



**End of Life Care and Care Pathways in Victoria:  
Report & Recommendations  
May 2011**

Prepared by the Centre for Palliative Care, St Vincent's and  
Collaborative Centre of the University of Melbourne

Funded by the Department of Health Victoria

**Authors:**

Nikola Stepanov  
Karen Quinn  
Jennifer Philip  
Mark Boughey

**Non-author Contributors:**

Jo Hall  
Jo Kelly

# 1. END OF LIFE CARE AND CARE PATHWAYS IN VICTORIA: REPORT AND RECOMMENDATIONS

Report was prepared by:

The Centre for Palliative Care, St Vincent's and Collaborative Centre of the University of Melbourne

PO Box 2900

Fitzroy VIC 3065

Telephone: - + 61 3 9416 0000

Fax: - + 61 3 9416 3916

Website: - <http://www.centreforpallcare.org>

Email: - [nikola.stepanov@svhm.org.au](mailto:nikola.stepanov@svhm.org.au)

©The Centre for Palliative Care 2011

This work is copyright. Apart from any use as permitted under the copyright Act 1968 No part might be reproduced by any process without prior written permission from the Centre for Palliative Care or the Department of Health. Requests and enquiries concerning reproduction and rights should be addressed to the Communications Manager, the Centre for Palliative Care, PO Box 2900, Fitzroy, VIC, 3065, Australia.

## **Recommended citation:-**

Stepanov, N; Quinn, K; Philip, J; & Boughey, M. *End of Life Care and Care Pathways in Victoria: Report and Recommendations*, 2011. Centre for Palliative Care, Fitzroy, VIC.

## **Disclaimer:-**

The Centre for Palliative Care does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. The centre for Palliative care develops material based on the best of evidence available at the time of compiling the report; however it cannot guarantee and assumes no responsibility or legal liability for the currency and completeness of the information.

Copies of this report can be downloaded from the Centre for Palliative Care website:-

<http://www.centreforpallcare.org>

Or by emailing [nikola.stepanov@svhm.org.au](mailto:nikola.stepanov@svhm.org.au)

## 2. ABSTRACT

### Background

Determining best practice in hospitals is largely driven by evidence based care but the availability of such evidence is provisional upon adequately funded well-designed studies. Currently there is little empirical evidence of benefit or harm to patients who are cared for using end of life care pathways. However, this lack of empirical data has not limited the introduction of end of life care pathways across numerous setting both internationally and nationally. Within Victoria many services have or are introducing end of life care pathways as quality assurance tools to aid and guide care at the end of life. This project was established to develop an integrated approach for health care service providers interested in the use of end of life care pathways in Victoria, Australia.

### Objectives

The objectives of the project included, but were not limited to,

- Identifying end of life care pathways currently in use in the national and international palliative care setting;
- Developing a business case and work plan documents for use within Victoria;
- Providing practical solution/s to enable the introduction of a pathway to facilitate consistent and quality care throughout the palliative and health care sector irrespective of setting or disease.

### Key Methods

The objectives were realised using the following processes:-

- A broad review of the literature surrounding care pathways and end of life care pathways including a search of the grey literature;
- Garnering and incorporating service provider opinion to present a an accurate account of current practices;
- Consultation and review by an expert advisory panel;
- Developing practice recommendations to accurately reflect all such evidence.

### Literature Search Strategy

A literature search was conducted using EBSCO host, CARESearch and NCBI which included articles from PUBMed/ Medline, PSYCHInfo and CINAHL with EMBASE. The search was carried out in March 2011 and a further search was carried out in May 2011 due to the recent publishing of several key economic papers around end of life care.

## **Results of the Literature Review**

The study identified the following key points:-

### ***End of life care***

- The needs of the dying are complex and care is often multi-disciplinary. There is a recognised need to monitor and provide consistent, quality end of life care. Consistent care can only be provided with community wide consensus.
- The quality of death may be dependent on the experience of the practitioner and the resources that are available to him or her. This has resulted in a wide variation in practices between different institutions and service providers.
- Patients and/ or their families have a fundamental legal and ethical right to be involved in decisions about care, including being informed when the primary goal of care has changed.

### ***End of life care pathways***

- Provide recognition of multi-disciplinary consensus that death may be impending.
- Provide documentation that the patient and /or their family have been informed that death may be impending and that life prolonging treatment options, including resuscitation, are now futile.
- Address inconsistencies in care provisions by providing structured patient management strategies.
- Facilitate the most appropriate management by the most appropriate providers' at the most appropriate time.
- May enhance and guide the delivery of care across all disciplines and settings, enabling the many needs of the each dying person to be addressed. This may in turn lead to an improved /greater quality of death.
- A recent Cochrane review of end of life care pathways excluded all previous studies due to the quality of the study designs including all studies involving less than two settings. However, despite the limitations of the excluded studies, there is substantial anecdotal evidence of the benefits of end of life care pathways.
- Are recognised as the gold standard in palliative care.

### ***Liverpool Care Pathway***

- The Liverpool Care Pathway (LCP) is the most widely used end of life care pathway internationally.

- The majority of end of life care pathways and integrated care pathways in use throughout Victoria are approved modifications of the LCP or a version of the LCP.
- The LCP is the recommended best practice model by the Department of Health in the UK.
- The LCP undergoes a rigorous process of ongoing improvement and development including comprehensive audits and a dedicated research program.
- The LCP has been implemented into hospitals, residential care homes, hospices, and in the individuals own home / community.
- The most recent version, Version 12 was developed as part of a two year consultation exercise with UK hospitals.
- Version 12 is now available. The ethos in this and previous iterations has not changed since its initial inception in 1994.

### ***State specific***

- The decision to support the use of end of life care pathways in palliative care in Victoria has occurred largely as a result of individual services recognizing locally the value of introducing an end of life care pathway. Most services have chosen to implement the Liverpool End of Life Care Pathway or modifications thereof.
- The Liverpool End of Life Care Pathway/ approved modifications thereof are already in use across the State in a range of settings.
- There is no evidence to support the use of another integrated care pathway over the use of the Liverpool End of Life Care Pathway (or modified version) therefore there is little justification for the provision of resources to support the development of alternative end of life care pathways. Exceptions to this may include the development of setting specific pathways not currently available, such as for the emergency department setting.
- Currently there is only minimal coordination between services implementing/ maintaining end of life care pathways and this has resulted in inconsistencies in approaches to implementation and resource allocation. There is no one central point of contact to aid and support services, and there is no formal consensus recognising one pathway.

### ***Setting specific***

- There is a need for a systematic and deliberate approach to introducing an end of life care pathway within each particular setting.
- Adequate resources and ongoing support are needed to ensure a smooth transition to implementation, and to ensure the success in maintaining the pathway.
- Services would benefit from having one central point of contact for support and further resources including educational packages and governance documents.

### **Summary of recommendations**

- The majority of end of life care pathways and integrated care pathways in use throughout Victoria are approved modifications of the Liverpool Care Pathway (LCP) or adaptations of integrated care pathways therefore:-
  - All services considering the introduction of an end of life care pathway should be strongly encouraged to use the Liverpool End of Life Care Pathway or existing modifications of, to ensure consistency, enable benchmarking between services, and to ensure that resources are not consumed developing further pathways.
  - Funding should be allocated to health care provider services who meet defined criteria and that are wishing to implement an end of life care pathway.
  - Services should have access to one central point of contact for advice and guidance.
  - Ideally funding would be allocated to further develop studies aimed at identifying the impact and implications of introducing an end of life care pathway.
  - Modifications to the existing pathways should be evidence-based in an effort to conserve the further use of resources.
- The Department of Health Victoria should facilitate/ support the further progression of the collaborative relationship with the Marie Curie Palliative Care Institute with the aim of progressing the State of Victoria to a Level 1 Partner.
- The best way to maintain momentum and ensure continuity of support is to provide one key point of contact for palliative care services in Victoria who wish to investigate/ implement an end of life care pathway and this would:-
  - Provide resources for the ongoing provision of advice and support to services wishing to investigate the use of an end of life care pathway.
  - Make available key documentation including an educational package and governance documents to further assist in the implementation process.

- Work with and support Project Management Committees, Project Managers and Project Nurses appointed to implement an end of life care pathway.
- Work with services using unapproved modifications of an end of life care pathway.
- Facilitate the development of multisite coordinated evaluation of pathway implementation.
- Provide support for the ongoing facilitation of the 'End of Life Special Interest Group'.
- Provide support for the ongoing maintenance of the web resource developed from this Project.
- Aid in the development of a data bank of end of life care pathway projects in Victoria.
- Provide support for the ongoing support and facilitation of a state wide coordinated approach to the use of end of life care pathways in Victoria
- Provide support for the ongoing development of collaborative networks between palliative care providers in the interests of further research into this field.
- Aid the development of a workshop to facilitate communication with services interested in implementing the pathway.
- Ensure that momentum and goodwill gained through the project will not dissipate.

### 3. PLAIN LANGUAGE SUMMARY

End of life care pathways are structured care provisioning frameworks that are informed by clinical expertise and which guide care by providing prompts, recommendations and appropriate timeframes. End of Life care Pathways can enhance and guide the delivery of care across all disciplines and settings, enabling the many needs of each dying person to be addressed. This in turn may lead to an improved quality of death.

End of life care pathways have been widely implemented nationally and internationally. The evidence supporting the use of end of life care pathways has been limited due to a lack of appropriate studies measuring outcomes. There is also a limited awareness regarding the economic implications of implementing an end of life care pathway.

The most widely used and recognised pathway nationally and internationally is the Liverpool End of Life Care Pathway. The Liverpool End of Life Care Pathway or approved modified versions are already in use across the State in a range of settings. There is significant and positive momentum in the palliative and health care sectors in Victoria for the use of end of life care pathways.

This discussion paper has been developed based upon a systematic review of the literature (143 published papers), as well as clinical and expert opinion. The main recommendations resulting are: that there is an improved and more consistent level of documentation with the use of end of life care pathways; there are no documented risks or burdens associated with end of life care pathways; that there is a recognised need to provided consistent quality care within the palliative care sector; and that this care may be achieved through the use of an end of life care pathways.

This paper details the use of end of life care pathway and makes recommendations to the Department of Health concerning the use of end of life care pathways in Victoria.

## 4. TABLE OF CONTENTS

1. Citation.....	p 2
2. Abstract.....	p 3
3. Plain Language Summary.....	p 8
<b>4. TABLE OF CONTENTS.....</b>	<b>p 9</b>
5. List of Appendices.....	p 10
6. Executive Summary.....	p 11
7. Introduction-End of life care	
7.1 Background.....	p 14
• End of life care	
• Integrated and clinical care pathways	
• The hospice model of care and end of life care pathways	
• State environment	
8. Project	
8.1 Background.....	P 17
8.2 Objectives of the Project.....	p 18
8.3 Method.....	p 19
• Literature review	
• Search strategy	
• Inclusion and exclusion criteria	
• Data Extraction	
• Analysis	
• Comments	
• Search results	
9. Discussion	
9.1 Key Findings.....	p 23
9.2 Limitations of the Report.....	p 25
9.3 Areas for future research.....	p 25
10. Author's conclusions & recommendations.....	p 26
12. References.....	p 29
<b>14. ACKNOWLEDGEMENTS.....</b>	<b>p 32</b>
13. Appendices.....	p 35

## 5. LIST OF APPENDICES

Appendix A- Flowchart for inclusion of articles in the review

Appendix B- Project Methodology, Evaluation and Timeframes

Appendix C- Examples of Current or Recent Projects

Appendix D- End of Life Care Pathway Business Plan

Appendix E- List of Useful Resources

## 6. EXECUTIVE SUMMARY

In November 2010 the Australian Health Ministers' Conference endorsed the National Palliative Care Strategy. The Strategy document provides a guide for the further development of palliative care policy and service delivery across Australia. The development of the Strategy document by the Australian Government and State and Territory governments acknowledged the national importance placed on improving the care of Australia's dying [1].

In seeking to improve care, the Strategy addresses four main goals:-

1. Improving and enhancing awareness to significantly improve the appreciation of dying and death as a normal part of the life continuum and to enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services.
2. To deliver needs based palliative care that is appropriate and effective to all Australians.
3. To provide leadership and governance to support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.
4. To build on and enhance capacity and capability of all relevant sectors in health and human services to provide quality palliative care.

Consistent to addressing the goals of the National Strategy, the Department of Health Victoria allocated funding for the purpose of uncovering areas of care that could potentially be improved in the Victorian Palliative Care sector, and to develop strategies and identify aids that may contribute to the realisation of the National goals. The End of Life Care Pathways Victoria Project (EOLCP) was initiated by the Centre for Palliative Care and the Department of Health Victoria and provides recommendations and advice to the Palliative and Health Care Sector on resources and processes that may enhance the quality of care in the last days and hours of life.

The EOLCP involved an extensive review of the literature surrounding end of life and end of life care pathways. The EOLCP is an evidenced based study that sought to provide practical solution/s to enable consistent and quality care throughout the palliative sector irrespective of setting or disease. The study identified that the best quality of care for each person with a palliative illness can only be achieved if care needs are identified and addressed systematically and collaboratively. The needs of the dying are complex and care is often multi-disciplinary. By identifying tools that can enhance and guide the delivery of care across all disciplines and

settings, the many needs of each dying person can be addressed and may lead to an improved quality of death.

A final review of the draft report was available for consultation by Members of the Palliative Care Clinical Network and advisors at the Department of Health Victoria.

### **Improving the Care of the Dying**

There is recognition within the palliative care sector that the quality of dying in society today is less than ideal. The difficulties and complexities of providing care across settings may result in fragmented care for the dying. A poor quality death may result in patients dying alone, frightened and without dignity [2]. Many patients and/ or their families are often unaware of their terminal prognosis despite death being anticipated by the treating clinician/s [2].

There is a recognised need to monitor and provide consistent quality care in the palliative sector. Optimal care for all can only be achieved with a systematic, coordinated approach encompassing shared goals and a standardised level of care. The quality of death is often dependent on the experience of the practitioner and the resources that are available. This has resulted in a wide variation in practices between different institutions and service providers [2, 3].

The evidence demonstrates that the quality of care for our dying can and should be improved [1-5]. The introduction of an End of Life Care Pathway is a practical approach to addressing gaps in care that could potentially be improved and improving care of the dying has been identified as a National and State priority.

Consistent and guided multi-disciplinary palliative care is the international gold standard of care. The use of an End of Life Care Pathway ensures that across all care settings, each dying patient is assessed consistently and all areas of needs are addressed. The quality of care and the specific needs of each patient should not be dependent on the skill, understanding and expertise of the treating staffs. Each patient will be entitled to a systematic and considered consistent approach [1, 2, 6].

End of Life Care Pathways provide a supportive tool for use in services that have limited access to Palliative Care Specialists, and for services seeking to provide a standardised tool to aid decision making by less experienced practitioners. End of Life Care Pathways also provide an aid to a consistent and manageable approach in settings employing a varied and large number of Health Practitioners, or where the range of services is diversified [2, 7-11].

Whilst the quality of care and the needs of each individual palliative patient are addressed with End of Life Care Pathways, the Pathways are also a useful quality assurance tool. Implementing an End of Life Care Pathway provides the opportunity for benchmarking and auditing to ensure that a service is providing best practice. It enables internal benchmarking within the organisation and comparisons/ benchmarking with external care providers to enable services to identify areas of need. Studies have demonstrated that the use of End of Life Care Pathways result in a marked improvement in documentation- a key requirement for ongoing organizational accountability and governance. The Pathways provide evidence of a demonstrated commitment to quality assurance [1, 2, 6].

## 7. END OF LIFE CARE

### 7.1. Background

There is a recognised need to provide high quality care to one of our most vulnerable populations, the dying. Palliative care has been identified as a worldwide priority due to our advancing age and our ability to live longer with more illness [7].

The quality of dying in society today is often poor [2]. The difficulties and complexities of providing care across settings may result in fragmented care for the dying. Many patients are dying alone, frightened and without dignity [2]. Patients and/ or their families may be unaware of their terminal prognosis despite death being anticipated by the treating clinician/s [2]. Of the approximately 144 000 people who die in Australia annually, it is estimated that death is anticipated in as many 36 000- 72 000 cases. Of these people approximately 54% will die in hospital [1, 4, 12].

Whilst the quality and place of death may vary there is some consensus as to what constitutes good end of life care [7]. Care provisions should be guided toward addressing

- Symptom management
- Addressing emotional and cognitive symptoms
- Improving quality of life
- Advance care planning and directives
- Functional status
- Spirituality
- Issues of grief and bereavement (including the potential for)
- Satisfaction and quality of care
- Caregiver wellbeing [7]

The care of the dying should also be extended to protecting the most basic human rights as directed in the Good Medical Practice: A Code of Conduct [13]. Basic rights, as identified in the Code of Conduct include, but are not limited to:-

- Informing patients that they are dying
- Helping patients and their families to understand what may be expected or what may occur
- Being respectful of the patients right to autonomy and maintaining a sense of control
- Respecting patient choices and wishes
- Providing patients and families with access to information and care including spiritual, religious and emotional support and

- Respecting and recognising the rights of their loved ones and carers.

There is a need to monitor and provide consistent, quality end of life care. Optimum care for all can only be achieved with a systematic, coordinated approach encompassing shared goals and a standardised level of care. The quality of death varies from person to person, and may be dependent upon the experience of the practitioner/s and the resources that are available to them. This has resulted in a wide variation in practices between different institutions and service providers. There is currently no shared framework for providing care to our dying within Victoria, and there is no collective and demonstrable agreement as to what should constitute a good quality end of life care in Victoria [2, 3, 5].

The Australian Best Care of the Dying Network identified that deficiencies in the care of the dying are best addressed through system change (2).

### ***Integrated and clinical care pathways***

Integrated and clinical care pathways are documents that outline specific steps of multi-disciplinary care. Care pathways are being used extensively in other medical disciplines and have been formally evaluated. Recent systematic literature reviews of care pathways found:-

- Care pathways may be associated with reduced complications
- Care pathways may be associated with improved documentation
- Implementing the pathways may not negatively impact on the costs of length of stay
- Can be effective in providing proactive care management in those with a predictable disease trajectory
- May ensure that patients receive clinical interventions and/ or assessments in a timely manner possibly leading to improvements in service quality and service efficiency
- Are an effective mechanism for promoting adherence to guidelines thereby reducing variations in practice
- Effective in improving documentation including the documentation of communication between staff, patients and carers
- May be effective in improving physician agreement about treatment options
- Provide an effective and supportive decision making tool [8]

### ***The hospice model of care and end of life care pathways***

The hospice model of care of the dying patient is regarded as the gold standard of care [14]. End of life care pathways and integrated care pathways were developed based on the hospice approach as a means of monitoring and guiding clinical practice in the multi-disciplinary setting outcomes [7, 8, 14].

Within the palliative care setting end of life care pathways were designed to guide the provision of care for the dying through the use of a single tool aimed at co-coordinating consistent multi-disciplinary practices [15]. The pathways address inconsistencies in care provisions by providing structured patient management strategies detailing essential steps in caring for patients in the final days and hours of their lives. They facilitate the most appropriate management by the most appropriate provider at the most appropriate time, and represent a formalised multi-disciplinary agreement that is implemented with the aim of achieving the best patient outcomes [7, 8].

End of Life Care pathways are regarded as a powerful educational tool and a supportive practical framework to aid decision making. By guiding end of life care across service settings the pathways facilitate the provision of best practice and enable patients to experience a dignified death. End of Life Care Pathways provide a supportive tool for services that have limited access to Palliative Care Specialists, and for services seeking to provide a standardised tool to aid decision making by less experienced practitioners. End of Life Care Pathways also provide an aid to a consistent and manageable approach in settings employing a varied and large number of Health Practitioners, or where the range of services is diversified [2, 7-11].

End of life care pathways may enhance patient care through improved symptom control, facilitation of understanding of diagnosis, increased patient satisfaction, decreased health care utilization and improved resource allocation [16-21].

End of Life Care Pathways also provide the opportunity for benchmarking and auditing to ensure that each service is providing best practice. They provide for internal benchmarking within each organisation and comparisons/ benchmarking with external care providers to enable services to identify areas of need. The use of End of Life Care Pathways results in a marked improvement in documentation- a key requirement for ongoing organizational accountability and governance. The Pathways also provide evidence of a demonstrated commitment to quality assurance through the provision of an appropriate standard of documentation within the organisation and provide evidence of a clinical agreement that a person has met specific criteria and that death is anticipated. This guides care planning ensuring that care is aimed at symptom management and unnecessary and futile medical treatments are discontinued [2, 22].

## 8. PROJECT DETAILS

### 8.1 Background

As part of its strategic approach to addressing the goals of the National Strategy, the Department of Health Victoria allocated funding for the purpose of uncovering areas of gaps in care that could potentially be improved in the Victorian Palliative and Health Care sector, and to develop strategies and identify aids that may contribute to the realisation of the National goals.

The End of Life Care Pathways Victoria Project (EOLCP) was initiated by the Centre of Palliative Care and the Department of Health Victoria and provides recommendations and advice to the Palliative Sector on tools that may enhance the quality of care in the last days and hours of life. The End of Life Care Pathways Project (EOLCP) was funded by the Department of Health Victoria to support the initiatives of the State wide End of Life Care Pathways Special Interest Group and the Palliative Care Clinical Network.

The Palliative Care Clinical Network (PCCN) was established by Palliative Care, Continuing Care, Department of Health (the department) to oversee the clinical elements and implementation of:

- Strengthening palliative care: policy and strategic directions 2011-2015
- Service Delivery Framework and Service Capability Framework
- Clinical Service Improvement program

In an evaluation of the implementation of the 2004-09 palliative care policy there were several recommendations about the key strategic priorities to be addressed for 2011-15. This project arises from the recommendation “Establish a PCCN and a statewide program for the uptake of evidence into clinical practice” under *Principle 6. Quality care at all times* of the policy.

### 8.2 Objectives of the Project

This study incorporated a review of the literature to identify end of life care pathways currently in use both nationally and internationally. Based on this review and the input from key stakeholders recommendations were developed for the implementation of end of life care pathways within Victoria. The recommendations align with the Palliative care service delivery framework and service capability framework.

This project had six main objectives:-

- To review the literature (incorporating grey literature) to identify end of life care pathways currently in use in the national and international palliative setting. The identified pathways will be further examined to assess the applicability, feasibility and durability of the use of the identified pathways in the Victorian setting will be developed;
- To canvass opinion from experts from the Victorian palliative care sector in order to identify pathways already in use;
- To develop evidence- based web tool to aid health care practitioners/ industry in determining the economic feasibility, implications for productivity, implementation and ongoing management of the identified pathways. The tool will house links to external sites and the findings of the literature review;
- To develop a communication strategy to facilitate the dissemination of the results of the literature review and to promote the use of the new web tool.
- To provide a final report including results, implementation strategies and recommendations for future;
- To develop a strategy with funding sought for the provision of ongoing support and maintenance of the web tool.

The literature review and expert opinion focused specifically on end of life care pathways that were currently in use both internationally and nationally.

### **8.3 Method**

Preparation of this paper involved a comprehensive literature review of published and grey literature as detailed below. A systematic literature review was not undertaken. While systematic literature reviews are considered the highest form of evidence, the rigor involved in the inclusion and exclusion of information would have resulted in a discussion paper absent of a current and realistic interpretation of the environment surrounding end of life care pathways in Victoria. This is due to the dearth of literature published on end of life care pathways and in addition, there is a delay between the writing and publishing of results of studies. The most recent systematic literature review, *End-of-life care pathways for improving outcomes in caring for the dying*, completed in October 2010, has been used as an important reference however this review found no previous end of life care pathway studies were of adequate caliber to include [7].

The research methods chosen incorporated both the empirical quantitative data, information garnered from the studies that were excluded from the systematic literature review by Chan and Webster [7], and qualitative data. Relevant consensus guidelines and expert opinion were incorporated into the guidelines because of the lack of evidence. This provided the opportunity to reflect a more realistic and current understanding of the environment surrounding the use of end of life care pathways in Victoria by theorising more broadly around the context of end of life care [23-25].

## **Key Methods**

The recommendations were developed using the following process:-

- A broad review of the literature surrounding care pathways and end of life care pathways including a search of the grey literature;
- Incorporating expert and service provider opinion to present a more accurate account of current practices;
- Refining of guidelines with an expert advisory panel;
- Developing practice recommendations to accurately reflect all such evidence.

## ***Literature review***

A review of the literature was conducted including all publications from English language biomedical texts and journals, and all international journals and articles translated into English language covering the periods January 1980 to May 2011. Most studies were descriptive, examining provider practices and patient and/or caregiver views, attitudes, knowledge and behavior. In undertaking this review a number of key articles were included:-

### **1. *End-of-life care pathways for improving outcomes in caring for the dying (2010).***

This systematic literature review was prepared by Raymond Chan and Joan Webster, of Cancer Care Services, Royal Brisbane and Women's Hospital, Herston, QLD, Australia 4029. The review critically and empirically examined the literature to assess the effects of end of life care pathways compared with usual care. In total 920 articles were retrieved including thirty one studies. No studies fulfilled the study eligibility criteria and hence were all excluded from the review. This review found that there was a lack of available evidence for the use of end of life pathways but clinical pathways are effective in managing some clinical problems. The review recommended that future studies include outcomes measures in relation to patients, family, caregivers and health professionals [7].

## **2. *Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy (2010).***

This report was endorsed by the Australian Health Ministers and prepared by the Department of Health and Ageing, Commonwealth of Australia. The report explored key areas of palliative care service including awareness and understanding, appropriateness and effectiveness, leadership and governance, and capacity and capability [1].

## **3. *Pathways for care in the last days of life: A review of current utilisation in Victoria, November 2009.***

The project was undertaken by the Cancer and Palliative Care team, Department of health, Victoria. This project aimed to identify key information regarding the use of end of life care pathways in Victoria including barriers and enablers to implementation, outcomes of the introduction of pathway, and to determine if the use of pathways was linked to other activities[26].

## **4. *The Australian Best Care of the Dying project (ABCD): Phase One Report (2005).***

Professor JR Hardy compiled this report on behalf of the ABCD network, Queensland. The report provides rich qualitative data surrounding the dying and the care of the dying in Australia [2].

## **5. *Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers.***

This document was developed by a team from Sydney and Flinders Universities and funded by the National Health and Medical Research Council (NHMRC) [27].

### ***Search Strategy***

The selection of articles for consideration was based on the appropriateness and relevance to the research topic. All articles about end of life care and care pathways were considered with special emphasis on systematic literature reviews and articles from Australian authors. A variety of sources were used:

- Weekly reports on new publications produced by the Cancer Information Service at the Cancer Council of Victoria
- Weekly reviews of new journals received by the Centre for Palliative Care
- The Cochrane Library — visited regularly
- The literature database EMBASE — the project officer in charge retrieved relevant literature

### ***Search terms***

Search terms included end of life, terminal, palliative, terminally ill, dying, and assessment tool, care tools, clinical tools, critical tools, resource, care pathway, care goals.

### ***Databases***

Web of Science, Medline/ Pubmed, CINAHL, EMBASE, PsychInfo, SIGLE, CareSearch

### ***Inclusion/exclusion criteria***

Care was taken to include important reviews and key articles as outlined above.

Criteria for inclusion were restricted to English language articles in which both the population (end of life) and either the intervention (pathway) or the cost of end of life care were described or studied.

In general articles were excluded if they did not include both the population and the intervention, however, several articles concerning the economic implications of end of life care and the legal implications of end of life care were included to provide a greater awareness of other important variables.

### ***Data Extraction***

Where ever possible/ applicable the following data was extracted:-

- Authorship, aims and objectives, outcomes measures
- Methodology
- Population
- Intervention – LCP or other
- Summary of findings

### ***Analysis***

Articles were compared for homogeneity of themes

### ***Comments***

Special emphasis was placed on literature originating from Australian authors of their experience around end of life care pathways. Searches were continued until May 2011 to include all recent literature.

### ***Search results***

The search identified one hundred and forty five articles of interest. Articles cited as references in key documents were also sources to provide a broader perspective. Abstracts were retrieved and reviewed by the Project Officer. Relevant articles or articles that would further inform the project were retrieved in full and reviewed.

## 9. DISCUSSION

### 9.1 Key Findings

The evidence demonstrates that the quality of care for our dying can and should be improved. The introduction of an End of Life Care Pathway is a practical approach to addressing gaps in care that could potentially be improved and improving care of the dying has been identified as a National and State priority [1-5].

The introduction of an End of Life Care Pathway is a quality improvement measure to maximize the care of our most vulnerable population; the dying. The use of an End of Life Care Pathway ensures that throughout the care setting each dying patient is assessed consistently and all areas of needs are addressed. The quality of care and the specific needs of each patient are no longer dependent on the skill, understanding and expertise of the treating staffs. Each patient will be entitled to a systematic and considered consistent approach [2, 6, 22].

End of Life Care Pathways provide a supportive tool for use in services that have limited access to Palliative Care Specialists, and for services seeking to provide a standardised tool to aid decision making by less experienced practitioners End of Life Care Pathway's also provide an aid to a consistent and manageable approach in settings employing a varied and large number of Health Practitioners, or where the range of services is diversified [2, 7-11].

End of life care pathways also provide evidence of a shared consensus amongst treating physicians that the primary goal of care has changed from curative to palliative. Whilst many patients and their families are conflicted in the level of information they would like to receive, studies have indicated that patients and caregivers want to be included in discussions about likely illness trajectory, treatment options, life expectancy and what may be expected during end of life care [27-34].

#### ***End of Life Care Pathways in Use in Australia***

The majority of End of Life Care pathways and Integrated Care Pathways in use throughout Victoria are approved modifications of the Liverpool Care Pathway or adaptations of Integrated Care Pathways.

The Liverpool Care Pathway (LCP) was developed by the Marie Curie Palliative Care Institute in Liverpool to standardise the quality of care of the dying [35]. The LCP specifically targets 18 domains of care and provides a prescriptive template to guide care in hospice, palliative care,

and non-hospice settings [35]. The LCP is the most internationally recognised and widely used pathway and has been implemented at sites in 17 countries.

### ***End of Life Care Pathways used in Victoria***

A number of individual services in Victoria have introduced end of life care pathways in palliative care in response to a perceived need to provide a framework for the delivery of consistent care. The most widely introduced pathway is the Liverpool Care Pathway or approved modifications thereof.

Importantly throughout the duration of this project the momentum and interest in the use of end of life care pathways in Victoria has grown significantly with key staff at the Centre for Palliative Care largely taking on the role of lead agency in providing expert guidance and advice on the implementation of an end of life care pathway.

Raising awareness and maintaining interest in new interventions are two critical indicators of the potential success of projects. Currently within the palliative care sector in Victoria both of these elements exist and there is considerable positive momentum toward the continued use/ further introduction of end of life care pathways. There is also an End of Life Special Interest Group actively advocating for the use of end of life care pathways, and providing informal and unfunded support to other service providers.

There is a lack of data comparing the Liverpool Care Pathway to other care pathways including modified Liverpool Care Pathways. Until further well-designed studies have been done, there is no evidence to support the use of another integrated care pathway over the use of the Liverpool End of Life Care Pathway (or modified version). There is also little justification for the provision of resources to support the development of alternative end of life care pathways when the effect, feasibility and impact of current versions is not yet fully understood. Exceptions to this may include the development of setting specific pathways not currently available such as for the emergency setting.

Currently there is only minimal coordination between services implementing/ maintaining end of life care pathways and this has resulted in inconsistencies in approaches to implementation and resource allocation. There is no one central point of contact to aid and support services, and there is no formal consensus recognising one pathway. The appointment of one key point of contact for services within Victoria would enable a more coordinated and managed approach.

## 9.2 Limitations of the study

There were many limitations involved with finding evidence as there is a dearth of empirical published literature on this topic although end of life care pathways are well utilized internationally and nationally. This may be due in part to:-

- The lack of opportunity for publishing smaller studies or qualitative papers.
- The desire or plan to publish is rarely cited as an objective for introducing an end of life care pathway.
- There is often a significant delay of as much as two years from the time of submitting an article for review and the article being published. During this time articles may not be accessible.

This report has also been limited in nature due to the initial plan and funding for the project. The funding of this project also included the development of a web resource.

## 9.3 Areas for future research

Currently there is a lack of empirical evidence concerning the use of pathways. A recent Cochrane review of end of life care pathways found that due to the absence of well designed controlled studies and randomised controlled trials there is a lack of available evidence for recommending the use of end of life care pathways. However non-eligible before and after studies indicated that the use of end of life care pathways improved symptom management, improved documentation and assessment, improved prescribing practices for end of life, and impacted on the bereavement levels of relatives.

### ***Other areas for further research-***

- More evidence is needed regarding the impact and implications of introducing an end of life care pathway;
- Well designed studies measuring the economic impact of reducing and terminating futile treatments in the last week and days of life would contribute to further knowledge regarding the cost of end of life care pathways;
- There is a high level of interest in developing modified end of life care pathways for use in the Emergency setting;
- Well designed studies are needed to provide evidence into the use of end of life care pathways;
- Promotion of studies in how end of life issues are handled in different cultural settings.

## 10. CONCLUSIONS AND RECOMMENDATIONS

There is a recognised need to monitor and provide consistent quality care in the palliative and health sector. Optimum care for all can only be achieved with a systematic, coordinated approach encompassing shared goals and a standardised level of care. End of life care pathways are used extensively nationally and internationally and are widely regarded as the gold standard of palliative care. They address inconsistency in care by providing structured patient management strategies detailing essential steps in caring for patients in the final days and hours of their lives.

End of life care pathways facilitate the most appropriate management by the most appropriate provider's at the most appropriate time. They provide documentation of a formalised multi-disciplinary agreement that is implemented with the aim of achieving the best patient outcomes.

End of Life Care Pathways:-

- Maximize the care of our most vulnerable population by providing a tool to measure quality improvement;
- Provide an opportunity for benchmarking and auditing to ensure services are providing best practice;
- Providing a supportive tool for services that have limited access to Palliative Care Specialists, and for services seeking to provide a standardised tool to aid decision making by less experienced.

[2, 7-11].

The majority of end of life care pathways and integrated care pathways in use throughout Victoria are approved modifications of the Liverpool Care Pathway (LCP) or adaptations of integrated care pathways. There are also a number of modified pathways based on the Liverpool Care Pathway that are yet to be formally approved. It is recognised, without prejudice, that these pathways were developed in good faith and with the intent of improving the quality and consistency of end of life care. It would be the role of any lead agency appointed to work with and support these services in achieving the appropriate recognition of their pathway.

The Liverpool Care Pathway (or approved modification):-

- Is the most widely used end of life care pathway internationally, nationally and within Victoria;
- Is the recommended best practice model by the Department of Health in the UK;
- Undergoes a rigorous process of ongoing improvement and development including comprehensive audits and a dedicated research program;
- Use of the LCP provides an opportunity for providers/ services to benchmark nationally and internationally;
- Use of the LCP provides extensive access to resources, research, and the opportunity to engage with other LCP users;
- Use of the LCP provides the opportunity for services to be a part of a collaborative internationally research community with a shared purpose.

#### **Recommendations:-**

- All services considering the introduction of an end of life care pathway should be strongly encouraged to use the Liverpool End of Life Care Pathway or existing modifications of, to ensure consistency, enable benchmarking between services, and to ensure that resources are not consumed developing further pathways.
- Funding should be allocated to services wishing to implement an end of life care pathway.
- Ideally funding would be allocated to further develop studies aimed at identifying the impact and implications of introducing an end of life care pathway.
- The Department of Health Victoria should facilitate/ support the further progression of the collaborative relationship with the Marie Curie Palliative Care Institute with the aim of progressing the State of Victoria to a Level 1 Partner.
- Modifications to the existing pathways should be evidence based in an effort to conserve the further use of resources.
- The best way to maintain momentum and ensure continuity of support is to provide one key point of contact for palliative care services in Victoria who wish to investigate/ implement an end of life care and this would enable:-
  - Ongoing provision of advice and support to services wishing to investigate the use of an end of life care pathway
  - Ongoing facilitation of the 'End of Life Special Interest Group'
  - Ongoing maintenance of the web resource developed from this Project
  - Development of a data bank of end of life care pathway projects in Victoria
  - Ongoing support and facilitation of a state wide coordinated approach to the use of end of life care pathways in Victoria

- Ongoing development of collaborative networks between palliative care providers in the interests of further research into this field
- Development of a workshop to facilitate communication with services interested in implementing the pathway
- Further collaboration with the Marie Currie Palliative Care Institute with the aim of progressing the State of Victoria to a Level 1 Partner
- To ensure that momentum and goodwill gained through the project will not dissipate

Ideally a series of steps should be followed if considering the implementation of an end of life care pathway including around governance, institutional support and the provision of advice. Informative generic documents and templates are available from the *End of Life Care Pathways* website which can be accessed from [www.centreforpallcare.org/](http://www.centreforpallcare.org/).

## 12. REFERENCES

1. National Palliative Care Strategy 2010- Commonwealth of Australia, *Supporting Australians to Live Well at the End of Life*. 2010.
2. Hardy, J.R., *The Australian Best Care of the Dying Project (ABCD): Phase One Report*. 2005: p. 1-18.
3. Smith, R., *A good death*. British Medical Journal, 2000. 2000(320): p. 129-130.
4. CareSearch Palliative Care Knowledge network, *Preferred Place of Death*. 2010, CareSearch.
5. Weissman, D. and M. Meier, *Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting*. Journal of Palliative Medicine, 2011. 14(1): p. 17-23.
6. Tolson, D., et al., *Developing a managed clinical network in palliative care: a realistic evaluation*. International Journal Of Nursing Studies, 2007. 44(2): p. 183-195.
7. Chan, R. and J. Webster, *End-of-life care pathways for improving outcomes in caring for the dying*. Cochrane Database Of Systematic Reviews (Online), 2010(1): p. CD008006.
8. Allen, D., E. Gillen, and L. Rixson, *The Effectiveness of Integrated Care Pathways for Adults and Children in Health Care Settings: A Systematic Review*. JBI Library of Systematic Reviews, 2009. 7(3): p. 80-129.
9. Ellershaw, J.S., C; Overill, S; Walker, S; Aldridge, J., *Care of the Dying: Setting Standards for Symptom Control in the Last 48 Hours of Life*. Journal of Pain & Symptom Management, 2001. 21(1): p. 12-17.
10. Ellershaw, J., *Care of the dying: what a difference an LCP makes!* Palliative Medicine, 2007. 21(5): p. 365-368.
11. Veerbeek, L., et al., *Front line dispatch. Audit of the Liverpool Care Pathway for the Dying Patient in a Dutch cancer hospital*. Journal of Palliative Care, 2006. 22(4): p. 305-308.
12. Palliative Care Australia, *A Guide to Palliative Care Service Development: a population based approach*. 2005.
13. Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia*. 2005.
14. Department of Health, *End of life care strategy: promoting high quality care for all adults at the end of life*. 2008, Department of Health: London.
15. WA Cancer and Palliative Care Network, G.o.W.A., Department of Health, *A pilot study of the use of the Liverpool Care Pathway in Western Australia: Final report*. June 2009.
16. Virik and P. Glare, *Profile and evaluation of palliative medicine consultation services within tertiary teaching hospital in Sydney*. Journal of Pain & Symptom Management, 2002. 23(17-25).
17. Higginson, I., et al., *Is there evidence that palliative care teams alter end of life experiences of patients and their caregivers?* Journal of Pain & Symptom Management, 2003. 25: p. 150-168.
18. Manfredi, P., et al., *Palliative care consultations: how do they impact the care of hospitalized patients?* . Journal of Pain & Symptom Management, 2000. 20: p. 166-173.
19. Rodrigues, H.C.M.L., J. Deprest, and P.P.v.d. Berg, *When referring physicians and researchers disagree on equipoise: the TOTAL trial experience*. Prenatal Diagnosis, 2011: p. n/a-n/a.
20. Hansen, E., *Successful Qualitative Health Research: A Practical Introduction*. 2006, Corws Nest NSW: Allen & Unwin.
21. Huong Canh Le, B. and J.N. Watt, *Care of the Dying in Australia's Busiest Hospital: Benefits of Palliative Care Consultation and Methods to Enhance Access*. Journal Of Palliative Medicine, 2010. 13(7): p. 855-860.

22. Pugh, E.J., M. McEvoy, and J. Blenkinsopp, *Use of the proportion of patients dying on an End of Life Pathway as a quality marker: considerations for interpretation*. Palliative Medicine, 2010. 24(5): p. 544-547.
23. Burdess, N., *The Really Understandable Stats Book*. 1994, Allambie Heights: Prentice Hall Australia.
24. O'Leary, Z., *Researching Real- World Problems: A Guide to Methods of Inquiry*. 2005, London: SAGE Publications.
25. Thomas, J.D., *Doing Critical Ethnography*. 1993, Newbury Park: SAGE Publications
26. Department of Health Victoria, *Pathways for care in the last days of life: A review of current utilisation in Victoria*. November 2009, Department of Health Victoria.
27. Clayton, J., et al., *Discussing end-of-life issues with terminally ill cancer patients and their carers: a qualitative study*. Support Care Cancer, 2005. 13: p. 589-599.
28. Clayton JM, B.P., Arnold RM, Tattersall MHN, *Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers*. Cancer, 2005. **103**: p. 1965-1975.
29. Kirk P, K.I., Kristjanson LJ, *What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study*. British Medical Journal, 2004. **328**: p. 1343-1347.
30. Greisinger, A., et al., *Terminally ill cancer patients: their most important concerns*. Cancer Practitioner, 1997. **5**: p. 147-154.
31. Johnson, D.C., C.T. Kassner, and J.S. Kutner, *Current use of guidelines, protocols, and care pathways for symptom management in hospice*. The American Journal Of Hospice & Palliative Care, 2004. 21(1): p. 51-57.
32. Gattellari M, V.K., Butow PN, Tattersall MH, *When the treatment goal is not cure: are cancer patients equipped to make informed decisions? J Clin Oncol 2002; 20: 503-513*. Journal Of Clinical Oncology. 20: p. 503-513.
33. Iconomou G, V.A., Koutras A, et al, *Information needs and awareness of diagnosis in patients with cancer receiving chemotherapy: a report from Greece*. Palliative Medicine, 2002. 16: p. 315-321.
34. Josephine M Clayton, K.M.H., Phyllis N Butow, Martin H N Tattersall and David C Currow, *Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers*. Medical Journal of Australia, 2007. 186 (12 supp): p. 77-108.
35. Lo, S.H., et al., *The implementation of an end-of-life integrated care pathway in a Chinese population*. International Journal Of Palliative Nursing, 2009. **15**(8): p. 384-388.
36. Bookbinder, M., et al., *Improving end-of-life care: development and pilot-test of a clinical pathway*. Journal Of Pain And Symptom Management, 2005. **29**(6): p. 529-543.
37. Veerbeek, L., et al., *The effect of the Liverpool Care Pathway for the dying: a multi-centre study*. Palliative Medicine, 2008. 22(2): p. 145-151.
38. Veerbeek, L., et al., *Does recognition of the dying phase have an effect on the use of medical interventions? Journal Of Palliative Care, 2008. 24(2): p. 94-99.*
39. Veerbeek, L., et al., *Using the LCP: bereaved relatives' assessments of communication and bereavement*. The American Journal Of Hospice & Palliative Care, 2008. **25**(3): p. 207-214.
40. Luhrs, C.A., et al., *Pilot of a pathway to improve the care of imminently dying oncology inpatients in a Veterans Affairs Medical Center*. Journal Of Pain And Symptom Management, 2005. **29**(6): p. 544-551.

41. Mirando, S., P.D. Davies, and A. Lipp, *Introducing an integrated care pathway for the last days of life*. *Palliative Medicine*, 2005. 19(1): p. 33-39.
42. Bailey, F., et al., *Improving processes of hospital care during the last hours of life*. *Archives of Internal Medicine*, 2005. 165(15): p. 1722-1727.
43. Currie, V.L. and G. Harvey, *The use of care pathways as tools to support the implementation of evidenced-based practice*. *Journal of Interprofessional Care*, 2000. 14(4): p. 311-324.

## 14. ACKNOWLEDGEMENTS

The End of Life Care Pathways Project (EOLCP) was funded by the Department of Health Victoria to support the initiatives of the State wide End of Life Care Pathways Special Interest Group and the Palliative Care Clinical Network.

The Project Management Committee of the End of Life Care Pathways Project would like to extend their gratitude and thanks to the Project Advisory Committee for their assistance and advice throughout the duration of the project.

The Project Management Committee would also like to extend their thanks to the many individuals working in the Victorian palliative care sector who have provided their advice, assistance and guidance.

It is hoped that this Report is an accurate reflection of the current climate surrounding end of life care pathways in Victoria, and the thoughts and experiences of the majority of dedicated individuals and services working in the field of palliative care.

## Appendix A

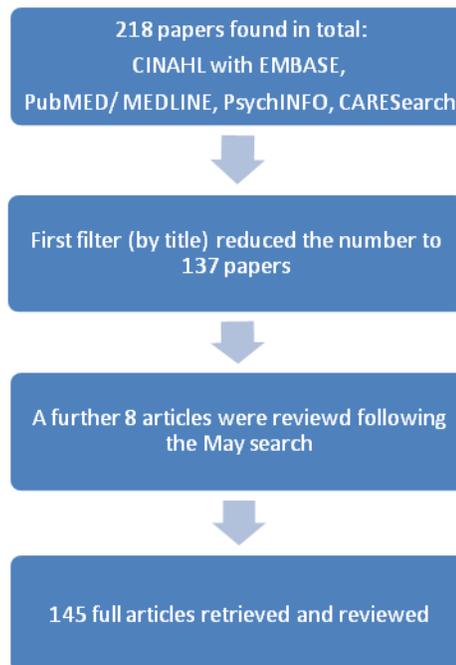
### Flowchart for inclusion of articles in the review

Search terms: - Major headings were identified in each database for articles relating to end of life and pathways/ health care cost.

Date: - 1980- May 2011

Inclusion criteria:-  
English language  
End of life specific

Exclusion criteria: - non- English language, date outside limits, duplicate articles, articles relating to non-end of life clinical pathways



## Appendix B

### Project Methodology, Evaluation and Timeframes

#### Objectives

This study will incorporate a review of the literature to identify end of life care pathways currently in use both nationally and internationally. Based on this review and the input from key stakeholders a specific tool(s) will be recommended for implementation within Victoria. The recommendations should align with the Palliative care service delivery framework and service capability framework.

This project has six main aims:

- A review of the literature (incorporating grey literature) to identify end of life care pathways currently in use in the national and international palliative setting. The identified pathways will be further examined to assess the applicability, feasibility and durability of the use of the identified pathways in the Victorian setting will be developed.
- Canvassing of opinions (via discussions) with experts derived from the Victorian palliative care sector in order to identify pathways already in use.
- An evidence- based web tool will be developed to aid health care practitioners/ industry in determining the economic feasibility, implications for productivity, implementation and ongoing management of the identified pathways. The web tool will house links to external sites and the findings of the literature review.
- A communication strategy will be developed to facilitate the dissemination of the results of the literature review and to promote the use of the new web tool.
- A final report including results, implementation strategies and recommendations for future will be prepared.
- A strategy will be developed with funding sought for the provision of ongoing support and maintenance of the web tool



## Appendix B Cont'd

### Methodology

1. A review the literature (incorporating grey literature) to identify end of life care pathways currently in use in the national and international palliative setting. The identified pathways will be further examined with specific criteria developed aimed at assessing the applicability, feasibility and durability of the use of the identified pathways in the Victorian setting will be developed
2. Discussions/ semi- structured interviews will be conducted with experts derived from the palliative care sector to identify and examine pathways that are currently in use in Victoria.
3. A short list of pathways, as identified by the literature review. A comparative critical analysis of the identified pathways will be conducted. A final report including results, implementation strategies and recommendations for future research will be prepared.
4. Findings of the report will be disseminated via an evidence-based web tool developed for the purpose of facilitating and enhancing the use of end of life care pathways in Victoria.

## Appendix B Cont'd

### Project Governance

A project management committee was established to oversee the key tasks and deliverables of the project. The project management group was responsible for, and had the authority to, endorse or approve the management of the project. Membership included: Dr Mark Boughey (CPC), Dr Jenny Philip (CPC), Ms Karen Quinn (CPC) and Ms Nikola Stepanov (CPC). An initial meeting was held in January, 2011 and the scope and focus of the project revised. The project management group met fortnightly.

An advisory group was established to make recommendations to assist the project management group to achieve the key tasks and deliverables of the project. The group was comprised of 4-6 members representing the Victorian Palliative care sector. The advisory committee met monthly and provided advice and recommendations regarding the direction of the project.

On occasion when members of either group were unable to attend in person, an allowance was made in the Terms of Reference for the inclusion of a circular resolution in order that the project would proceed in a timely manner. The draft of the report and the draft of the web-pages were forwarded to Members of both the Project Management Committee and the Project Advisory Committee for feedback. An agenda was prepared prior to each meeting of both Committee's and all meetings were minuted.

## Appendix B Cont'd

Budget	Cost
Project officer - allowing for 288 hours	\$12096
Non salaries, eg printing, catering, travel	\$ 1,000
Contingency	\$ 1,500
Capital / operational expenditure	\$ 404
Total budget	\$ 15000

## Appendix C

### EXAMPLES OF RECENT PROJECTS IN VICTORIA

Location	Number of Sites	Setting Specific	Version of EOLCP	Eft Allocation	Current Status
Metropolitan	2	General Medical	Approved modification of LCP	0.5 for 6 months	Successfully implemented in two wards in 2009. The project is now being extended and two further wards are about to being Phase 1
Metropolitan	2	General medical- one regional site, one metropolitan site	LCP version 12	0.4 eft for 6 months	This project commenced in April 2011 and is in Phase 1. A project officer was recently appointed to manage the introduction of the pathway in 2 services concurrently.
Metropolitan	4	Disease specific across four metropolitan sites	Approved modification of LCP	1.0 eft allocation for 10 months	This project commenced in January 2011 and involves one project manager facilitating the implementation of an end of life care pathway in four large metropolitan institutions. The pathway is disease specific.
Regional	4	2 General medical, 1 aged care, 1 hospice	LCP version 12	Currently no eft allocated	Currently pre-phase 1
Rural	1	Palliative Care	LCP	No eft was allocated	The managers have since identified that there are issues with compliance and there is a need to re-educate staff
Metropolitan	2	1 Palliative Care, 1 Acute Care	Approved modification of LCP	No eft was allocated No funding	Success has been attributed to the ongoing support and commitment of senior staff and clinicians

## Appendix D

### KEY ELEMENTS OF A BUSINESS PLAN

#### Introducing an end of life care pathway

Introducing an end of life care pathway requires co-ordination, leadership and support. There are many considerations to explore before deciding to introduce an end of life care pathway in your setting. A staged and carefully planned and well-resourced approach is considered important to the successful implementation. The introduction of a new resource often requires a considerable multi-disciplinary education program enabling a change in prescribing and care practices [6, 7, 36-43].

#### ***Considerations include:-***

- Identifying the aims of goals of the initial pilot introduction.
- Identifying an appropriate pilot setting.
- Ongoing in principal support of the executive committee.
- Adequate allocation of resources to plan and develop the education, implementation and maintenance strategies including resources directed to assessing pre and post audits.
- Adequate allocation of resources to facilitate a multi-disciplinary educational program including pre and post education audits.
- Ongoing onsite support during the initial implementation phase to build awareness, support staffs, to monitor progress, and to record variances.
- Ongoing senior/ enthusiastic medical support to aid clinical care directives and decision making at the ward level.
- The successful implementation of an End of Life Care Pathway is dependent on planning and resources, and the ongoing support of Quality Unit staff, Service Management and the Executive.

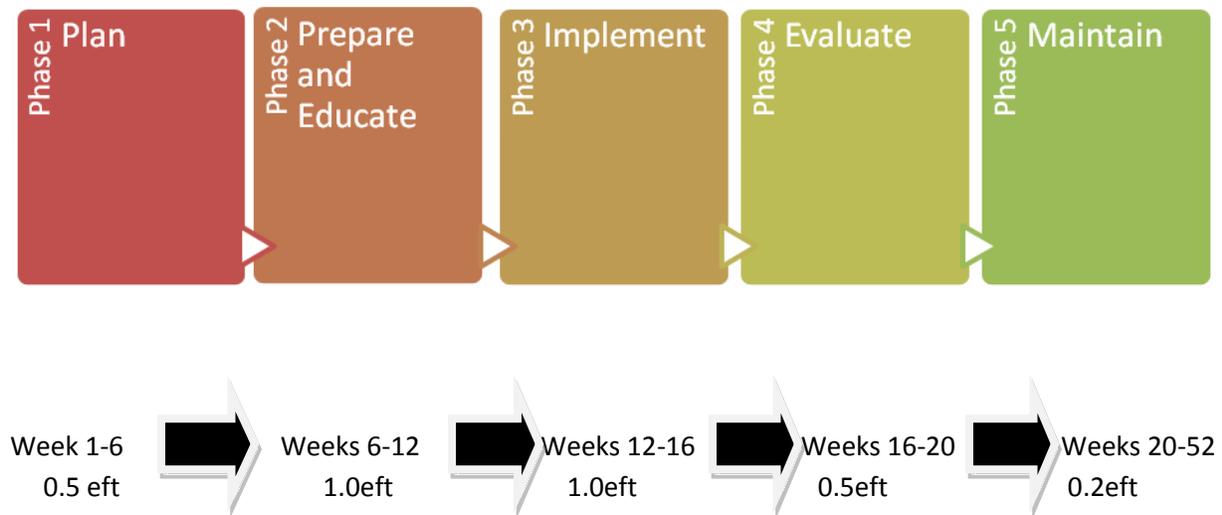
#### ***Aims of the use of resources include:-***

- Facilitating and enhancing an awareness of the appropriate use of the Pathway through education,
- The provision of onsite assistance to aid decision-making for Practitioners applying the pathway,
- Data collection for quality assurance.

## Appendix D Cont'd

The successful implementation of an end of life care pathway is reliant on a systematic and coordinated approach facilitated by a committed multi- disciplinary Project Management Team and a dedicated Project Manager/ Project Nurse [41].

### Proposed Timeline & eft (Project Manager/ Project Nurse) for the Implementation of EOLCP.



## Appendix D Cont'd

### Projected Budget EOLCP

#### Salary and Wage Expense

Job class		Budget
<i>Project Manager/ Project Nurse</i>	<i>Refer below for detailed account</i>	<b>\$30,268</b>
<b>Total Salary and Wage Expense</b>		<b>\$30,268</b>

#### Other Expenses

Expense		Budget
<b>Administrative support</b>	<i>Telephone, printing, photocopying, catering</i>	\$1000
<b>Capital/ Operational Expenditure:-</b>		
Low Risk Ethics	<i>HREC application- approx</i>	\$600
Travel/ Parking		\$500
Contingency		\$1000
<b>Total Other Expenses</b>		<b>\$3100</b>

#### Salary and Wage Expenses- Detailed

Job class		Budget
<i>Project Manager/ Project Nurse</i>	<i>Phase 1 : 1 x .5EFT for 6 weeks Project Manager/ Nurse- \$ 33 per hour x 7.6 hour day (including on costs)</i>	\$3,750
	<i>Phase 2 : 1 x 1.0EFT for 6 weeks Project Manager/ Nurse- \$ 33 per hour x 7.6 hour day (including on costs)</i>	\$7,500
	<i>Phase 3 :</i>	\$7,500

	<i>1 x 1.0 EFT for 6 weeks Project Manager/ Nurse- \$ 33 per hour x 7.6 hour day (including on costs)</i>	
	<i>Phase 4 : 1 x .5 EFT for 4 weeks Project Manager/ Nurse- \$ 33 per hour x 7.6 hour day (including on costs)</i>	\$2,500
	<i>Phase 5 : 1 x .2 EFT for 32 weeks Project Manager/ Nurse- \$ 33 per hour x 7.6 hour day (including on costs)</i>	\$9,018
<b>Total Salary and Wage Expense</b>	<b>For 12 months</b>	<b>\$30,268</b>

## Appendix D Cont'd

### Phase 1

#### Plan

The first phase of implementation is largely administrative. It is during this stage that staff will be appointed or invited to key roles.

During this stage a service should aim to:-

- Seek support from service Managers and the Executive.
- Appoint a multi-disciplinary Project Management Committee to oversee the project
- Appoint a Project Manager/ Project Nurse to coordinate the project
- Identify suitable Wards/ Services for the proposed introduction of the end of life care pathway. Many services have chosen to first introduce an end of life care pathway in general medical areas.
- Consider the evaluation requirements
- Consider service quality plan opportunities
- Develop suitable timeframes for the implementation
- Develop measureable outcomes to determine the feasibility of continuing the use of an end of life care pathway specific to the setting
- Project Manager/ Project Nurse to comply with the ethics and governance requirements of the site including completing low risk ethics applications to facilitate baseline and baseline versus post-implementation audits, variance audit, and training evaluation audit.
- Project Manager/ Project Nurse to plan training sessions

#### KEY TASKS:-

- Seek support from service Managers and the Executive
- Appoint Project Management Committee, Project Manager/ Project Nurse
- Identify suitable wards and clinical champions
- Consider the evaluation requirements and service plan opportunities
- Develop measureable outcomes

## Appendix D Cont'd

### Phase 2

#### Prepare and educate

Education is an important consideration in the successful introduction of an end of life care pathway. Education sessions should be planned for all multi-disciplinary staff with an assessment of pre and post education levels.

During this phase the Project Manager should:

- Conduct education/ inservice training over a one month period
- Conduct a pre-training assessment of the level of staff knowledge
- Invite all multi-disciplinary staff including ancillary and casual staff
- Conduct a post-training assessment of the level of staff knowledge

Further to the educational requirements it is during this phase that the Project Manager

- Conducts a baseline audit of existing services
- Collaborates with unit/service managers to identify clinical champions
- Engage Education Unit and include in the ongoing educational plan, orientation package, etc

#### KEY TASKS:-

- Conduct education/ inservice training over a one month period
- Conduct a pre-training assessment of the level of staff knowledge
- Invite all multi-disciplinary staff including ancillary and casual staff
- Conduct a post-training assessment of the level of staff knowledge
- Conducts a baseline audit using All Wales Project
- Collaborates with unit/service managers to identify clinical champions

### Phase 3 Implement

A systematic and well-planned implementation phase with the services of a dedicated and experienced palliative care nurse is important to ensure the success of the introduction of an end of life care pathway. The optimum times for implementation includes when the staff have the project manager, project nurse or a senior clinician to provide support, leadership and to sanction decision making.

#### KEY TASKS:-

- The Implementation of the pathway in identified wards during pre-specified times
- Clinical staff to record variances from the end of life pathway
- Project Manager/ Project Nurse to monitor and audit variances recorded by clinical staff
- Project Manager/ Project Nurse to be available to support staff
- Project Manager/ Project Nurse to conduct training evaluation audit
- Key senior clinical and medical staff to be available to support more junior/ inexperienced staff during decision-making process
- Invite open discussion regarding patients included and excluded from being placed on a pathway during multi-disciplinary, team, and medical meetings

## Appendix D Cont'd

### Phase 4 Evaluate

During the initial planning of the project the Project Management Committee would have determined the key objectives of the project. It is during this phase that the audits are undertaken to determine if the pathway has been successfully introduced and if any barriers to use have been identified. Some services that experience a high turnover of staff, or who engage casual staff may choose to rerun the education sessions. This is particularly applicable to training hospitals where there is a regular and large turnover of both junior medical and nursing staff.

#### KEY TASKS:-

- The Project Manager/ Project Nurse will conduct a post-implementation audit
- The Project Manager/ Project Nurse will conduct Variance Audit
- The Project Manager/ Project Nurse will record the number of deaths on and off pathway and review all noted deaths of patients not on pathway
- The Project Manager/ Project Nurse will conduct a case review of deaths in patients who met EOLCP criteria but in who the EOLCP was not implemented to document why EOLCP not initiated

## Appendix D Cont'd

### Phase 5 Maintain

The successful implementation of an new initiative requires a change in workplace culture and ongoing support to facilitate that change. This includes incorporating education around end of life care pathways into the orientation program for new staff.

Engaging staff in the maintenance process may also maintain momentum by providing opportunities for quality assurance activities or research. Importantly informing staff of the outcomes of implementing and maintaining an end of life care pathway through the use of updates and newsletters enables ongoing engagement. Ideally clinical champions would have been identified during earlier phases to provide a support role in decision-making and ongoing education.

During this phase services may explore further opportunities to include in ongoing quality improvement program, National Standards Assessment Program, Australian Council on Healthcare Standards, Aged Care Standards, etc

#### KEY TASKS:-

- Incorporate education into orientation days for new staff
- Keep staff engaged and informed
- Consider provisioning for an ongoing role for a 'EOLCP Clinical Champion'
- Ongoing support for staff and patients and their families
- Ongoing role in on-ward education including education of new staff

## Appendix D Cont'd

### Possible barriers to implementation

Barriers identified in the literature largely centered on culture and work-place practices. Often the culture of workplace attitudes may be due to fears of harm and a number of these were cited in the literature including the potential for adverse effects:-

- A premature diagnosis may lead to the premature implementation of a pathway
- That pathways may mask signs of improvement in patients
- The use of a pathway may cause carer dissatisfaction

The recent Cochrane review of end of life care pathways found that there was no evidence of harm [7]

Other barriers include:-

- Difficulties of sustainability if the introduction/ implementation is unsupported by the Executive and Senior Staff
- Compliance to the pathway requires a change in organisational culture
- Lack of communication amongst decision makers and ward staffs
- Failure to recognise treatment futility
- Failure to implement an end of life care pathway in a timely manner

[2, 7, 21]

#### **BARRIERS TO IMPLEMENTATION:-**

- Requires ongoing support
- Requires organizational change
- Requires consensus amongst decision makers and ward staffs
- Requires the recognition that primary goal of care has moved from curative to palliative
- Must be implemented at the appropriate time

## Appendix E

### USEFUL RESOURCES

- Information on the Liverpool End of Life Care Pathway (<http://www.liv.ac.uk/mcpcil/>)
- Information from CPCRE website on [End of Life care pathways for Residential Aged Care Facilities](http://www.health.qld.gov.au/cpcrc/eol_pthwys.asp). ([http://www.health.qld.gov.au/cpcrc/eol\\_pthwys.asp](http://www.health.qld.gov.au/cpcrc/eol_pthwys.asp))
- The WA Cancer and Palliative Care Network have produced a report: [A pilot study of the use of the Liverpool Care Pathway in Western Australia](#). June 2009. ([http://www.health.qld.gov.au/cpcrc/eol\\_pthwys.asp](http://www.health.qld.gov.au/cpcrc/eol_pthwys.asp))
- The Tasmanian Department of Health and Human Services / Palliative Care Service has a [Hospital Integrated End of Life Care Pathway](http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0004/37534/Terminal_Care_Pathway.pdf). ([http://www.dhhs.tas.gov.au/\\_\\_data/assets/pdf\\_file/0004/37534/Terminal\\_Care\\_Pathway.pdf](http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0004/37534/Terminal_Care_Pathway.pdf))
- The Sydney South West Area Health Service, NSW has information on their [Liverpool Hospital End of Life Care Pathway Project](http://www.awards-expo.health.nsw.gov.au/winners/category_2c/liverpool_hospital_end_of_life_care_pathway_project). ([http://www.awards-expo.health.nsw.gov.au/winners/category\\_2c/liverpool\\_hospital\\_end\\_of\\_life\\_care\\_pathway\\_project](http://www.awards-expo.health.nsw.gov.au/winners/category_2c/liverpool_hospital_end_of_life_care_pathway_project))
- The Royal Australian College of General Practitioners has information on Medical Care of Older Persons in Residential Aged Care Facilities, which includes information on the Liverpool Care Pathway highlighting the [11 goals of care for the dying patient](http://www.racgp.org.au/silverbookonline/1-3.asp). (<http://www.racgp.org.au/silverbookonline/1-3.asp>)
- The Australian General Practice Network Rural Palliative Care Resource kit has information and resources on [End of Life Pathways](http://www.agpn.com.au/programs/rural-palliative-care-program/resource-kit/clinical-support--and--management/clinical-support/end-of-life-pathways). (<http://www.agpn.com.au/programs/rural-palliative-care-program/resource-kit/clinical-support--and--management/clinical-support/end-of-life-pathways>)
- The NHS (UK) has [End of Life Care Strategy](http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf) which includes information on EOL care pathways ([http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs\\_EoLC\\_Strategy\\_1.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf))