CareSearch: THE palliative care knowledge network

Deb Rawlings, CareSearch Project
¹Jennifer Tieman, ¹Deb Rawlings, ²Rosemary Cooper

¹Australian Knowledge Network Project
Department of Palliative & Supportive Services, Flinders University

²Palliative Care Nurses Australia, KN National Advisory Group
Nurses and the Internet

It has been shown that over 85% of nurses use a computer for some aspect of their work, with over 49% accessing the internet for clinical use (ANF, 2007)

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)


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
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 GP's ComPAC PPC4U

Proudly linked to:
Flinders University Health Insite

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

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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
Evidence based approach

• Website design and development
  Research from IT, education and psychology
  • Physical design of the pages – how people scan web pages
  • How pages are worded and presented
Searching for Information

• Google
  – ‘Palliative care’ = 4.7 million results
  – 288,000 pages from Australia

• CareSearch
  – Gateway to quality evidence based online palliative care information and resources
PubMed Topic Searches

• 17 million citations going back to the 50’s. Narrowing your search to one relevant topic can be difficult and time-consuming
  • 50+ topic searches available
  • English, palliative care related literature
  • Quick, real time (always current)
  • Designed to find highest level of evidence
  • Embed evidence and expertise into one click
PubMed Topic Searches

Follow these links to run real-time PubMed searches. They give you a broad entry point into the relevant English, palliative care related literature. When you select a topic, different search options will be provided.

**Patient problems**
- Airway Obstruction
- Anxiety
- Appetite
- Artificial Nutrition
- Bereavement
- Bowel Obstruction
- Cachexia (Weight Loss)
- Constipation
- Cough
- Delirium
- Depression
- Dyspnoea
- Existential Distress
- Fatigue
- Haemoptysis
- Nausea
- Pain
- Respiratory Infections
- Sexuality
- Sleeping Problems

**Specific groups**
- Aged
- Aged Care Facilities
- Carers (all)
- Carers (young)
- Dementia
- Disabled
- Homeless
- Indigenous Health
- Multicultural
- Paediatrics
- Rural & Remote Health

**Issues relating to care & treatment**
- Advance Care Planning
- Advance Directives
- Audit
- Complementary Therapies
- Dignity
- Euthanasia
- Family Distress
- Models of Service Delivery
- Multi-disciplinary Teams
- Palliative Sedation
- Patient Education
- Professional Burnout
- Resuscitation Orders
- Social Support
- Spirituality
- Terminal Care
- Volunteering
CareSearch Review Collection

This collection provides an easy way to find reviews on topics relevant to palliative care. It is dynamic and will change over time as new reviews are released. Our method for selecting reviews for inclusion is described in the Procedures page. This collection should not replace your own personalised search for systematic reviews on a particular topic. Users need to assess the quality of the individual reviews for their own purposes.

To submit details of a review which meets the CareSearch criteria for inclusion email caresearch@flinders.edu.au

Care Issues
Anorexia cachexia
Anxiety
Bereavement
Bowel
Breathing
Cognition
Constipation
Cough
Delirium
Depression
Dysphagia
Dyspnoea
End-of-life
Existential Distress
Fatigue
Fluids
Grief

Specific Populations
Aged
Carers
Children
Dementia
Families
Intellectual disability
Multicultural
Pediatrics
Patients
Rural and remote

Health Professionals
Chaplains
General Practitioners
Nurses
Occupational Therapists
Social Workers

Service / System Issues
Advance Care Planning
Advance Directives
Communication
Complementary Therapies
Decision making
Desire for hastened death
Economics
Education and training
Effectiveness
Ethics
Models of Service Delivery
Needs assessment
Organ donation
Outcome measures
Patient care training
Policy
Population issues

Font size A A A
Print page:
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

> HealthInfothe'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
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
  - Content pages follow described search method
National Palliative Care Program

Introduction

The National Palliative Care Program is funded by the Australian Government to improve access to, and quality of, palliative care services in Australia. The Program has been developed within the goals of the National Palliative Care Strategy agreed by the Australian Health Ministers’ Advisory Council in 2000.

The program has funded a variety of initiatives relating to four broad priority areas.

Support for patients, families and carers in the community

Families can experience an enormous burden caring for someone dying at home. Helping communities to provide practical support and measuring knowledge, awareness and understanding can alleviate some of this burden. The following major projects are currently underway or recently concluded:

- Caring Communities Program
- Indigenous Palliative Care Project
- Rural Palliative Care Program
- Local Palliative Care Grants

Increased access to medicines in the community

The use of medicine can help in the management of symptoms and maintaining quality of life. Ensuring access to medicines that achieve this purpose will support palliative care. The following major projects are continuing:
Clinical applications

Improve patient outcomes through treatment and practice

Scenario:
- A patient with intractable hiccups
- Search the literature via the palliative care filter for evidence to support practice
Create Your Own PubMed Topic Search

While the topics offered by CareSearch offer you quick and efficient entry into the palliative literature, you may be interested in a different topic. These instructions will help you restrict your own topic to the palliative literature. We suggest that you print these instructions to work from.

Instructions
Step 1: Run the palliative filter now
Step 2: CLEAR the search box
Step 3: Enter your topic search, select GO
Step 4: CLEAR the search box
Step 5: Select the HISTORY tag, identify the set numbers for Steps 1 and 2
Step 6: CLEAR the search box
Step 7: Combine the set numbers by typing in, eg, #1 AND #2, select GO

Example
Let’s say you are interested in anything to do with 'narrative' in the palliative care context. A useful keyword for this concept might be 'narrative', and the correct MeSH term is 'narration'.

Step 1: Run the palliative filter
Step 2: CLEAR the search box
Step 3: Enter the terms narrative OR narration, select GO
Step 4: CLEAR the search box
Step 5: Select the HISTORY tag, identify the set numbers for Steps 1 and 2
Step 6: CLEAR the search box
- Search History will be lost after eight hours of inactivity.
- Search numbers may not be continuous, all searches are represented.
- To save search indefinitely, click query # and select Save in My NCBI.
- To combine searches use #search, e.g., #2 AND #3 or click query # for more options.


#0 PubMed clipboard

19:01:27


Clinical applications

- Patient and carer support
  - Direct patients, families and friends to pages that have been specifically written for them
  - Download relevant resources to hand out, helping facilitate conversations
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.

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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 funeral advice plus information about topics such as complementary therapy. You can use these pages to learn more or to find other resources and contacts.

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Clinical applications

Facilitate evidence-based practice

Scenario:

• A patient presents with severe dyspnoea
• Different approaches to treatment
• Which is best practice?
  – Nebulised morphine
  – Oxygen
• Take best evidence and use to support discussions
Dyspnoea

Dyspnoea (shortness of breath) is described as ‘an uncomfortable awareness of breathing’. [1] It is a subjective symptom which may not correlate with measurable physical abnormalities such as hypoxia. Treating the dominant cause of breathlessness, including the contributing co-morbidities, is likely to be most effective, but is not always possible.

Shortness of breath becomes more frequent in patients as their disease progresses, [2] is associated with a poorer prognosis, [3] and is usually multifactorial in patients with advanced disease.

What is known

Evidence supports the use of either oral or parenteral opioids for relieving the symptom of dyspnoea. There is no evidence to support the use of nebulised opioids, however. [4]

A recent meta-analysis has shown that oxygen does not improve symptoms of dyspnoea in cancer patients who are mildly or non-hypoxaemic, although there may be a sub-population who do experience benefit. [5] A systematic review found no strong evidence for the benefit of oxygen in patients with dyspnoea and advanced disease from any cause, although the numbers studied were very small. [6]

If drainage of a malignant pleural effusion is required and is clinically appropriate, evidence supports the effectiveness of thorascopic talc pleurodesis. [7]

Research from small trials supports non-pharmacological interventions including
Education opportunities for others

• Provide CareSearch packs at in-service
• Find an article to present at journal club
• Download information to take to RACF
Nurses

These pages provide access to resources and literature relevant to the practice of palliative care for nurses.

Role in palliative care

The Palliative Care Nurses Australia (PCNA) website has information on palliative care nursing. The Macmillan Cancer Support website provides information on the role of Macmillan nurses, who specialise in improving the lives of people with cancer in the United Kingdom (UK).

Several peak bodies have recognised the role of nursing in palliative care provision.

> The Royal College of Nursing Australia has a position statement on the role of the nurse in palliative care

> The Hospice and Palliative Nurses Association of America has a position statement on the Value of Advanced Practice Nurse in Palliative Care which has been endorsed by the American Nursing Leaders (2002) as a document Advanced Practice Nurses role in Palliative Care. They also have position statements on the roles of nursing assistants and the professional nurse in end-of-life care.

The following are competencies for specialist palliative care nurses:

> The PCNA website has the Competency Standards for Specialist Palliative Care Nursing developed by the Centre for Palliative Care Research and Education (Queensland)
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.
Education opportunities for others

Scenario

• On average GP’s see only 3 – 5 palliative patients per year
• You worry that they may not have up-to-date resources
• Direct them to the GP pages
GP Resources

Palliative Care Australia
Peak body for palliative

ANZSPM (Australian New Zealand Society of Palliative Medicine)
Professional association for medical practitioners working in palliative care

Online reference books

- Palliative Medicine Handbook
- Manual of Palliative Care
  The IAHPC Manual of Palliative Care 2nd ed. online. International Association of Hospice and Palliative Care; 2008
- WHO Cancer Pain Release
  Online journal WHO Pain & Palliative Care Communications Program; 2008

Downloadable publications (PDFs)

- Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer
  National Health & Medical Research Council; 2005
- Clinical Practice Guidelines for communicating prognosis and end-of-life issues with adults
  Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. 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
Education opportunities for yourself

• Find University courses, short courses, web based learning modules

• Get the latest evidence to support your study
<table>
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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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<td>CancerNursing.org</td>
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<td>Cleveland Clinic Center for Continuing Education</td>
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<td>CLIP 15 Minute Online Tutorials</td>
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<td>Dying Well Discussion Guide</td>
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<td>EndLink - Resource for End-of-Life Care Education</td>
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<td>EPERC Fast Facts</td>
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<td>Hospice Manager Development Program</td>
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<td>National Association of Social Workers Web Ed</td>
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<td>Web-based Training Opportunities in Pain</td>
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<td>Topics in Pain Management - A Slide Compendium</td>
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<td>EPERC for Geriatrics</td>
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News and Updates

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