactions of people from different cultures. Each module can be completed as a separate learning activity or the modules combined.

Support of and Communication with the Family: This resource had been developed to help you support and communicate with the families of residents in residential aged care facilities. Topics include: identifying the family, understanding of a cultural care consideration, the importance of communication, and strategies to enable the provision of support to families, identify support structures for the family, discuss the importance of family in the palliative approach and identify barriers which may cause ineffective communication.

Advance Care Planning: These resources have been designed to enable staff to gain an understanding of the purpose and process of advance care planning as a component of holistic care in the aged care setting. Topics covered in these resources include: Introduction to Advance Care Planning, The Legal Underpinnings of Advance Care Planning and Implementing Best Practice in Advance Care Planning.

Appendices

- Appendix 1: Opioid conversion chart
- Appendix 2: Clinical Audit Data sheet
- Appendix 3: End of Life Clinical Pathway Template for RACF
- Appendix 4: State legislation for emergency medications in a RACF
- Appendix 5: Education evaluation form

Appendix 1: Opioid Conversion Chart with Principles of Pain Management

FROM ↓	TO →		Morphine		Hydromorphone		Oxycodone	Fentanyl
	Codeine PO mg/day	Morphine PO mg/day	SC mg/day	PO mg/day	SC mg/day	PO mg/day	TD mcg/hr	
Codeine mg/day PO		8	20	40	120	12	24	
Morphine mg/day PO	8		3	5	15	1.5	3	
Morphine mg/ day SC	20	3		2	6	0.6	1.2	
Hydromorphone mg/day PO	40	5	2		3	0.3	0.6	
Hydromorphone mg/day SC	120	15	5	3		0.1	0.2	
Oxycodone mg/day PO	12	1.5	0.6	0.3	0.1		2	
Fentanyl mcg/hr TD	24	3	1.2	0.6	0.2	2		

Ref: Calvary HealthCare Kogarah, Sacred Heart Hospice Darlinghurst

Add current opioid doses to get total milligram per 24 hours
 Multiply or divide current total by conversion factor, this will give dose per 24 hours
 Divide 24 hour total by appropriate no. to reflect frequency of dosing ie 2 for bd dosing

MULTIPLY	
DIVIDE	

PRINCIPLES of PAIN MANAGEMENT¹²

Pain relief needs to be balanced against the patient's desire to stay alert

Consider the WHO 3 step ladder: (non-opioid→low dose opioid→high dose opioid with co-analgesics added at any stage)

Consider appropriate co-analgesics early in management of neuropathic pain

Morphine is **opioid of choice** due to flexibility of doses & routes available

Oral route preferred

Time contingent ie schedule **regular** doses not prn

Titrate dose to effect with **immediate** release formulation.

Always prescribe rescue or **breakthrough** medication.

Breakthrough dose = usual 4 hour dose of immediate acting medication eg Ordine®, Endone® = **1/6 of 24 hour dose**

Change to sustained release when dose stable, maintain rescue doses.

Dose increases should be in the order of **30%**

Increase rescue dose as maintenance dose increases.

Prescribe **regular paracetamol** unless contraindicated.

Prevent/manage side effects: nausea, constipation, drowsiness

Initial drowsiness will improve after a few days

Constipation is almost universal & needs to be treated prophylactically & continuously

Nausea & vomiting may occur; tolerance develops after 1-2 weeks. Provide anti-emetic cover if required.

Dry mouth & dry eyes may need treatment.

Respiratory depression is rarely a problem if doses are increased gradually.

Parenteral administration: **SC morphine** = 1/3 of oral dose

Consider dose reduction

Renal impairment

Stimulus less noxious

Consider alternative to morphine

End-stage renal failure (fentanyl is drug of choice)

True allergy with histamine release *not nausea & vomiting*

Fentanyl patches

- **18-24 hours to onset** of action, provide additional cover
- care when ceasing patches, as **18-24 hours to offset**
- caution –heat affects absorption
- remember breakthrough orders

¹ Medical Observer 17/2/2006 Pain Management in Palliative Care

² eTG Palliative Care Version 2 2005

Appendix 2: End Of Life Clinical Pathway: Clinical Audit Tool

Name of person completing Audit: _____

Date of Audit: _____

RESIDENTS NAME: _____

RESIDENTS DATE OF DEATH: _____

ISSUES	YES	NO	NO EVIDENCE AVAILABLE
Was pain assessed?			
Was nausea and vomiting assessed?			
Was dyspnoea assessed?			
Was delirium/agitation assessed?			
Were these symptoms treated within 8 hours of assessment?			
Were medications ordered and accessible in a timely manner?			
Was having patient reviewed by a GP done in a timely manner?			
Was oral and eye care attended regularly?			
Were family educated about the dying process in the 72 hours prior to death?			
Were the family offered any grief or bereavement support?			

Appendix 3: End of Life Clinical Pathway Template for RACF

Page 1

SOUTHERN EUROBODALLA PALLIATIVE CARE END OF LIFE CLINICAL PATHWAY	NAME: DATE OF BIRTH: FACILITY:
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This Pathway is intended as a guide only in providing care for a dying resident and their family. The goals of care are:

- Consideration for the whole person
- Maximise quality of life through symptom management
- Multidisciplinary approach
- Support for the carer and family

This document is placed in the resident's notes upon commencement and is part of the medical record.

The Pathway can be commenced only with the authorisation of the patient's general practitioner.

INSTRUCTIONS FOR USE:

- Section 1.** Initial Medical Assessment is completed by an attending Medical Officer when the resident is entered onto the Pathway.
- Section 2** Pastoral Care Needs and Preferences at Death Information is completed by a Registered or Enrolled Nurse.
- Section 3** After Death Support and Bereavement Information is completed upon the residents death by the attending nurse.
- Section 4** Quality Indicators Chart is completed after the resident's death by the attending nurse.
- Section 5** Comfort Assessment Chart is completed regularly by nursing staff; A new chart is to be used each day.
- Section 6** Variance Record to be completed if there has been any deviation from the clinical pathway.

CRITERIA TO BE CONSIDERED BEFORE COMMENCEMENT ON PATHWAY:

Resident is medically assessed to be dying, with death anticipated within the next few days and at least two of the following apply to the resident:

- Bed bound
- Semi-Comatose
- Only able to take sips of fluid
- No longer able to take tablets
- Marked deterioration in condition in recent days
- Change in baseline behaviour for dementia patient

Eurobodalla Palliative Care Service can be contacted during office hours on 4474 5100
after hours on 1300 795 440.

Acknowledgement: This Clinical pathway is based upon the Clinical Pathway tools of The Mid North Coast Area Health Service, Sydney West Area Health Service and the Central Coast Area Health Service of NSW.

**SOUTHERN EUROBODALLA PALLIATIVE
CARE END OF LIFE CLINICAL PATHWAY**

NAME:
DATE OF BIRTH:
FACILITY:

Section 1: INITIAL MEDICAL ASSESSMENT TO BE COMPLETED BY GP
All Residents on the Pathway are to have regular and prn medication ordered for the following possible terminal phase symptoms:
Medications are to be ordered on Facility Medication Chart.

CURRENT CONDITION AND DURATION:.....

GP NAME:.....Signature.....

Assess existing pharmacological management/discontinue inappropriate interventions

- Discontinue non-essential current medication
- Appropriate oral medications converted to subcutaneous route
- Medications written up for specific symptoms (if present as indicated below)
- Medications written up for anticipated symptoms (see prn medications below)
- Discontinue inappropriate nursing interventions eg Vital signs/BGL's

PAIN (monitor response to initial Rx and review once pain stable) Regular prn

If resident is already on an oral morphine convert to the appropriate s/c morphine dose. Seek advice on dose equivalency if unsure.

If resident opioid naïve start on 2.5mg. 4/24.
(or morphine 1mg s/c 4/24 if frail)

Chart regular &/or prn breakthrough dose for all residents.

Breakthrough dose is one sixth of total daily dose of opioid

Caution in renal failure: use reduced morphine dose.
(Consult resources listed below if required)

NAUSEA AND VOMITING Regular prn

Metoclopramide 10mg po or s/c tds-qid
Haloperidol mg 0.5mg- 1mg sc bd - tds

CONFUSION AND DELIRIUM Regular prn

Haloperidol 0.5mg po/sc tds
Haloperidol 0.5mg-1mg s/c Q2hrs prn up to a total dose of 5mg in 24hrs

DYSPNOEA Regular prn

For opioid naïve resident Morphine 2-5mg po 4/24hrs or Morphine 1-5mg s/c 4/24.

For patient already on morphine (eg for pain) increase regular dose by 25-50% to cover dyspnoea. If breathlessness continues or anxiety prominent add Lorazepam 0.5-1mg sublingual bd - qid and prn

RESPIRATORY TRACT SECRETIONS Regular prn

Hyoscine hydrobromide 400-800mcg s/c 2 to 4 hourly prn (if resident is unconscious)

RESTLESSNESS AND AGITATION Regular prn

Assess and manage reversible causes eg pain / retention / distress / akathisia
Clonazepam 0.5mg up to 2mg po tds if patient alert and not distressed in daytime.
In acute distress consider Midazolam 1 to 2mg s/c.

STOMATITIS Regular prn

Prevent and treat thrush; Nilstat 1ml qid
Treat Herpes Simplex Virus if resident may gain benefit
Bicarbonate Soda mouthwash - ½ tsp in glass of water

Palliative Care Clinical Resources

Check Conversion Chart in the Palliative Care Resources Box at the main nurses station.
Palliative Specialist –Dr Frank Brennan at Calvary Hospital, 02 9553 3111
Palliative Pharmacist – Brian Donovan at Calvary Hospital, 02 9553 3111
Palliative Therapeutic Guidelines – www.clininfo.health.nsw.gov.au

SOUTHERN EUROBODALLA PALLIATIVE CARE END OF LIFE CLINICAL PATHWAY	Name: Date of Birth: Facility:
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Section 2: PASTORAL CARE NEEDS AND PREFERENCES AT DEATH
Section 2 and Section 3 is to be completed by the attending Registered or Enrolled Nurse

Nurses Name:.....Signature.....

Contact details of Next of Kin and/or Preferred contact:	
Preferred Contact Person: _____	Relationship to Resident: _____
Phone Numbers: (H) _____ (W) _____ (Mob) _____	
Does the preferred contact wish to be phoned at any time?	<input type="checkbox"/> Yes <input type="checkbox"/> No
State any Preferences: _____	

Is Preferred Contact also the Next of Kin?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Name of Next of Kin: _____	Relationship to Resident: _____
Do family wish to be present at the death?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown

Discussion with the resident and family, where appropriate, about the stage of their illness and the aims of the End of Life Clinical Pathway Yes No

Referred to Welfare Officer Yes No

Does resident or family wish pastoral care support to be organised Yes No

Who would family like to be notified: _____

Given Leaflet 'Understanding the Dying Process' Yes No

Are funeral arrangements known (Funeral Director, Burial, Cremation)? Yes No

Details if available: _____

Family are aware of support/comfort services available at this facility: Yes No

Other issues or cultural practices that family or resident would like known and considered: _____

Section 3: AFTER DEATH SUPPORT AND BEREAVEMENT INFORMATION
To be completed by nursing staff post death

The family has been notified of Death Yes No

The deceased is cared for in accordance with the Facility policy Yes No

Resident's family are kept well informed and supported around the time of death Yes No

Are family identified as a high- risk bereavement? Yes No

High risk factors include traumatic death, multiple family issues and unexpected manner of death

If 'Yes' please record this in progress notes and contact Welfare Officer or Eurobodalla Palliative Care Service (4474 5100) to facilitate bereavement support.

Family/Carer is made aware of bereavement support services available if needed (Offer Eurobodalla NALAG Brochure) Yes No

Resident's GP notified of death Yes No

SOUTHERN EUROBODALLA PALLIATIVE CARE END OF LIFE CLINICAL PATHWAY	Name: Date of Birth: Facility:
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DATE: _____ **NAME of ASSESSOR:** _____ **Signature:** _____

Section4: **QUALITY INDICATORS CHART**. To be completed at conclusion of Pathway by DON or delegate.

Item	Yes or No Please circle	Problem Description if 'No' response	Action Taken/ Recommendations
Symptoms were managed by the guidelines of the Clinical Pathway	YES NO		
Comfort needs were managed by the guidelines of the Clinical Pathway	YES NO		
Cultural/Spiritual needs were addressed by the guidelines of the Clinical Pathway	YES NO		
Support needs were addressed by the guidelines of the Clinical Pathway	YES NO		
Bereavement care was facilitated by the guidelines of the Clinical Pathway	YES NO		
Other Problems encountered were addressed by the guidelines of the Clinical Pathway	YES NO		
Overall death was satisfactory for:			
Resident	YES NO		
Family	YES NO		
Staff	YES NO		
Did ACF receive any feedback from the family?	YES NO		
Please comment.			

SOUTHERN EUROBODALLA
PALLIATIVE CARE END OF LIFE
CLINICAL PATHWAY

Name:
Date of Birth:
Facility:

DATE: _____

SECTION 5: COMFORT ASSESSMENT CHART

Instructions: Make an entry each shift for each symptom and comfort measure.

M for goal met U for goal unmet NA if not applicable.

If there is an unmet goal, please record in the progress note the reason for the variance.

SYMPTOM	GOAL	AM SHIFT	PM SHIFT	NIGHT SHIFT
PAIN	Resident is pain free Analgesia has been given as charted			
NAUSEA/VOMITING	Resident does not feel nauseated or experience vomiting Medication given as per chart Environmental factors are considered			
RESPIRATORY SECRETIONS	Resident breathing is not made difficult by noisy, rattly retained secretions Repositioning, gentle suctioning Hyoscine if required			
DYSPNOEA	Resident is not dyspnoeic: Fan on face, window upon if needed Reassuring presence Oxygen therapy if needed Morphine or Lorazepam if needed for anxiety			
AGITATION	Resident does not display signs of restlessness: Exclude other causes eg urinary retention, constipation, pain			
OTHER				
COMFORT MEASURES	GOAL	AM SHIFT	PM SHIFT	NIGHT SHIFT
SUPPORT	Resident and family are supported, procedures are explained, information on changes in condition are provided, encourage caring activities as appropriate/individualised to the family situation and culture. Encourage verbalisation			
SPIRITUAL/CULTURAL NEEDS	Provide opportunity for expression of beliefs, fears and hopes. Facilitate religious practice for resident and family			
OPTIMAL POSITIONING	Comfortable position maintained, comfort aids used as required			
MOUTH CARE	Mouth, lips and teeth kept clean and moist. Check for ulceration or presence of thrush			
EYE CARE	Eyes are clean and moist			
SKIN CARE	Skin is clean, moisturiser applied to dry areas Hand, feet or other massage attended if desired. Any dressing attended to broken skin			
MICTURITION	Resident is dry and comfortable. Urinary aids used if incontinent/retention			
BOWEL CARE	Resident is not agitated or distressed due to constipation or Diarrhoea			
OTHER				
	NURSES INITIAL			

Variance record

Definition of a variance It is any deviation from the clinical pathway.

If a stated goal, as listed in the COMFORT ASSESMENT CHART, can not be achieved, this is a variance from the clinical pathway.

Variances are not 'right' or 'wrong'; they merely indicate the complexity of individualised Palliative Care.

Directions....If a stated goal can not be achieved in any shift, please record:

- **Date variance occurred**
- **Type of variance (by code)**

CODE:

1. Issues relating to relatives needs, including notification of residents condition, unable to meet emotional or spiritual needs
2. Issues relating to complex symptom management
3. Issues relating to prescribing or availability of medications.
4. Other ... please describe.

- **Why the variance occurred**
- **What actions were taken (if any).**
- **What was the outcome by the end of the shift**

DATE	VARIANCE CODE	WHY DID the VARIANCE OCCUR	ACTION	OUT OUTCOME

Appendix 4: State legislation for access to emergency medications

STATE	NAME OF REGULATION	WEBSITE FOR COPY OF REGULATION	DEPARTMENT OF HEALTH PHONE
Western Australia	Poisons Regulation 1965a	- http://www.slp.wa.gov.au/statutes%5Cregs.nsf/PDFbyName/E0F4D79061DF6EA5482566DA002C9CF9?OpenDocument	08.9222.4222
Tasmania	Poisons Regulation 2002	http://www.austlii.edu.au/au/legis/tas/consol_reg/pr2002230/	1300.135.513
Northern Territory	Poisons and Dangerous Drugs Regulation 2005	http://www.austlii.edu.au/au/legis/nt/consol_reg/paddr405.txt/cgi-bin/download.cgi/download/au/legis/nt/consol_reg/paddr405.rtf	08.8999.2809
South Australia	Controlled Substances (poisons) Regulation 1996	http://www.austlii.edu.au/au/legis/sa/consol_reg/csr1996451	08.8226.7137
Victoria	Poisons and Controlled substances Regulations 2006	http://www.health.vic.gov.au/dpu/downloads/summary_for_nurses_agedcare.pdf http://www.health.vic.gov.au/dpu/downloads/guide-dpusr-06.pdf	03.9096.9977 1300364545
New South Wales	Poisons and Therapeutic Goods Regulation 2006	http://www.health.nsw.gov.au/archive/cib/information-bulletins/2003/ib2003-10.pdf	02.98793214
Queensland	Health (Drugs and poisons) Regulation 1996	http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/H/HealDrAPoR96.pdf Appendix 3 is Who must sign certain purchase orders for controlled or restricted drugs Appendix 6 is Minimum requirement for controlled Drugs receptacles	07.3234.0938
Australian Capital Territory	Poisons and Drug Regulation 1993	http://www.austlii.edu.au/au/legis/act/consol_reg/padr1993292.txt/cgi-bin/download.cgi/download/au/legis/act/consol_reg/padr1993292.rtf	02.6205.1700

Appendix 5: Education evaluation form

SOUTH EAST NSW
DIVISION OF GENERAL PRACTICE LTD
ABN: 32 066 905 931

'GPs caring for South East NSW'

TOPIC: ASSESSMENT AND MANAGEMENT OF TERMINAL DYSPNOEA, DELIRIUM AND AGITATION

DATE: _____

VENUE: _____

SPEAKER: _____

Learning Objectives:

The objectives of this workshop are to provide information and understanding on:

- How to assess a resident with symptoms of terminal dyspnoea, delirium and agitation to determine the nature and possible causes of this symptom.
- Possible non-pharmacological treatments.
- Pharmacological treatments for terminal dyspnoea, delirium and agitation.

Workshop Overview:

Please rate the workshop generally using the following scale:

	1 Excellent	2 Very Good	3 Good	4 Poor	5 Very Poor
1.The learning objectives were met					
2.The presenters were clear and logical					
3.The topics presented were relevant					
4.The venue was suitable					
5.I will use this information in my practice					

6. Name two things you learnt from this workshop

a. _____

b. _____

7. What other areas would you like to have seen addressed?

Your completion of this Evaluation Form is much appreciated and will allow us to continue to improve our service to you.

PLEASE FAX TO 02 xxxxxxxxx

OR POST TO SOUTH EAST NSW DIVISION OF GENERAL PRACTICE xxxxxxxxxx, MORUYA NSW 2537