CareSearch: a palliative care resource for rural and remote Australia

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Palliative Care

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

World Health Organisation, 2006
CareSearch *palliative care knowledge network*

- A website that enables access to information and resources
  - For health professionals involved with palliative care as their major role, or as part of their health care role
- **AND** for patients, families and community
Rural and remote needs

- “The challenge to government, as well as specialist and primary health care providers is to identify efficient and effective strategies for the recurrent upskilling of local primary health care team members who provide palliative care” (Reymond et al, 2005)

- “Families described not knowing what their information needs were until a crisis occurred. Lack of information on a range of areas, from practical resources to providing physical care, and managing medications, was problematic” (Wilkes et al 2000)

Reymond L, Charles M, Israel F, Reid. T and Preston P. A strategy to increase the palliative care capacity of rural primary health care providers (2005) Aust J Rural Health 13, 156-61
Rural and remote issues

• Being able to find and access information
  – web-based 24/7
• Recognises locality differences
  – State-based, rural and remote pages
• Diverse problems and solutions
  – Multiple entry points
  – Shared resources for whole community
Searching for Information

- Google
  - ‘Palliative care’ = 4.7 million results
  - 298,000 pages from Australia
- CareSearch
  - Gateway to quality evidence based online palliative care information and resources
Quality processes

• All materials on the website are developed and reviewed by Australian health professionals
  – to ensure that they relate to palliative care
  – that they are trustworthy and reflect the best available evidence
  – Where possible the evidence relates to rigorous research work.
Welcome to CareSearch. CareSearch is an online resource of palliative care information and evidence. All materials included in this website are reviewed for quality and relevance.

What's New... on CareSearch? in the community? in the literature?

Quick Links
Using CareSearch Indigenous GPS ComPAC PCC4U

Introduction to CareSearch Audio Version

Proudly linked to: Flinders University Health Insite

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Rural Palliative Care Program

The Australian General Practice Network (AGPN) managed the pilot National Rural Palliative Care Program (NRPCP) from 2003 to 2006. It was one of a number of initiatives designed to achieve the goals of the National Palliative Care Strategy.

A successful pilot project, implemented in Griffith, NSW (GAPS) led to eight projects with diversity in geography, population, remoteness and palliative care service delivery developing and implementing collaborative models. Projects were able to demonstrate improvement in their rural communities’ access to quality, coordinated palliative care.

Several components of the GAPS model were employed locally in each project:

- Direct care delivery
- Management and use of patient information
- Professional participation
- Governance and management

Formal evaluation of each project and the program as a whole was undertaken by the Centre for Health Service Development, University of Wollongong.

The Department of Health and Ageing also supported the development of a Resource Kit which consolidates the resources that were developed in this program.

The 2008-2010 Rural Palliative Care Project aims to further build upon the successes of the pilot project by resourcing 25 further rural and remote divisions of general practice, or...
For Patients

When you are told you have a life-limiting illness, things change. The focus of care changes from curing a disease to helping you have the best quality of life possible and managing your symptoms.

During this time you may have questions that you want to ask. There may be information that you want to find. There are many things that you can do to help you understand what is happening and be more in control.

These pages are not intended to replace the care or advice of your health professionals. They can help you find information and resources to help you manage better.
For Carers

When someone in your family or one of your friends has an illness that requires palliative care, you may take on the role of carer providing emotional and physical support. As a carer you are helping the person with the life limiting illness manage at home and achieve what they see as important in the time they have left.

Caring for someone with a life threatening illness can be exhausting. Looking after yourself physically and emotionally during this time is important, not only for your sake but for the person you are caring for as well.

In these pages you can find more about palliative care. There are also links to quality information and resources.

The pages are not intended to replace the care or advice of your health professionals. They provide a set of resources that may help you learn more and access materials that could help you manage better.
For Families and Friends

Learning that a family member or a friend has a life-limiting illness and cannot be cured of their disease can be very difficult and upsetting. It can be hard to know how to help and what to say. Often we do not have much experience in talking about death or in dealing with this important part of life.

There are many things we can do as members of the families, friends, neighbours and colleagues to help support the person with the life-limiting illness and their partner or carer.
This section provides information on many palliative care matters. It includes links to disease information, help in understanding financial issues, wills and funerals advice plus information about topics such as complementary therapy. You can use these pages to learn more or to find other resources and contacts.

This page was created on 26 March 2007 and is due for review in March 2008.
Rural and Remote

Contacting Palliative Care Services
If you live in a rural or remote area of Australia, you may find it difficult to find palliative care. Information on palliative care services is available on the Palliative Care Australia website in its [service directory](https://www.palliativecareaustralia.org.au/services). State by state information on services and other resources are available in the CareSearch [State Resources section](https://www.caresearch.org.au/).

You may not be aware that some local health services provide palliative care as well as practical help in country areas. Your GP is also able to help and there is information for GPs on the [CareSearch GP Pages](https://www.caresearch.org.au/gp).

Problems specific to rural Australians

**Depression**
Feeling lonely and isolated sometimes happens in rural and remote areas. Distance can be an issue, and this is especially true if someone has an illness. It can be easy to become depressed. The beyond blue website has [information specifically for people in rural areas](https://www.beyondblue.org.au/roaming-remote-areas).

**Transport**
Travelling to health appointments can be a problem. Each state and territory has a patient transport scheme. The Health Connect website has [information and contact details on these schemes](https://www.healthconnect.org.au/). 

**Managing in rural and remote areas**
The Breast Cancer Network Australia website has a page on [helpful hints and tips](https://www.bca.net.au/living-life-in-cancer-care/rural-and-remote) that can be helpful.
Finding Services

Palliative care will affect all of us at some stage in our lives. This may be as a patient, carer, family member, neighbour or friend. Yet many of us do not have a clear understanding of what palliative care is. When an illness cannot be cured, the focus of care changes to helping patients have the best quality of life possible while managing their symptoms. Palliative care maintains quality of life by addressing physical symptoms such as pain or nausea, as well as helping with emotional, spiritual and social needs.

There are many issues that arise when dealing with a life-limiting illness. These pages provide information and links to resources that may help you.

The pages are not intended to replace the care or advice of your health professionals. They provide a set of resources that may help you learn more and access materials that could help you manage better.

This page was created in December 2007 and is due for review in December 2009.
Clinical applications

• Improve patient outcomes through treatment and practice
  – Literature search for symptom control in a rare condition

• Patient and carer support
  – Direct patients, families and friends to pages that have been specifically written for them, or download relevant resources

• Facilitate evidence-based practice
  – Find information on a clinical symptom such as dyspnoea, and use the associated PubMed searches
PubMed Topic Searches

- PubMed has over 17 million citations that go back to the 1950’s. Narrowing your search to one relevant topic can be difficult and time-consuming
  - 50+ topic searches available
  - Weblinks to saved searches on pages
  - English, palliative care related literature
  - 5 search options per topic (eg, free full text)
  - Quick, real time (always current)
  - Designed to find highest level of evidence
  - Embed evidence and expertise into one click
Appetite Problems

Overview

Loss of weight (cachexia) and appetite (anorexia) are significant concerns for many palliative care patients, and independently predict a poorer prognosis. [1]

The palliative conditions in which cachexia anorexia occurs most frequently are progressive malignancy, HIV/AIDS, end-stage cardiac failure, and stage respiratory failure, chronic renal failure, chronic liver disease, and advanced dementia.

Potentially reversible contributors to appetite problems should be sought and treated as appropriate. These may include:

- Pain
- Nausea
- Depression
- Family, social and cultural expectations related to food, diet, and body weight
- Inappropriate presentation of food
- De-conditioning/reduced level of activity
- Changed sense of taste and smell
- Mouth problems — mucositis, oral thrush
- Malabsorption
- Constipation
- Dyspnoea
Rural & Remote Health PubMed Topic Search

Select one search option for your chosen search topic.

**Free full text only** (likely to reduce the number of results)
- *Strongest evidence* (systematic reviews or randomised controlled trials)
- *Everything*

**All citations**
- *Strongest evidence* (systematic reviews or randomised controlled trials)
- *Everything*
- *Last 3 months only*

This search focuses on rural health populations, hospitals and services.

To choose another topic, go back to [PubMed Topic Searches](#)

This page was created on 20 April 2008 and is due for review in April 2010.
Web Based Learning

Introduction
There are an increasing number of online teaching resources in palliative care. These vary in relation to:

- Their intended audience
- The detail in which content is covered
- Whether they are accredited for use in continuing professional education
- Whether they require registration and/or a fee.

Some are fully developed educational programs with training and self-evaluation activities, some are compendia of teaching materials or PowerPoint slides on relevant topics, and a few are discussion starters.

Modules included on this list have been appraised for the quality of their content, and their relevance for palliative care. If there are other resources that should be included in this list, please contact the CareSearch Team and let us know!

Web based modules by topic

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<tr>
<th>General palliative care approach and philosophy</th>
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<tr>
<td>NHPCO Audio Web Seminars</td>
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| General palliative care approach and philosophy | NHPCO Audio Web Seminars  
CancerNursing.org  
Cleveland Clinic Center for Continuing Education  
CLIP 15 Minute Online Tutorials  
Dying Well Discussion Guide  
EndLink - Resource for End-of-Life Care Education  
EPERC Fast Facts  
Hospice Manager Development Program  
National Association of Social Workers Web Ed |
| Pain management                      | CancerNursing.org  
Centre for Palliative Care Education - HIV Education Modules  
CLIP 15 Minute Online Tutorials  
Complementary and Alternative Medicine  
Online Continuing Education Series  
Web-based Training Opportunities in Pain  
EndLink - Resource for End-of-Life Care Education  
EPERC for Geriatrics  
EPERC Fast Facts  
Pain Management - The Online Series  
Topics in Pain Management - A Slide Compendium |
| Symptom management                   | The Centre for Palliative Care Education HIV Education Modules  
CLIP 15 Minute Online Tutorials  
Complementary and Alternative Medicine  
Online Continuing Education Series  
EndLink - Resource for End-of-Life Care Education  
EPERC Fast Facts  
Multidisciplinary Training in Psycho-Oncology |
| Communication and end-of-life decision making | Centre for Palliative Care Education HIV Education Modules  
CLIP 15 Minute Online Tutorials  
Dying Well Discussion Guide  
EndLink - Resource for End-of-Life Care Education  
EPERC for Geriatrics |
Aboriginal Health Workers

Working as an Aboriginal Health Worker in palliative care

> An article from the Department of Health & Ageing [Palliative Care for Aboriginal and Torres Strait Islander People](http://www2.health.gov.au) magazine describes what it is like working in palliative care.
> The [Aboriginal & Islander Health Worker Journal](http://www.aihw.gov.au) provides Aboriginal and Torres Strait Islander Health Workers with up to date and relevant health information.
> Two Aboriginal Health Workers wrote about their role in an article for the Medical Journal of Australia called [The Aboriginal Health Worker](http://www.aihw.gov.au).

Information on courses
There are different ways to develop your knowledge and skills in palliative care. Web-based learning modules, short courses and specialist palliative care courses are offered in many organisations and universities. Further information can be found in the Education pages of CareSearch.

The [Program of Experience in the Palliative Approach (PEPA)](http://www.aihw.gov.au) is an initiative under the National Palliative Care Program. It is a supported multidisciplinary course with work placements offered across Australia and it is funded until 2010. An article about the Program of Experience in the Palliative Approach and Aboriginal Health Workers called [Learning about the palliative approach](http://www.aihw.gov.au) may be of interest.

A [Cancer Care Course](http://www.aihw.gov.au) is available in central and southern Queensland for Aboriginal and Torres Strait Islander Health Workers.
About CareSearch

CareSearch is an online resource consolidating evidence-based and quality information for various groups within the palliative care community. The website has been funded by the Australian Government as part of the National Palliative Care Program.

A series of principles have guided the development of the CareSearch project.

- Evidence from development to application; the knowledge translation cycle
- Multidisciplinary
- Broad concept of palliative care community (those providing and those affected)
- Granularity - many needs, many points of entry, many ways of communicating
- Quality processes - evidence for activity not merely content
- Currency - Updatable processes
- Relationship between the print and web page so they can function independently as sources of information.

This project is a work in progress that reflects the changing nature of palliative care needs and practice and the underlying evidence and literature base that supports clinical care and service delivery.
Indigenous Summary

There is information on the CareSearch website that may be of relevance and interest to Aboriginal and Torres Strait Islander people and to those who are looking after them.

This information is not displayed within the one area, but can be found across the website in different sections. This information can be found in the following areas:

What is Palliative Care?
In this section there is information under the heading of ‘National Palliative Care Program’, The Indigenous Palliative Care Project gives information on the development of the Providing culturally appropriate palliative care: Aboriginal and Torres Strait Islander Resource Kit.

For patients and Families
In this section for consumers, information is available under the ‘Specific groups’ heading. The Indigenous page gives information on family, Aboriginal Health Workers, traditional medicine and a brochure that has been developed specifically for Indigenous Australians about palliative care.
News and Updates

- What’s new on CareSearch
- What’s new in the community
- What’s new in literature
- @CARESEARCH
- Register for page alerts
Using CareSearch

• Print ready pages for patients, families
• Leaflets available for use in your practice
• Create your own PubMed topic search
Summary

• Importance of evidence in practice
• Online resources are increasingly being used to disseminate information / evidence and to find information by both clinicians and consumers
• Play safe: CareSearch provides a resource for trustworthy and current information
CARESEARCH
Evidence-based information to palliative care

Health professionals and nurses face new challenges each day with regard to an ever-expanding information base and the requirements for accountable and effective practice. Patients, their families and carers have difficulties in finding relevant and validated information regarding their health and care. Without appropriate and timely access to these resources can be more complicated due to the complex care needs and specific wishes of those with a life-limiting illness.

To assist patients and families with their decision-making pertaining to their health care, this evidence-based information needs to be accurate. However, as in the past, there are many thousands of sources of information available. Individual families and professional groups can vary significantly. It is better for people to find relevant, quality, informative resources.

A new palliative care resource

The Project of Health and Ageing has funded work to help clinicians, patients and families find palliative care services and information. There are websites, information and resources that can be accessed through a wide range of websites.

The Project’s resource is a web-based resource that is designed for health professionals to assist in providing quality, evidence-based palliative care. It is also for health professionals who are interested in palliative care.

The materials that are included are:

- Rationales pages: The materials include over 200 topics, including pages for specific groups of care. There are also pages, information and resources that can be accessed through a wide range of websites.

- Resources for palliative care literature are provided, as well as information on cancer research papers to palliative care as a specialist.

- Education: Options for formal qualifications and information regarding conferences and short courses are made available. It also links to a wide range of evidence-based learning resources.

- Research: Data Management System: an online system enabling data entry from anywhere in the world, and research management with a single query is possible.
CareSearch would like to thank the many people who contribute their time and expertise to the project including members of the National Advisory Group and the Knowledge Network Management Group.

CareSearch is funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program.

www.caresearch.com.au