Enhancing Community Understanding of Palliative Care

Final Report

A project funded

under

The Caring Communities Program

by the Australian Government Department of Health & Ageing

Elizabeth Bennett, Project Consultant
and Shirley Sutton, Secretary/Executive Delegate
ACT Palliative Care Society
20 May 2005

Project commencement date:	May 2003
Project completion date:	May 2005
Fund holder (auspice body):	ACT Palliative Care Society Inc (name changed 8 December 2003)
Name of service conducting the project:	Elizabeth Bennett, Project Consultant, ACT Palliative Care Society

Project Profile

The main goal of the **Enhancing Community Understanding of Palliative Care Project** was to enhance community understanding of palliative care within the ACT region. The project aimed to achieve this goal via the development of a comprehensive and individually tailored resource kit, and the development and trialling of a community education package about palliative care. This goal was successfully achieved during the life of the project (2003-2005).

A Project Plan was developed at the beginning of the project (Appendix A) and six monthly reports tracking the progress of the project were produced during the 2003-2005 period (Appendix B). The project was completed on time and within budget.

The project was overseen by a reference group which was coordinated by the Secretary/Delegate of the ACT Palliative Care Society, Ms Shirley Sutton. The day to day management of the project was undertaken by a part time project consultant, Ms Elizabeth Bennett.

Literature Review

Prior to developing the resource kit and the community education package, an extensive review of existing palliative care literature and resources was undertaken. This review included an analysis of local publications/resources as well as resources/publications from other state/territories, and a range of national and international publications/resources. A sample of the resources/publications reviewed can be referenced at the following web addresses:

http://www.nhpco.org/i4a/pages/index.cfm?pageid=3254&openpage=3254
http://www.hospicecare.com/
http://www.hospice-spc-council.org.uk/
http://www.ejpc.co.uk/ejpchome.asp
http://www.growthhouse.org/palliat.html
http://www.leeds.ac.uk/lmi/ppc/ppcmain.html
http://www.jr2.ox.ac.uk/cochrane/
http://is.dal.ca./%7Epedpain/pedpain.html
http://www.aap.org/policy/re0007.html
http://www.hospicebc.org/
http://www.griefworksbc.com/
http://www.palliativecarenursing.net/
http://www.stoppain.org/palliative_care/
http://www.stoppain.org/for_professionals/cancerbk.pdf

The best features and leading practice aspects of these and other resources were drawn on and duly acknowledged in the production of the new ACT palliative care resource kit and community education package.

Operational Details

The resource kit and community education package were developed with input from the ACT Palliative Care Society Reference Group, an expert focus group, and a community focus group. The Reference Group included representatives of Clare Holland House, the ACT Home Based Palliative Care Team, palliative care workers from ACT hospitals, as well as representatives from the ACT Palliative Care Society and consumer representatives (Appendix C). The expert focus group included palliative care clinicians, the manager of Clare Holland House, palliative care social workers and pastoral carers. The community focus group included a broad range of 18 community members. Some had lived a palliative care experience with someone they cared for and some had not. Focus group members were drawn from the local community via existing community networks and via an advertisement in the local community newspaper ***The Chronicle***.

Project Outcomes

Resource Kit

The resource kit that was developed includes two publications written and produced by the Reference Group – a **flyer** (with very general information about palliative care in the ACT in it and key contact numbers), and **Booklet 1** titled ***Palliative Care in the ACT*** (with more detailed information and the answers to the most frequently asked questions about palliative care in it along with links to key contacts/resources for further information). Also included in the resource kit is **Booklet 2** written by Peter Hudson, PhD titled ***Supporting a Person Who Needs Palliative Care – A Guide to Family and Friends.*** It includes more detail again about palliative care. A **bookplate** was produced to stick on the front of **Booklet 2**, acknowledging Peter Hudson's willingness to have the book included in the ACT resource kit and drawing attention to ACT specific information/references.

A range of other local information of relevance to palliative care in the ACT is also in the resource kit – e.g., the ACT Cancer Council's Directory of Services, and Centrelink information about entitlements for those caring for someone with a life limiting illness etc.

As well as the **flyer, Booklet 1, Booklet 2** and the other inclusions referred to above, a range of **clinical fact sheets** was also developed by the ACT Palliative Care Reference Group for inclusion in the resource kit on an 'as needs' and 'as appropriate' basis. The clinical fact sheets cover a range of specific palliative care issues in clinical detail. **Examples** of clinical fact sheet topics include:

- Nutrition, appetite changes, weight loss
- Fluids, intravenous and subcutaneous infusions
- Thirst and mouth care
- Bowel care
- Bladder care
- Skin care, pressure areas, bruising
- Sweating, itching, swelling
- Breathlessness

- Nausea and vomiting
- Difficulty with swallowing
- Fatigue and weakness
- Sleep disturbance
- Confusion and restlessness
- Possible complications:
    - living with spinal cord compressions
    - seizures
    - possible haemorrhage
    - hypercalcaemia
- Behavioural changes
- Personality changes
- Intimacy
- Financial considerations
- Bereavement
- Funeral arrangements

Community Education Package

The reference group drew on the newly developed resource kit material when developing the community education package. In addition, other palliative care presentations (local, national and international) were examined and the best features of all of them were taken into account. A significant part of the community education package was drawn from a package developed in Queensland. It was used and modified with permission, and tailored to suit the ACT region. It includes a Power Point presentation that can be adapted and used as an overhead projector presentation, and accompanying handouts. Other inclusions in the community education package include Palliative Care Australia's video ***Palliative Care – More than Just Pain Control*** and flyers from relevant local ACT services, to be used on an 'as needs' and 'as appropriate' basis (depending on the audience, time frame, type of presentation requested etc).

The community education package was trialled on four different community groups during the course of the project. The groups chosen were intentionally diverse in nature. They included a secondary school (Yrs 11 and 12), a group of church carers, a service club, and a general community group. Positive feedback was received from all presentations and refinements to the package were made along the way.

The ACT Palliative Care Society resource kit and community education package are now complete and fully usable[1]. As per the initial grant application, 1000 copies of the resource kit have been produced.

[1] At the time of writing this report the clinical fact sheets were still being printed. They were due to be completed by 31 May 2005.

Enhancing Community Understanding Of Palliative Care

Final Report

Appendix A – Project Plan

ACT Hospice Palliative Care Society
Enhancing Community Understanding of Palliative Care
Project Plan: June 2003 – May 2005

Stage	Goals/Strategies	Target Audience	Activities/Tasks to achieve Goal(s)	Outcomes/Deliverables	Timing	Location	Responsibility
1	Draft a comprehensive, high quality palliative care resource kit.	Carers, consumers, health professionals.	• Review existing package. Identify out of date material and gaps in information. • Establish a focus group(s) to determine level of existing knowledge of palliative care and palliative care services. Identify information needs. • Update existing resource package as appropriate and write new material for inclusion in response to the information needs identified by review of existing kit and focus group(s). • Present draft of new kit to focus group(s) and ACTHPC steering committee, and make any additional amendments/inclusions.	• List of documents to be retained, updated and/or removed from existing kit. • List of new documents, references etc to be written/included in kit. • Summary of focus group feedback including type and level of current knowledge about palliative care and palliative care services, and identified information needs. • A comprehensive draft kit with all relevant inclusions and references, developed in consultation with key stakeholders and interest groups.	July – Dec 2003	Canberra, ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee

1	Develop a palliative care presentation package for use in community education sessions.	Carers, consumers, general public.	• Using material from the draft palliative care resource kit, and taking into account the information needs and interests of the focus group(s), write a presentation about palliative care, palliative care services etc. • Develop different ways/mediums of using the presentation so as to cater for different types of audiences and the availability/non-availability of technology – eg, an overhead presentation, a Power Point presentation, verbal only presentation etc. • Develop hand-outs/fact sheets summarising the information covered in the presentation. • Develop a questionnaire for community education audiences to provide feedback on the usefulness of the presentation.	• A script covering the key aspects of palliative care and palliative care services in the ACT, associated visuals (eg, overheads, Power Point file), and associated hand-outs/fact sheets. • A questionnaire for community education audiences to provide feedback on the usefulness of the presentation.	July – Dec 2003	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
1	Provide external evaluator with relevant project information.	University of Wollongong	• Meet with and provide external evaluator (University of Wollongong) with relevant information for first stage of external evaluation.	• Completion of first part of external evaluation of project.	November 2003	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.

1	Conduct first internal evaluation of project	ACTHPCS	• Evaluate progress and effectiveness of project to date.	• Progress report for the ACTHPC Executive	November 2003	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
1	Provide Department of Health and Ageing with Project Progress Report	Department of Health and Ageing	• Write and forward first progress report to Department of Health and Ageing, incorporating achievements to date, difficulties encountered, immediate project plans, and supporting documentation.	• Progress report for the Department of Health and Ageing.	November 2003	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
2	Trial the ACTHPC draft resource kit and finalise contents.	Carers, consumers, health professionals	• Trial draft resource kit on selected sample of carers, consumers and health professionals (no. and selection of sample to be determined following advice from focus group(s) and ACTHPC steering committee.) • Design and distribute a questionnaire with specific questions about the usefulness of the draft resource kit to trial participants. • Follow up trial participants and seek additional qualitative data if appropriate. • Compile and analyse data/feedback from trial. • Utilise feedback from trial for further refining draft resource kit. • Finalise kit.	• List of comments and recommendations from trial feedback regarding strengths and weaknesses of kit, and suggestions for improvement. • Final version of resource kit.	Jan 2004 – Mar 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.

2	Design and Print resource kit	Carers, Consumers, health professionals	• Engage graphic artist to design/layout kit. • Print kit (1000 copies). • Distribute kit to carers, consumers, and health professionals. • Include in kit a survey form for users seeking feedback on usefulness of kit, suggestions for improvements etc.	• Proofs of kit, refined until complete. • Final version of kit (1000 copies).	Mar 2004 – May 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
2	Provide Department of Health and Ageing with 2nd Project Progress Report	Department of Health and Ageing	• Write and forward second progress report to Department of Health and Ageing, incorporating achievements to date, difficulties encountered, immediate project plans, and supporting documentation.	• 2nd Progress report for the Department of Health and Ageing.	May 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
2	Provide external evaluator with relevant project information.	University of Wollongong	• Meet with and provide external evaluator (University of Wollongong) with relevant information for second stage of external evaluation.	• Completion of second part of external evaluation of project.	May 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee

2	Undertake two community education sessions	General community	• Approach community organisations and offer to provide community education sessions about palliative care (incl service clubs, health related, special interest and general community groups). • Advertise (Canberra Times Public Notices and Northside/Southside Chronicles) availability of palliative care education sessions. • Schedule and conduct two community education sessions. • Develop and distribute questionnaires at community education sessions seeking feedback on usefulness of sessions. • Analyse feedback from community education sessions.	• List organisations interested in community education session. • Schedule community education sessions. • Conduct of two community education sessions. • Collate and evaluate feedback from community education sessions. • Schedule two future community education sessions for Nov-Dec 2004.	May 2004- June 2004	Canberra ACT (one Northside, one Southside)	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
2	Undertake internal evaluation of project.	ACTHPC	• Consolidate and analyse all focus group feedback, data from resource kit trial, feedback from community education sessions. • Incorporate information/data from external evaluation and Department of Health and Ageing feedback.	• Report on effectiveness of resource kit and community education sessions to date, and recommendations for future.	May 2004-June 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.

3	Monitor success of resource kit and act on evaluations.	Carers, consumers, health professionals	• Act on evaluation of survey forms from kits distributed since May 2004. • List recommended enhancements to kit. • Plan update to kit if necessary.	• List enhancements to be made to resource kit and proposed time frame in which to make them.	July 2004 – Dec 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
3	Monitor success of community education sessions and act on evaluations	General community	• Act on evaluation of questionnaires from community education sessions.	• List enhancements to be made to presentation kit and proposed time frame in which to make them.	July 2004 – Dec 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
3	Provide Department of Health and Ageing with 3rd progress report.	Department of Health and Ageing	• Write and forward third progress report to Department of Health and Ageing, incorporating achievements to date, difficulties encountered, immediate project plans, and supporting documentation.	• 3rd Progress report for the Department of Health and Ageing.	November 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
3	Provide external evaluator with relevant project information.	University of Wollongong	• Meet with and provide external evaluator (University of Wollongong) with relevant information for third stage of external evaluation.	• Completion of third part of external evaluation of project.	November 2004	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.

3	Undertake two community education sessions	General community	• Approach community organisations and offer to provide community education sessions about palliative care (incl service clubs, health related, special interest and general community groups). • Advertise (Canberra Times Public Notices and Northside/Southside Chronicles) availability of palliative care education sessions. • Schedule and conduct two community education sessions. • Develop and distribute questionnaires at community education sessions seeking feedback on usefulness of sessions. • Analyse feedback from community education sessions.	• List organisations interested in community education session. • Schedule community education sessions. • Conduct of two community education sessions. • Collate and evaluate feedback from community education sessions.	Nov 2004 – Dec 2004	Canberra ACT (one Northside, one Southside)	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
4	Undertake internal evaluation of Project.	ACTHPC	• Consolidate and analyse all resource kit and community education feedback. • Incorporate information/data from external evaluation and Department of Health and Ageing feedback.	• Report on effectiveness of resource kit and community education sessions to date, and recommendations for future.	May 2005-June 2005	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.

4	Provide Department of Health and Ageing with final report and financial acquittal for project.	Department of Health and Ageing	• Write final report and financial acquittal for project,	• Completion of final project report for Department of Health and Ageing including financial acquittal of project.	May 2005	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.
4	Recommend specific sustainability, capacity building and transferability strategies for the resource kit and community education sessions into the future.	Carers, consumers, health professionals, Department of Health and Ageing, ACTHPC	• Write a list of specific strategies with identified resources for the continued use of the resource kit and community education sessions.	• A list with practical strategies that may be implemented by key stakeholders and interested parties.	June 2005	Canberra ACT	ACTHPC Project Consultant under the guidance of the ACTHPC Steering Committee.