Working Together: Palliative Care Resources for General Practice

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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
Health professional needs

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

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
Searching for Information

• Google
  – ‘Palliative care’ = 4.7 million results
  – 298,000 pages from Australia

• What will you find?
  – Personal blogs?
  – Drug company sponsored sites?
  – No assurance of quality
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
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...
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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.
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.
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.
Patient and carer needs

“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)

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 caregiver providing emotional and physical support. As a caregiver 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-limiting 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.
People with Dementia

Dementia is not a single disease, but a range of diseases. It affects brain function. This can result in difficulty with language, memory, personality, the way in which information is processed, and activities of daily living. The most common type of dementia is Alzheimer’s disease.

Issues common to people with dementia who require palliative care

Planning in advance

Advance care planning is a process that helps you to make decisions about your future health care. It is usually done in consultation with your healthcare providers, family members and other important people in your life.

An Advance Care Plan, or Advance Directive, is one way of putting this plan into writing. It needs to be done when you are well, and before you can no longer make decisions for yourself. A written Advance Care Plan can help those providing care for you to know what...
# Northern Territory

These links help you to practical support or services in Northern Territory (NT), or to put you in touch with support groups.

## Palliative care organisations

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td><strong>Department of Health and Families</strong></td>
<td>Top End 08 8922 6761, Alice Springs 08 8951 6762</td>
</tr>
<tr>
<td><strong>Palliative Care Australia</strong></td>
<td>Freecall: 1800 660 055</td>
</tr>
</tbody>
</table>

## Carers support and respite

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td><strong>NT Carers Association</strong></td>
<td></td>
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<tr>
<td><strong>Young Carers Australia - Northern Territory</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Commonwealth Carer Respite Centres</strong></td>
<td>Freecall: 1800 059 059</td>
</tr>
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</table>

## Health services

<table>
<thead>
<tr>
<th>Service</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carers Australia</strong></td>
<td>Information sheets on dealing with hospitals</td>
</tr>
<tr>
<td><strong>Northern Territory Community Care Centres</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Health Ombudsman</strong></td>
<td>Phone: 1800 806 380</td>
</tr>
</tbody>
</table>
Clinical applications

• Facilitate evidence-based practice
  – Find information on a clinical symptom such as dyspnoea, and use the associated PubMed searches
  – Also look at SR collection
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-hypocaemic, although there may be
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@finders.edu.au

Care Issues
- Anorexia
- Cachexia
- Anxiety
- Bereavement
- Bowel
- Breathing
- Cognition
- Constipation
- Cough
- Delirium
- Depression

Specific Populations
- Aged
- Carers
- Children
- Dementia
- Families
- Intellectual disability
- Multicultural
- Paediatrics
- Patients
- Rural and remote
Clinical applications

• Improve patient outcomes through treatment and practice
  • Eg, a patient with intractable hiccups
    – No related PubMed search
    – Nothing in CareSearch review collection
    – How to find information?
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
Palliative Care Filter

- 50+ topic searches available
- Weblinks to pages
- English, palliative care related literature
- 5 search options per topic (e.g., free full text)
- Quick, real time (always current)
- Designed to find highest level of evidence
- Embed evidence and expertise into one click
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. You can follow the steps below or print out the illustrated guide "How to Create your Own PubMed Topic Search".

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'.

Instructions
Step 1: Select the CareSearch link: Run the palliative filter now
Step 2: CLEAR the search PubMed 'for' box
Step 3: Enter your topic search, eg, narrative OR narration, select GO
Step 4: CLEAR the search PubMed 'for' box
Step 5: Select the PubMed HISTORY tag
Step 6: Identify the 'set numbers' for Steps 1 and 2 (eg, #1 AND #2)
Step 7: Combine the 'set numbers' by typing them in the PubMed search 'for' box, eg, #1 AND #2, select GO
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 NCEI.
To combine searches use #search, e.g., #2 AND #3 or click query # for more options.

Search:

#1 Search advance care planning[mh] OR attitude to death[mh] OR bereavement[mh] OR terminal care
[journal] OR (advance care plan*[text word] OR attitude to death*[text word] OR bereavement*
{text word} OR terminal care*[text word] OR life support care*[text word] OR terminally ill*[text word]
AND English[lang]

#7 Search #2 AND #5 AND #6


intractable hiccups


4: Takahashi T, Miregawa I, Mizu T, Takano R, Nakashima I, Fujihara K, Tobita M, Itoyama Y
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.
Gabapentin for intractable hiccups in palliative care.
PMID: 18292481 [PubMed - indexed for MEDLINE]

Reversal effect of electroacupuncture on the symptom of intractable hiccups in hepatitis B virus carriers.
PMID: 18230122 [PubMed - indexed for MEDLINE]

Midazolam for long-term treatment of intractable hiccups.
PMID: 15791172 [PubMed - indexed for MEDLINE]

PMID: 15728315 [PubMed - indexed for MEDLINE]

Management of hiccups in the palliative care population.
PMID: 12692688 [PubMed - indexed for MEDLINE]

Successful treatment of intractable hiccups with methylphenidate in a lung cancer patient.
PMID: 12550943 [PubMed - indexed for MEDLINE]
Clinical applications

• Patient and carer support
  – Direct patients, families and friends to pages that have been specifically written for them
  – Download relevant information yourself to help facilitate conversations
Advance Care Planning

What is Advance Care Planning?

Advance care planning is about documenting your wishes. Having conversations about your wishes can help your family and friends make important decisions when you are no longer able to do so. You also need to tell your health professionals that you have a plan, or you may wish to discuss your choices with them when writing it. The process includes appointing a Medical Power of Attorney and making a statement of choices. The Respecting Patient Choices Program is a program to support advance care planning in Australia.

The Consumers Health Forum has a brief article on Advance Care Planning that explains some of the terms and issues.

What is an Advance Directive?

An Advance Directive is a legal document that provides guidance for medical and healthcare decisions. It is very similar to an Advanced Care Plan. Advance Directives can tell the doctors that you don't want certain kinds of treatment (such as life support), or that you do want a certain treatment no matter how ill you are (such as antibiotics). With an Advance Care Plan or Advance Directive in place, your wishes are more likely to be understood and taken into account in decision making.
Resources for Advance Care Planning

Communication resources
Practical guidance for approaching discussions of advance care planning with patients and families, and for teaching the relevant communication skills, is available at the [End of Life Palliative Education Resource Centre](http://www.endoflife.org), a US website which provides peer reviewed, one-page outlines of key information on end-of-life clinical topics for educators and clinicians. Follow the links to Fast Facts and look at the listings under Communication and Ethics. An approach to dealing with conflict about end of life decisions is provided in the NSW document [Guidelines for end-of-life care and decision making (2005)](http://www.health.nsw.gov.au/croh/guidelines/endoflife/endoflife.pdf).

The US organisation Growth House has provided online extracts of the book [Handbook for Mortals: Guidance for People Facing Serious Illness](http://www.growthhouse.com/resources/Handbook_for_Mortals/) by Joanne Lynn. This can be used to give simple language explanations for patients and their families about the kinds of procedures involved in end of life medical interventions, and the implications of choices to accept or refuse treatment.

Links to State legislation
Each state has different arrangements for advance care planning. The following links
Short Courses

Short courses related to palliative care are detailed below. Please contact the relevant institution for further information on these palliative care short courses. If you are running a short course that you would like added to this list, please contact us at CareSearch@flinders.edu.au

October 2008

<table>
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<tr>
<th>Title</th>
<th>Management of Advanced HIV Disease (osh6pdf.doc)</th>
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<td>Date</td>
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</tr>
<tr>
<td>Institution</td>
<td>Sacred Heart Palliative Care &amp; Rehabilitation Services</td>
</tr>
<tr>
<td>Location</td>
<td>Darlinghurst, NSW, Australia</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:depl@stvincents.com.au">depl@stvincents.com.au</a></td>
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<tr>
<td>Telephone</td>
<td>(02) 8382 9441</td>
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<td>Date</td>
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<tr>
<td>Institution</td>
<td>Banksia Palliative Care Service</td>
</tr>
<tr>
<td>Location</td>
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<td>Email</td>
<td><a href="mailto:learningcentre@banksiapalliative.com.au">learningcentre@banksiapalliative.com.au</a></td>
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<tr>
<td>Telephone</td>
<td>(02) 8487 3100</td>
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## Web-based modules by topic

<table>
<thead>
<tr>
<th>Category</th>
<th>Modules</th>
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<tbody>
<tr>
<td><strong>Aged care issues</strong></td>
<td>Complementary and Alternative Medicine Online Continuing Education Series</td>
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<td>Dementia Education Online</td>
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<td></td>
<td>EPEC for Geriatrics</td>
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<td></td>
<td>Nursing Home End-of-Life Care</td>
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<td><strong>Communication and end-of-life decision making</strong></td>
<td>Centre for Palliative Care Education HIV Education Modules</td>
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<tr>
<td></td>
<td>CLIP 15 Minute Online Tutorials</td>
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<td></td>
<td>Dementia Education Online</td>
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<td></td>
<td>Distress management training for oncology nurses</td>
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<tr>
<td></td>
<td>Dying Well Discussion Guide</td>
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<td></td>
<td>EndLink - Resource for End-of-Life Care Education</td>
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<tr>
<td></td>
<td>EPEC for Geriatrics</td>
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<tr>
<td></td>
<td>EPERC Fast Facts</td>
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<td>Frontline Psychosocial Support</td>
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<tr>
<td></td>
<td>Ian Anderson Continuing Education Program in End-of-Life Care</td>
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<tr>
<td></td>
<td>Multilingual core curriculum in psycho-oncology</td>
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<tr>
<td></td>
<td>National Association of Social Workers Web Ed</td>
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<tr>
<td></td>
<td>Strengthening Cancer Care: Psychosocial support module</td>
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<tr>
<td><strong>General palliative care approach and philosophy</strong></td>
<td>Cancer 101 for mental health professionals</td>
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<tr>
<td></td>
<td>CancerNursing.org</td>
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<tr>
<td></td>
<td>Cleveland Clinic Center for Continuing Education</td>
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<tr>
<td></td>
<td>CLIP 15 Minute Online Tutorials</td>
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</table>
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
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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.
GPs and Palliative Care

• Although palliative medicine has developed as a specialty, the likelihood of all care being taken over by specialists is remote. GPs will continue to be key providers of palliative care for patients who die in the community.

• Patients are best served in community palliative care when the general practice is part of a team approach.

Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. 2002. 16: 457
• On average GP’s see only 3 – 5 palliative patients per year
• It is difficult to keep up-to-date with evidence and resources
• Go to the GP pages
Pain and Symptom Management

Palliative care practice is evolving rapidly. The following resources offer up-to-date advice:

- **Palliative Medicine Handbook**: Online book giving detailed, evidence-based prescribing advice. Well referenced, with links to published guidelines where these exist. To use, connect to the site and click on Notes on Prescribing. Note that this handbook was written in the United Kingdom, and some medications listed may not be available in Australia.

- **Therapeutic Guidelines - Palliative Care**: Follow the link to order a copy or pay for online registration. Not freely available. This is the best available Australian consensus document on management of...
Palliative Care in Aged Care Facilities

Nursing homes are frequently a site of care for people who are dying. There are some particular challenges in providing good quality palliative care for patients in residential aged care facilities. Palliative Care Australia has guideline resources for managing palliative care in aged care facilities and is a current focus of palliative care policy and service development.

Tips for improving pain management for your nursing home patients

1. Communicate your concerns regarding pain with a nursing supervisor; discuss how to maximise opportunities for (a) pain assessment and (b) provision of timely feedback to you for medication changes. Review with the nursing supervisor the facility’s method of pain assessment documentation and standards for pain assessment and treatment.

2. Write an order for a registered nurse to do a complete pain assessment on a regular
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Bereavement Counsellors
Dietitians
Doctors

General Practitioners

> Assessing Prognosis
> Pain and Symptom Management
> Effective Communication
> Practical Skills
> Opioid Information
> The Dying Patient and Their

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; 2006
> WHO Cancer Pain Relief
Online manual WHO Pain and Palliative Care Communications Program; 2018
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 Australia. 2007;186(12 suppl):S77-S100

- Medical Care of Older Persons in Residential Aged Care
  RACGP Medical Care of Older Persons in Residential Aged Care Facilities: the Silver Book 4th ed. Royal Australian College of General Practitioners; 2005

- Guidelines for a Palliative Approach in Residential Aged Care

- Pain in Residential Aged Care

- Multicultural Palliative Care Guidelines
  Taylor A, Box M. Multicultural palliative care guidelines Palliative Care Australia; 1999

- Providing culturally appropriate palliative care to Indigenous Australians
  Providing culturally appropriate palliative care to Indigenous Australians: resource kit Commonwealth of Australia 2004

- Palliative Care Service Development
  A Guide to Palliative Care Service Development: A population based approach Palliative Care Australia; 2005

Full-text articles and documents for downloading (PDFs)
Full-text articles and documents for downloading (PDFs)

- Until the chemist opens: palliation from the doctor's bag

- Managing comorbidities at the end of life

- Analgesic choices in persistent pain
  Analgesic choices in persistent pain Prescribing Practice Review No 35 National Prescribing Service 2006

- Buprenorphine
  Buprenorphine transdermal patches (Norspan) for chronic severe pain RADAR Review National Prescribing Service December 2005

- Fentanyl
  Fentanyl patches (Durogesic) for chronic pain RADAR Review National Prescribing Service October 2006

- Opioid conversion chart
  Information for Health Professionals, Calvary Health Care Bethlehem

- The Use of "As Needed" PRN Range Orders for Opioid Analgesics in the Management of Acute Pain - American Society for Pain Management Nursing and American Pain Society Consensus Statement 2004

- Palliative Care Special Edition
  Australian Family Physician October 2005 - Palliative care Vol 35, (10) 753 - 832

- Issues in palliative care for indigenous communities

- Schwarz Center Rounds

Schwarz Center Rounds
A set of articles in The Oncologist looking at ethical, psychosocial and human aspects of end-of-life care

Patient Management Resources

- **EPERF Fast Facts** (US)
  Succinct evidence-based summaries of issues related to clinical, communication and decision making aspects of end of life care
- **Australian Centre for Grief and Bereavement**
- **Advance Care Plans**
  RACGP webpage including state information, resources and links
- **CISCaT**
  Australian website for detailed information about cancer treatment protocols
- **Coping with Cancer**
  Supportive care information from the National Cancer Institute in the US

Education and Support for Practitioners

- **Online training on opioids**
  Information on how to access via Rural and Remote Medical Education Online (RRMEO) or the elearning website - a module from Palliative Care Australia
- **Communication with Patients and Families** (Canada)
  An online education module
- **Chapter in Palliative Medicine**
  Information about specialty training in palliative medicine for GPs
- **PEPA** (Program of Experience in the Palliative Approach)
  Information about a program enabling palliative care placements for GPs
Support services for doctors

Other palliative care links and resources

- [Cause of Death Certification](#) (Australian Bureau of Statistics)
- [Centre for Palliative Care Research and Education](#) (Aust)
- [Gold Standards Framework](#) (UK) for provision of palliative care in the community
- [Liverpool Care Pathway](#) (UK) for information about end-of-life care pathways used in the National Health Service

Complete list of assessment tools

Routine use of symptom assessment tools can greatly improve the quality of care. They allow regular documentation and monitoring of symptoms, and of the effectiveness of treatment.

Valicated tools which can be easily used by GPs include:

**Pain assessment tools**

The Partners against Pain website has a series of useful pain scales including

- [Visual Analogue Scale](#)
- [Pain Faces Scale](#) is a pain scale for children
- [Memorial Pain Assessment Card](#)
- [Brief Pain Inventory](#) can be used for a more detailed pain assessment

The Dementia Care Australia website provides access to the [Abbey Pain scale](#), which can be used for assessment of pain in patients with dementia who cannot verbalise.

**Other Assessment Tools**

The Centre to Advance Palliative Care has a series of useful tools including
Aboriginal Health Workers

Working as an Aboriginal Health Worker 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 2019. 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.
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.


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

[Image: Nature's New Beginning]
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
www.caresearch.com.au
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