



KNOWLEDGE NETWORK PROJECT DAW HOUSE 700 GOODWOOD ROAD DAW PARK SA 5041

# The Australian Palliative Care Knowledge Network

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CareSearch Project

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## Knowledge, evidence and practice

- Improve patient outcome through treatments and care practices (e.g. drugs or procedures)
- Develop and improve services (e.g. palliative care service or diabetes community nurse)
- Support equity and access to healthcare (e.g. special needs groups)

Presumes that we have access to and use relevant information and evidence

## Issues relating to evidence and palliative care

- Palliative care is an emerging discipline
  - Multidisciplinary base
  - Different care providers and site of care
  - Patient and family as unit of care
  - Bereavement, grief and loss
  - Transitions and movements
- Evidence development can be difficult
  - Historical and social barriers to doing research with death and dying
  - Lack of a research culture, infrastructure
  - Funding difficulties
  - Clinical load of staff
  - Methodological considerations

## What is CareSearch?

- A website, a project and a resource for those involved in providing palliative care
- Funded by Department of Health and Ageing
- “One stop” shop for palliative care information, evidence and resources
- Website as both a product and an entry point
- Designed for those providing palliative care and those affected by palliative care.



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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.

### For Patients, Carers, Families & Friends

Palliative care will affect all of us at some stage in our lives as a patient, carer, family member, neighbour or friend. The following resources may help.

*For Patients  
For Carers  
For Families & Friends  
State Based Resources  
National Palliative Care Program*

### For Health Care Providers

There are different disciplines and individuals involved in providing palliative care. These resources provide information and resources for health care professionals.

*General Practitioners  
Health Care Providers  
Education and Training  
National Palliative Care Program  
PubMed Searches*

### For Researchers and Palliative Specialists

Palliative care researchers and palliative care specialists may benefit from a range of specific resources and tools including:

*Non-indexed Database  
Finding Evidence  
Research and Grants  
PubMed Searches  
Research Data  
Management System  
Conferences  
Care Providers*

- QUICK LINKS**
- GP pages
  - Patients & Carers
  - PubMed Palliative Care Searches
  - CareSearch eNews
  - Project News
  - Indigenous Resources



**What's new on the site...** CareSearch promotional materials... Indigenous Resources... [click for more](#)

**What's new in the Palliative Care Community...** Communicating prognosis guidelines...NHMRC National Statement Information Sessions ... [click for more](#)

**Have you heard?...** CareSearch visitor numbers and community feedback

By using this site you are agreeing to the terms and conditions of this site

The CareSearch website and the Australian Palliative Care Knowledge Network project are funded by the Australian Government Department of Health and Ageing

## Behind the website: Quality processes and research

- Needs assessment
- Governance structures
- Quality manual
- Knowledge translation approaches
- Formative and summative evaluation program

## Sections in the current website

- National Palliative care program
- Patients and carers
- Non-indexed databases
- Finding evidence
- Research and grants
- Care providers
- Education
- Forums



PATIENTS, CARERS, FAMILIES & FRIENDS

- PATIENTS
  - Understanding palliative care
  - Your health care team & you
  - Living with illness
  - Having difficult conversations
  - Being prepared for end-of-life decisions
  - Feelings & emotions
  - Your carer & family
  - Are things changing?
  - At the end

CARERS

FAMILIES & FRIENDS

USEFUL INFORMATION

DO YOU NEED HELP NOW?

Patients

Having a life limiting illness changes things. The focus of care changes from curing a disease to helping patients have the best quality of life possible while managing their symptoms. There may be questions that you want to ask and to have answered. There may be information that you want to access. There are many things that you can do to help you understand what is happening and be more in control.

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.

The following pages have been written specifically for patients.

- *Understanding palliative care*
- *Your health care team and you*
- *Living with illness*
- *Having difficult conversations*
- *Being prepared for end-of-life decisions*
- *Feelings and emotions*
- *Your carer and family*
- *Are things changing?*
- *At the end*

**& FRIENDS INTRODUCTION****PATIENTS****CARERS**[What do carers do](#)[Communicating well](#)[Looking after yourself](#)[Practical caring matters](#)[Disability stickers](#)[Transport issues](#)[Patient care resources](#)[Financial considerations](#)[Respite and support](#)[Caring at the end](#)[Bereavement](#)**FAMILIES & FRIENDS****USEFUL INFORMATION**

## Help when caring at home

Nursing an ill person at home creates over time, a mini-hospital atmosphere. You will be helped by your health team with the delivery of various types of equipment. This can help make your ill family member feel more comfortable and equally importantly, help you care more safely and easily. It is important for you to continue to keep talking with your health team, especially about the most useful equipment for your situation.

While services differ from state to state and region to region, a surprisingly wide variety of help is often available – from local councils, local hospitals, regional community and health centres, Cancer Councils and various local voluntary bodies. This can include the loan of equipment and other practical items. Many of these services can be found in the [National Resources](#) and [State Resources](#) pages.

There may also be volunteer help from people who have been through your experience. They can be part of the local hospice or palliative care service.

## Medicines and patient care

For those with a serious illness, [managing medicines](#) is an important task. There are many products now available at the local pharmacy. It is also possible that, with a GP script, they may count towards your [PBS entitlements](#). Members of the health team can assist with this matter.

There are also online resources that can help you with practical aspects of [patient care](#).

## Transport

Even when patients are seriously ill, they benefit from specialist medical review in the clinic setting. Over time, access may become difficult. Consider getting a [disability sticker for motor vehicles](#). This will allow you to park in special parking bays near your medical clinic.

There are also [transport issues](#) that can be investigated.

## Financial Costs



## EDUCATION

Conferences

Short courses

Formal university qualifications

Web based learning modules

## Web based learning modules

### 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

#### General palliative care approach and philosophy

- [Audio Web Seminars](#)
- [Cancernursing.org online courses](#)
- [Cleveland Clinic Center for Continuing Education](#)
- [CLIP 15 minute online tutorials](#)
- [Dying Well discussion guide](#)
- [EPERG Fast Facts](#)
- [Hospice Manager Development Program](#)
- [National Association of Social Workers Web Ed](#)

#### Pain management

- [Cancernursing.org online courses](#)
- [Centre for Palliative Care education HIV education modules](#)
- [CLIP 15 minute online tutorials](#)
- [Core curriculum for professional education in pain](#)
- [EPEG for Geriatrics](#)
- [EPERG Fast Facts](#)
- [Pain Management - the online series](#)
- [Topics in Pain Management - a slide compendium](#)

#### Symptom management

## FINDING EVIDENCE

### DATABASES & INFORMATION SOURCES

- Bibliographic & evidence databases
- Full text journals
- Links to lists of databases & sources
- Subscription based databases

### SEARCH STRATEGIES

- PubMed palliative care searches
- PubMed General searches
- Validated palliative care search

- Ovid Medline version
- PubMed version

### Ovid Medline searches

### GUIDE TO SEARCHING EFFECTIVELY

- Developing a search strategy
- Textword searching
- How database subject indexing works
- Combining searches
  - combining searches example
- Palliative care subject headings
- Samples searches
- Searching tips for bibliographic databases

## PubMed palliative care searches

These searches are designed to give you immediate access to subject-specific literature available in PubMed. When you select a search, PubMed retrieves current citations from the biomedical literature databases maintained by the National Library of Medicine. **(See NCBI disclaimer and copyright notice)**

Typically searches use 1-2 key medical subject headings and text words, and are restricted to palliative care. Eight different search variations per subject are available to help you explore the literature. A sensitive search is a broad search, whereas a specific search is narrower. All searches have been restricted to English language, and to humans.

They are a good starting point but they are not comprehensive, and have not been validated. After searching, always check the PubMed 'details' tag on the screen to verify that you are satisfied with the approach taken. You can then modify the search if required. Some searches may currently yield zero results, but this should change over time as new citations are added to PubMed.

Search Topic	Retrieve References	Retrieve References Restricted to Free Full Text Only	Systematic Reviews Only <sup>1</sup>	Systematic Reviews Restricted to Free Full Text Only	RCTs Only <sup>2</sup>
<b>Advance Directives</b>	<i>Sensitive</i> <i>Specific</i>	<i>Sensitive</i> <i>Specific</i>	<i>Systematic Review</i>	<i>Systematic Review</i>	<i>Sensitive</i> <i>Specific</i>
<b>Anorexia</b>	<i>Sensitive</i> <i>Specific</i>	<i>Sensitive</i> <i>Specific</i>	<i>Systematic Review</i>	<i>Systematic Review</i>	<i>Sensitive</i> <i>Specific</i>
<b>Bereavement</b>	<i>Sensitive</i> <i>Specific</i>	<i>Sensitive</i> <i>Specific</i>	<i>Systematic Review</i>	<i>Systematic Review</i>	<i>Sensitive</i> <i>Specific</i>

## NON-INDEXED DATABASE

Search the literature database

Understanding the evaluation schema

Evaluator login

Non indexed journals

Grief Matters

Social Networks

Frequently Asked Questions

## Search The Literature Database

### Search the Literature Database

The literature database comprises four sections:

- Journal articles: Abstracts of articles from 12 palliative care journals that have not been indexed in the major electronic databases
- Conference abstracts: Abstracts from Australian conferences from 1980 that deal with issues in palliative care
- Theses: Masters and PhD theses from Australian universities that deal with issues in palliative care
- Grey Literature: Government documents, policy and research reports from agencies involved with palliative care.

Keywords Or Phrases:

Boolean Logic

Fields To Search:

Title  Author  Abstract  Keywords  ALL

Order By:

Date  Author  AbstractID  Title

Publication Year:

From:  To:

Type Of Literature:

Journal Article  Conference Abstract  ALL  
 Thesis  Government Grey

Search

Clear

Back

## CareSearch and OSWA – Now

- Patient and carer pages (useful info by state)
- Page in health professional groups
- Include abstracts on non-indexed databases- palliative relevant theses, conference abstracts,
- Research activities – access to RDMS, research register

## CareSearch and OSWA – future

- Geographically distributed virtual communities
- Consolidating specialist literature and policy
- Discipline specific communications and also from discipline to clinical community communications
- Capacity building through education, networks
- Cooperative base consumers and health professionals

## Acknowledgements

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