CareSearch: an online palliative care resource to support oncology practice

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Palliative Care

- Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organisation, 2006).
- Oncology nurses describe key aspects of palliative care as a core part of their professional practice (Pavlish and Ceronsky, 2007).

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
Online Resources

- The internet should be regarded as an important tool in the suite of evidence-based resources that nurses use (Estabrooks et al 2003)

- In this age of technology, the internet is increasingly becoming an important source of information for patients (Penson et al, 2002)


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

• HonCode, Health\textit{Insite}
• 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.

• CareSearch identifies and enables access to evidence relevant to palliative care
  – Content pages follow described search method
  – PubMed topic searches
  – Systematic Review Collection
  – Grey Literature provides access to other otherwise unavailable literature (theses and conference abstracts).
Evidence based approach

• CareSearch encourages use of evidence
  – There is a section on Finding Evidence with the PubMed searches enabling immediate access to the literature and evidence.
  – There is a section on Using Evidence

• Used evidence in the design and development of the website
  – Research from IT, education and psychology
  – Physical design of the pages – how people scan webpages
  – How pages were worded and presented
Finding Evidence

These pages are designed specifically for health professionals. They look at the role, nature and sources of evidence and the application of evidence in practice.

While patients and families may find helpful information here, more tailored links are available, such as Topic Information and Finding Out More in the Patients and Families pages.
Is it Trustworthy?

The Internet has become a very important source of health information for consumers. However not all of this information is reliable. Sometimes dangerous or misleading advice can be given. Information on the web is not controlled like much printed material can be. When using the web you will need to use your own common sense about the value of the information you find.

Several projects have looked at the indicators of what makes a good website. The most common things to look for are:

1. A clear statement of what it is about and why it was developed
2. Easily identifiable and credible authors
3. A 'Contact Us' option
4. Balanced information supported with references or links to other sites
5. Information that has been written or updated recently
6. A site that is well presented and easy to navigate
7. Clear distinction between information and advertising.

Finding out more

> Healthinsite's How to Assess Health Information Online
> Medical Library Association's Medical Information on the Internet: Guide for Health Reporters and Consumers

Related CareSearch pages
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 PCG4U

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
Content Pages

• 300 pages on palliative care topics
• Sections for consumers and for health professionals
• Subject to quality review processes
  – Each page is reviewed twice initially (NAG, clinicians, academics, researchers, peak bodies, national organisations)
  – Each page has formal peer review, usually by an expert in that field
Links and Resources

• Connecting to more information
• Page hyperlinks
• Summary sets of resources
  • Finding services
  • State information
  • Disease resources
  • Indigenous
• Finding out more
• Evaluated for quality and relevance
What is Palliative Care?

Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. However, many of us do not understand what palliative care is.

When an illness can not 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.

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 useful materials.
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.
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 page was created on 26 March 2007 and is due for review in March 2009.
Topic Information

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.
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
PubMed Topic Searches (cont’d)

– 5 search options per topic - free full text only (strongest evidence, everything) OR all citations (strongest evidence, everything, last 3 months)
– Quick, real time (always current)
– Designed to find highest level of evidence
– Embed evidence and expertise into one click
Fatigue

Background
Fatigue is an extremely common problem amongst palliative care patients and causes significant distress, but our understanding of its natural history and causes is still evolving. [1] A systematic review of symptoms in patients with advanced cancer indicated that over half of the patients studied experienced fatigue. [2] It is likely that the presence and intensity of symptoms increases as the disease progresses. The negative impact on quality of life of patients and their caregivers is substantial. [1] The prevalence of fatigue is likely to be similar in patients with other progressive chronic diseases, including HIV/AIDS, heart disease, chronic obstructive pulmonary disease, and renal disease. [3] Guidelines for the management of cancer related fatigue are developing. [4] although few studies have included patients with fatigue associated with advanced disease.

Fatigue: the palliative context

> Advanced cancer
> End stage chronic disease
> HIV/AIDS

Important contributing factors
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, end-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
Anxiety

Overview
Anxiety is estimated to occur in up to fourth fifths of patients diagnosed with cancer or AIDS, one third with heart disease, and two thirds of those with chronic obstructive pulmonary disease or with renal disease. [1] It can be a natural response to impending death, but may result from other untreated conditions or symptoms.

Anxiety: the palliative context

- Untreated pain
- Untreated or poorly managed symptoms
- An underlying anxiety disorder (e.g. panic disorder, phobia)
- Fear of death
- Family distress
- Drug induced

Important contributing factors

- Previous psychiatric history
- Alcohol and nicotine dependence
- Long term benzodiazepine use
- Loss of control — real or perceived
**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**

<table>
<thead>
<tr>
<th>General palliative care approach and philosophy</th>
<th>IH-PCO Audio Web Seminars</th>
</tr>
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<tbody>
<tr>
<td>CancerNursing.org</td>
<td>Cleveland Clinic Center for Cancer Education</td>
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<td>Topic</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  
EPEC 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  
EPEC for Geriatrics |
Professional Groups

Palliative care within Australia is provided by many different health professionals in a variety of health settings and in the community. Health professionals have different types of involvement with palliative care. For some, palliative care is a small but ongoing part of their practice. Others may have an intermittent involvement depending on the needs of their individual patients. For others, palliative care is their area of professional responsibility.

Many different disciplines and professional groups contribute to palliative care individually and as part of multidisciplinary care teams. These pages provide access to resources and literature relevant to the practice of palliative care for the individual professional group. They have been developed either in association with professional bodies or by individual practitioners from that area.
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 - Updateable 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
In recognising that patients will probably search for information in the media and the internet, pre-emptive measures to ensure they find appropriate, reliable resources and have assistance interpreting information may reduce the risk of inaccurate information causing distress to themselves and their families (Newnham et al, 2005)

Newnham GM, Burns WI, Snyder RD, Dowling AJ, Ranieri NF, Gray EL and McLachlan S-A (2005) Attitudes of oncology health professionals to information from the Internet and other media MJA 183: 197-200
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 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