Palliative Care – strengthening relationships, accessing resources through CareSearch

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Palliative care – what, who, where

- **What** – non curative phase of disease (e.g. end stage care, symptom control)
- **Who** – people with cancer, end stage organ failure, other end stage diseases
- **Where** – palliative care units, oncology units, general wards, surgical wards, private/public hospitals
OT & Palliative Care

- Majority of OTs won’t work in a specialist palliative care unit
- Many palliative patients aren’t in specialist units
- Palliative patient needs
  - physical, psychosocial, emotional, spiritual
- What is the role of OT with palliative patients?
OT & Palliative Care

• “Providing comfort and providing opportunities to experience a sense of control and helping patients adapt to losses are some of the key features of OT in hospice” (Rahman, 2000)

• “Therapy allows concentration on elements of care within the scope of practice, empowers the family and patient, diminishes anxiety, decreases the incident of injury and most important, restores dignity” (Frost, 2001)


Accessing resources

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

OT SIG Palliative Care Survey

- Victorian OT Oncology & Palliative Care SIG surveyed via CareSearch Research Data Management System (RDMS)
- 11 responses to the online survey
  - Variety of work settings (onc hosp, general acute hosp, community pall care, inpt pall care)
  - FTE (40%), 0.1 to 0.4 FTE (20%), 0.5 to 0.9 FTE (40%)
  - 80% did not feel there was enough education to help develop their practice as an OT in onc/palliative care
OT SIG Palliative Care Survey

• Priority areas for skills development on scale of 0 to 6 (10 responses only)
  – symptom management – (80% scored 5 or 6)
  – understanding lymphoedema in pc (80% scored 4 or 5)
  – understanding neuro management & assessment in pc (60% scored 5 or 6)
  – pressure care (60% scored 5 or 6)
  – self care for practitioners (60% scored 5 or 6)

• 90% of respondents use online resources to support their practice
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.
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.

Quick Links
Using CareSearch
Indigenous GPS
CompAC
PCC4U

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

What is Palliative Care
For Patients and Families
Finding Services
Clinical Practice
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About CareSearch

Proudly linked to:

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This page was last updated on 26 May 2008.
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:

- Caring Communities Program
- Indigenous Palliative Care Project
- Rural Palliative Care Program
- Local Palliative Care Grants.
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.
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 28 March 2007 and is due for review in March 2008.
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.
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.
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 and anorexia occur 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
Clinical scenario

• You are an OT in a rural area, working with a lady who has advanced disease
• She appears unrealistic about her future, not acknowledging she is deteriorating & dying
• She does not want to see any other health professionals, but is happy that you come to visit her as she sees therapy as a way of helping her to get better
• How could CareSearch help you to help her?
Clinical scenario

• Looking at the literature would help to understand the issues
• CareSearch patient and carer pages contain information that would help you work through difficult issues with her. These include:
  – Understanding what’s happening
  – Changes over time
  – Difficult conversations
  – Feelings and emotions
- 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.

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 textword 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
A reliability and validity study of the palliative performance scale.

Pstrang N, Barker C, Humphreys K.


Mastropietro CW, Clark JA, Dohre PE, Walters HL 3rd, Sarnak AP.

Arginine vasopressin to manage hypoxemic infants after stage I palliation of single ventricle lesions.

Ryvatt FP, Feustner C.

Call for Papers: Palliative Care, Dying, and Bereavement

Centers for Medicare & Medicaid Services (CMS), HHS
1: Klager J, Ducett A, Sandler S, Moskowitz C
Huntington's disease: a caring approach to the end of life.
PMID: 1601087 [PubMed - in process]

2: Paralp S, Trost MR
Communication issues at the end of life: reports from hospice volunteers.
PMID: 18469581 [PubMed - in process]

3: Gepp JG, Meyker S, Mooney NE, Lyon C, Faco R, Julliard K
Provider Insights About Palliative Care Barriers and Facilitators: Results of a Rapid Ethnographic Assessment.
PMID: 18526750 [PubMed - as supplied by publisher]

4: Claxton-Olfield S, Claxton-Olfield I
Some common problems faced by hospice palliative care volunteers.
PMID: 18442862 [PubMed - indexed for MEDLINE]

5: Jones SL, Beck E
1. **Zimmermann C.**
   Death denial: obstacle or instrument for palliative care? An analysis of clinical literature.
   PMID: 17381818 [PubMed - indexed for MEDLINE]

2. **Colombo S.**
   Grief in facing one's own mortality: denial and loneliness.
   PMID: 16229396 [PubMed - indexed for MEDLINE]

3. **Zimmermann C.**
   Denial of impending death: a discourse analysis of the palliative care literature.
   PMID: 15279932 [PubMed - indexed for MEDLINE]

4. **Stephenson PS.**
   Understanding denial.
   PMID: 15378099 [PubMed - indexed for MEDLINE]

5. **Zimmermann C, Rodin G.**
   The denial of death thesis: sociological critique and implications for palliative care.
   PMID: 15046408 [PubMed - indexed for MEDLINE]

6. **Rousseau P.**
   Death denial.
   J Clin Oncol. 2003 May 1;21(9 Suppl):32s-33s. No abstract available.
   PMID: 12743193 [PubMed - indexed for MEDLINE]
I Don’t Know What to Say

Learning that someone you know has a terminal illness can be confronting. It may make you think about your own life and how you will one day face the thought of dying. You may also be worried about what to say and what not to say. You may feel uncomfortable being with someone who is obviously unwell. If you have already experienced the loss of a loved one this may affect how you are feeling now.

You need to remember that there is no proper or right thing to say. Being there and being willing to listen is the most important thing you can do. The Cancerbackup website has a section on Talking to someone with cancer which provides information on how to help and support them. The Hospice Net website provides some advice on Helping a friend who is dying.

Over time you may find that you will talk about different things. As their illness progresses, they may talk less or find it difficult to have people come and visit. The disease or treatments for the disease may change their mood or personality. Don’t take things personally and remember that the carer may still need company and support. The Capital Health website provides an outline of some of the changes that may happen and how to continue to be involved in The Final Journey.

It can also be difficult when somebody has died. It is important to acknowledge what has happened and to not try and ignore it.
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>NHPCO Audio Web Seminars</th>
</tr>
</thead>
<tbody>
<tr>
<td>CancerNursing.org</td>
<td>Cleveland Clinic Center for Continuing Education</td>
</tr>
<tr>
<td>Topic</td>
<td>Resource</td>
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<tr>
<td>--------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Symptom management</td>
<td>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</td>
</tr>
<tr>
<td>Communication and end-of-life decision making</td>
<td>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</td>
</tr>
</tbody>
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Occupational Therapists

These pages provide access to resources and literature relevant to the practice of palliative care for Occupational Therapists (OTs).

Role in palliative care
This information will help you to find out more about working in palliative care. It may include narratives from those working in the area, descriptions of the role, or identify why the position is important:

- The Sacred Heart OT Service in NSW have defined their role within palliative care
- Calvary Healthcare, Bethlehem (specialist palliative care service) have information on their website about Occupational Therapy in their organisation
- The Cancer Council of NSW and the Peter MacCallum Oncology Hospital in Victoria define the roles of OTs.

Several peak bodies have recognised the role of OT in palliative care:

- OT Australia encourages service providers to adopt the Australian 'Standards for providing quality palliative care to all Australians' on a voluntary basis
- The Canadian Association of Occupational Therapists position statement (2005) on Occupational Therapy and end-of-life care can be found on their website
- The College of Occupational Therapists in the UK has a document that may be of interest – 'Occupational therapy intervention in cancer – guidance for professionals, managers and decision makers'
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

- 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
• Valuable resource for OTs working with palliative patients in specialist or non-specialist settings
• 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