CareSearch: a palliative care resource for all

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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
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.
Evidence based approach

• An evidence based approach is one that looks to the evidence to answer clinical and service related questions, using the best available evidence to do so
  • About Evidence section
  • Finding, appraising, applying, generating and communicating evidence
  • Reduce evidence-practice gaps
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

What is Palliative Care For Patients and Families Finding Services
Clinical Practice Finding Evidence Education
Research Resources Professional Groups About CareSearch

Proudly linked to:

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

This page was last updated on 26 May 2008.
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.

"New life always begins again after loss. The twenty-one little white flowers represent the days I spent in Daw House with my grandmother. This painting was inspired by the love and friendship which grew during that time."
Implementation Phase

Providing culturally appropriate palliative care: Aboriginal and Torres Strait Islander Resource Kit Project

Implementation Phase (2004-2006)

To ensure that the Resource Kit and the delivery of any training and education associated with this project reflected the needs of Aboriginal and Torres Strait Islander peoples in each jurisdiction, the Australian Government, through the National Palliative Care Program, provided funds to each state and territory government to locally tailor the Resource Kit to meet the needs of the Aboriginal and Torres Strait Islander communities within their jurisdiction. Details on the specific projects can be found on the State and Territory projects page. In addition funds were provided to Wodonga Institute of TAFE to provide a co-ordinating and supporting role to state and territory project officers.

During the implementation phase over 3000 copies of the Resource Kit were distributed nationally. During this period Wodonga Institute of TAFE produced a number of additional resources to support project officers. These resources included:

- Posters and pamphlets to promote the Resource Kit
- A Facilitator’s Guide
- Power point presentation
- A Resource Directory

Facilitator’s Guide (79kb pdf doc)
State Information

Providing culturally appropriate palliative care: Aboriginal and Torres Strait Islander Resource Kit Project

Summary of State and Territory projects

In recognition that many Aboriginal and Torres Strait Islander peoples had little understanding of palliative care services and how services could support communities in providing care to people with a life-limiting illness, additional funds were provided to jurisdictions specifically to raise awareness of palliative care within Aboriginal and Torres Strait Islander communities.

Whilst individual jurisdictions approached the implementation of the Resource Kit differently, all approached the project with the common objective of improving the provision of quality, appropriate palliative care that is responsive to the needs of Aboriginal and Torres Strait Islander peoples.

The following is a brief summary of the activities, approach and resources developed by some of the states and territories:

- Australian Capital Territory
- New South Wales
- Northern Territory
- South Australia
- Victoria
- Western Australia
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.

This page was created on 26 March 2007 and is due for review in March 2009.
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.

This page was created on 26 March 2007 and is due for review in March 2009.
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 2009.
Indigenous

It is important that Aboriginal and Torres Strait Islander people are able to get the palliative care that they need. This can involve support from the Indigenous community, Aboriginal community controlled health services (ACCHS), mainstream health professionals, and palliative care specialists. It is important that these groups work together in a way that best meets the needs of people requiring palliative care.

Family and community
Family and community are a very important part of life. Not all health professionals will know who is important to you or who they should talk to about your illness. It may help if you could tell your nurse or doctor about your family.

Aboriginal and Torres Strait Islander Health Workers
Aboriginal and Torres Strait Islander Health Workers have an understanding of the culture and traditional ways of Indigenous people. They can work with palliative care services to care for Indigenous people. Health Workers can also support families arrange supports from non-Indigenous nurses or doctors.

Traditional medicine
Many people use traditional medicines, and may also see traditional healers. This is part of culture and tradition and is recognised as such. Getting support from traditional healers, as well as Aboriginal and Torres Strait Islander Health Workers, nurses and doctors may be helpful.

When someone is very ill
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. State by state information on services and other resources are available in the CareSearch State Resources section.

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.

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.

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.

Managing in rural and remote areas
The Breast Cancer Network Australia website has a page on helpful hints and tips that can be
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.
Indigenous

The Aboriginal and Torres Strait Islander people are a diverse group of peoples, made up of many different nations and language groups. We acknowledge that past policies have had very negative impacts on these peoples. Despite this, the Australian Indigenous people are strong, richly diverse peoples. Aboriginal and Torres Strait Islander culture is a living culture, made up of both contemporary and traditional peoples.

When talking about how to provide palliative care for Indigenous Australians, it is important to look to the context in which many Aboriginal and Torres Strait Islander people are living today. Indigenous people are less like to live to an old age than other Australians, with higher disease rates for diabetes, cardiovascular disease and cancer. Australian Indigenous HealthInfoNet has a page providing a summary of Australian Indigenous health.

The circumstances of Aboriginal and Torres Strait Islander people impacts on how they view the world, and how they interact with others and with themselves. Learning more about Indigenous culture and history may help to understand the principles for practising in a culturally appropriate way, in conjunction with the other information and resources provided here.

Issues for Aboriginal and Torres Strait Islander people

There are substantial barriers for many Aboriginal and Torres Strait Islander people in accessing services, such as difficulty with communication and a lack of understanding by non-Indigenous service providers. This is often made more difficult with a lack of trust of
Using CareSearch in practice

The question is how could you use this site?

- Students
- Nurses working in the clinical setting
- Educators
- Researchers
- Aboriginal and Torres Strait Islander Health Services
- Patient, Carers and Family
Using CareSearch in practice

The Future?

- Information in different languages
- Information with Audio
- Information in a video content
How can you inform the site?

How can you inform the Site?

- Feedback on content
- Inform CareSearch about
  - palliative information, resources and research.
Indigenous 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

Indigenous Health = Health care provided to specific cultural or tribal peoples which incorporates local customs, beliefs, and taboos. (Source: MeSH Thesaurus). This search specifically includes the Oceanic Ancestry Group, i.e., individuals whose ancestral origins are in the islands of the central and South Pacific, including Micronesia, Melanesia, Polynesia, and traditionally Australasia. (Source: MeSH Thesaurus)

To choose another topic, go back to PubMed Topic Searches

This page was created on 30 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 compendiums 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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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' magazine describes what it is like working in palliative care.

> The Aboriginal & Islander Health Worker Journal 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.

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) 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 may be of interest.

A Cancer Care Course 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.
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 - Summary

- Print ready pages for patients, families
- Leaflets available for use in your practice
- Refer colleagues to the website
- 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
Quote

“Information is a source of learning. But unless it is organized, processed, and available to the right people in a format for decision making, it is a burden, not a benefit.”

William Pollard
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