CareSearch: Supporting Nurses in Primary Healthcare

This event is part of the Quality Use of CareSearch Project.

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

• Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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
Nurses and Palliative Care

- Palliative care patients at the end of life will often spend the majority of their time at home.

- Many would also like to die at home.

- When at home they will usually be cared for by a GP, by community nurses or by nurses in RACF
Nurses and Palliative Care

• Practice nurses will often come into contact with patients requiring palliative care
  – Over 70’s healthchecks
  – In clinics

• Patients requiring palliative care are sometimes obvious and sometimes not
  – Not all cancer
  – What about dementia, end-stage heart failure, disabling stroke, MS, Parkinsons’?
The Quality Use of CareSearch Project

• Created to help people to use CareSearch (palliative care website) well

• CareSearch can be useful to Practice Nurses

• The information provided here can be shared with colleagues within the local DGP
Quality Use of CareSearch

• The website has over 900 pages

• It can be difficult to know what is there and/or how to find it

• The Quality Use of CareSearch project is about using CareSearch well
Quality Use of CareSearch

- A set of resources has been developed, which can be ordered (CD)
  - Train the trainer
  - Power point modules (intended as ‘stand-alone’) with notes
  - Fact sheets
  - A hospital liaison kit

- A Training & Support pack provides further information
Quality Use of CareSearch

• A travelling road show is underway
  – Resources provided (including CD)
  – Targeted to audience (eg, selected modules)
  – Disseminate information on the website and the QU project/resources
  – Evaluation
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)

• 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)


The Web is an unregulated environment
- Anyone can create a website
- Unlike journals, websites and webpages may not have a peer review process
- The information may be outdated
- The information may be moved or removed without notice
Health Information on the internet

- Google alone reports 150 million searches per day:
  - If even 1 or 2% of these are health related searches…
  - There are many thousands of health-related websites
  - A search on the internet can return thousands of possible matches
  - It may also return many irrelevant items
“palliative care”

- Google “palliative care”
  - 9.8 million results
  - 665,000 (pages from Australia)
Quality processes

• All materials on the website are developed and peer reviewed by Australian health professionals to ensure:
  – that they relate to palliative care
  – that they are trustworthy and reflect the best available evidence
  – that 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 is CareSearch?
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
PubMed Searches
GP Hub
Conferences
Nurses[HUB]

VPCNPC

Proudly linked to:

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This page was created on 26 May 2008. This website was last updated on 19 November 2010
CareSearch *palliative care knowledge network*

- There for everyone (publically available)
- There when you need it (24 hours a day)
- There at no cost (FREE)
  - no cost to access web pages
What is CareSearch?

- Sometimes called *palliative care knowledge network*

- A website that enables access to information and resources

- A project to help move evidence to practice

- Funded by the Australian Government
What is CareSearch?

- Sometimes called *palliative care knowledge network*
- A website that enables access to information and resources
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- Funded by the Australian Government
Who is it for?

- Those providing care: specialist palliative care, other specialties, primary care
- Multidisciplinary care
  - E.g, palliative medicine trainees, practice nurses, allied health, volunteers
- Provided in many settings
- Provided by many agencies
Information written for Nurses

Information to help in the management of palliative care patients in the community, with information on:

- Clinical
- Areas of practice
- Research
- Education
- Policy, standards, quality
- Nurses providing palliative care
Nurses[HUB] news

Monthly e-newsletter
6 times a year the newsletter features:
• Case scenario
• Nurse in the spotlight
• Clinical uses
• Evidence-based practice
Information written for GPs

Information to help in the management of palliative care patients in the community, with information on:

- patients needing palliative care
- managing symptoms
- making it work in your practice
- the dying patient
- following up the bereaved, and
- professional development.
GP pages

• On average GP’s see only 3 to 5 ‘palliative patients’ per year

• In actual fact this number is much larger

• Direct them to the GP pages
GP Home

Patients Needing Palliative Care
- Discussing Palliative Care
- Monitoring Prognosis
- Advance Care Planning
- When to Refer

Managing Symptoms
- Opioids and Pain
- Important Skills
- Support for Carers
- Managing Emergencies
- Specific Populations
- If Patients and Families Aren't Coping
- Complex Problems

Making It Work In Your Practice
- Medicare Information
- Prescribing Issues
- Home Visits
- In Residential Aged Care
- For Rural GPs
- Continuity of Care

The Dying Patient
- Helping You Support Families
- State by State Requirements

Following up the Bereaved
- When to Refer (Bereaved)

Professional Development
- Self Care

Resources
- GP Resources (All by topic)
- Printable Patient and Carer Resources

PubMed Search: General Practitioners
Free full text only
- Strongest Evidence
- Everything
- All citations
- Strongest Evidence
- Everything
- Last 3 months

Review Collection
- General Practitioners

What's New!
- Complementary and Alternative Medicine edition
- Cancer Forum March 2011
- eviOpioid Calculator
- Conversion calculator helps to manage patients on opioids.
Who is it for?

- Those working in other areas of Palliative Care: Academics, Students, Researchers, Policy Makers
  - Information and resources on the National Palliative Care Program Projects
  - Research resources
Who is it for?

- Those receiving care
  Patients, carers, families, community
  - Can affect anyone at any time
  - Patient and family as unit of care
  - Specific section for Patients and Families (Patient and Family pages have a different readability level to clinical pages)
Online Resources

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

• We need to be ready for this

Palliative Care

• Palliative care will affect most people at some stage whether as a patient, carer, family member, neighbour or friend.

• Patients and carers are often unprepared for living with illness or for the care giving experience.
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)
Information written for Patients & Carers

- Direct patients, families and friends to pages that have been specifically written for them
- Download relevant information to help facilitate conversations
What is CareSearch?

- Sometimes called *palliative care knowledge network*
- A website that enables access to information and resources
- A project to help move evidence to practice
- Funded by the Australian Government
Evidence into Practice

- Rapidly developing and expanding knowledge base
  - Many disciplines contribute to literature and evidence

- CareSearch can help:
  - Find research evidence
  - Content based upon evidence
  - Helps apply evidence to practice
CareSearch: Introduction to the sections within the website
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.

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This page was created on 26 May 2000. This website was last updated on 16 August 2010

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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
  - For patients, carers, families and community
CareSearch *palliative care knowledge network*

- **There for everyone** (publically available)
- **There when you need it** (24 hours a day)
- **There at no cost** (FREE)
  - no cost to access web pages, but there may be costs associated with more comprehensive use of the Research Data Management System
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About CareSearch

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This page was created on 26 May 2008. This website was last updated on 16 August 2010.
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 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.

The role of palliative care within Australia is described in Understanding Palliative Care. The National Palliative Care Program provides an overview of the Australian Government's national initiatives in this area since 2000.

Specific information for patients, carers, families and friends can be found in the For Patients and Families section. Health professional information can be found in Clinical Practice and Professional Groups.

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.
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What's New...
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For Patients and Families

Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. The sections below will take you to detailed information and resources.

### About Palliative Care
What is palliative care and why is it important?

### Living with Illness
Information on living with illness, and changes over time.

### How to Care
Information on the practical things that can help daily life.

### At the End
What happens when someone is nearing the end of life?

### Bereavement, Grief, Loss
Information on how to manage after someone has died.

### Groups with Specific Needs
Some groups have specific needs such as older or homeless people.

### Finding Out More
Learn more about how to search for quality information.

### Do you need help now?
Contact numbers if you need help now.

This page was created on 26 May 2009 and is due for review in May 2011.
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Finding Services

Proudly linked to:
Flinders University
HealthInsure
HON certified

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This page was created on 26 May 2008. This website was last updated on 16 August 2010
# Western Australia

Use these links to find practical support or services in Western Australia (WA), or to put you in touch with support groups.

| Polliative care organisations | Polliative Care Australia Freecall: 1800 660 055  
Palliative Care WA Phone: (08) 9212 4330 |
|-------------------------------|--------------------------------------------------|
| Carers support end respite    | Australian Red Cross Freecall: 1800 059 059  
Carers WA  
Commonwealth Respite and Carelink Centre Ph: 1800 052 222  
Young Carers Australia - Western Australia |
| Health services               | Carers Australia: [information sheets](#) on dealing with hospitals  
Health Ombudsman Freecall: 1800 813 583  
Home and Community Care (HACC) Program  
Kimberley Area Health Services Directory  
Regional Community Health Services provide palliative care. [Links to an alphabetical listing by location of Community Health Services]  
WA Health Services Directory call the Department of Health's information line Phone: 1300 135 030 |
| Information and advice        | Commonwealth Respite and Carelink Centre Ph: 1800 052 222  
Kids Help Line Freecall: 1800 551 800  
Legal Aid - WA  
Lifeline Phone: 13 11 14  
Public Trustee of WA |
| Equipment and supplies        | Independent Living Centre WA  
Palliative Care Equipment Program provides equipment loans to families. For more information about the program and how to access equipment, contact Palliative Care WA Inc, Phone: (08) 9212 4330 |
| Transport and travel          | Accessible public transport in WA  
Aural Flight Australia - Coordinator can arrange flights for patients who are in need of visits to other areas of Australia |
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.
Clinical Practice

Palliative care as a specialist health field draws upon a multidisciplinary body of evidence to support its practice. These pages are designed to support clinical practice by summarising the state of the evidence and by providing clinicians with access to relevant literature where possible.

There are sets of pages relating to the following areas:

- **Physical symptoms:**
  Information on the evidence relating to the assessment and management of common symptoms such as fatigue, breathing problems, pain and nausea.

- **Psychological, social and spiritual issues:**
  Comprehensive care needs to recognise psychological, spiritual and social care and support.

- **Patient Considerations:**
  Issues such as Advance Care Planning and Complementary Therapies

- **Professional and Service Issues:**
  Issues relating to service provision and professional practice.

- **Carers and Families:**
  Information for health professionals on carer and family considerations.

- **Diseases and Conditions:**
  Evidence relating to some of the underlying diseases and conditions of palliative care patients that may influence aspects of their care.

- **Specific Populations:**
  Provides information about a range of groups such as those with dementia, Aboriginal and Torres Strait Islander people and Paediatric patients.

The content for these pages has been developed following a search of multiple literature.
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

- Anemia
- Cachexia and nutritional deficiencies
- Dyspnea
- Hypothyroidism, hypogonadism, adrenal insufficiency
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Proudly linked to:

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This page was created on 26 May 2008. This website was last updated on 16 August 2010
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.

The Palliative Care PubMed Searches and the CareSearch Review Collection are efficient ways of accessing the palliative care literature base quickly.

The CareSearch Grey Literature is a database of "hard to find" literature that includes, "unpublished" and non-indexed palliative care information from within Australia.

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.

This page was created in May 2008
Last updated 4 May 2009
Communicating Evidence

There is increasing recognition of the need to make sure that research findings are not only made available but are actually used. Traditionally, findings have been published in peer reviewed journals at the completion of a study. However, the diversity of potential uses for, and users of, the evidence may not be fully served by a single strategy of journal publication.

Planning to disseminate and communicate progress and findings is becoming part of the research cycle although the most effective strategies are still unclear. [1, 2] The Cochrane Library includes several reviews on communication strategies such as the use of local opinion leaders [3] and educational outreach visits. [4]

Many aspects of the process for communicating evidence are considered in a recent report funded by the Canadian Health Services Foundation and Ontario Health Quality Council Public Reporting on the Quality of Health Care. This report looks at the purpose, content, audience, products, distribution and impacts of the research. [5]

Finding out more
Knowledge Management Tools and Techniques

Related CareSearch pages
Disseminating Evidence
Knowledge Translation
Finding Evidence

References
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
- PubMed Topic Searches
- GP Hub
- Conferences
- Indigenous resources
- Palliative Dementia Care COP
- CareSearch DVDs

CareSearch is funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program.
Lifelong learning is the process of acquiring knowledge or skills throughout your life. This can be through education, training, work and general life experience.

The following resources are available to assist you in identifying formal training and education opportunities to support lifelong learning:

- CareSearch Training Modules
- Community Education Activities
- Conferences
- Short Courses
- University Courses
- Web Based Learning

This page was created on 13 March 2007
Last updated on 28 September 2009
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Research Resources

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This page was created on 26 May 2008. This website was last updated on 16 August 2010

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Research Resources

Research provides an integral link in the development of evidence-based practice. The following resources are currently available to support the work of researchers in palliative care:

- Research Data Management System to assist in designing surveys and collecting data for research conducted at a single or multiple sites
- Information about conducting research in palliative care
- Research Studies Register that contains information on Australian research work in palliative care
- Research presentations: list of conference posters, presentations and papers
- Researchers may also be interested in finding about Grants and Granting Agencies.
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?

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What is Palliative Care
For Patients and Families
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Research Resources
Professional Groups

Proudly linked to:

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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. Each main group has an individual webpage. There are more extensive sets of resources for:

> General Practitioners
> Nurses Hub

These pages provide access to resources and literature relevant to the practice of palliative care for different individual professional groups. They have been developed either in association with professional bodies or by individual practitioners from that area.

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Last updated 27 August 2010
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About CareSearch

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Consumer information on CareSearch
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
- PubMed Searches
- GP Hub
- Conferences
- Nurses[HUB]

Proudly linked to:

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This page was created on 26 May 2009. This website was last updated on 19 November 2010.
Consumer information. Who is it for?

- Those receiving care such as patients
- Those involved in caring such as carers, families
- Members of the community such as neighbours, friends or work colleagues
Carers

- A **carer** is an individual who provides personal care, support and assistance to another individual who needs it because that other individual:
  (a) has a disability; or
  (b) has a medical condition (including a terminal or chronic illness); or
  (c) has a mental illness; or
  (d) is frail and aged.

*Carers Recognition Act 2010*
For Patients and Families

• Good quality information can help with decision making

• It helps to know where to access information even if you don’t want to read it right now

• Pages can be printed and shared with others
  – to help discuss issues or
  – for those without a computer
For Patients and Families

- Information in this section has been sourced and written differently to the other pages
  - This section has been built upon evidence from the published literature
  - But also based on searches for relevant tools and resources accessible through the web
  - Readability scores have been recorded on all pages to ensure they are targeted at the right level
Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. The sections below will take you to detailed information and resources.

### About Palliative Care
- **What is palliative care and why is it important?**

### Living with Illness
- **Information on living with illness, and changes over time.**

### How to Care
- **Information on the practical things that can help daily life.**
- **At the End**
  - What happens when someone is nearing the end of life?
- **Bereavement, Grief, Loss**
  - Information on how to manage after someone has died.
- **Groups with Specific Needs**
  - Some groups have specific needs such as older or homeless people.

### Finding Out More
- Learn more about how to search for quality information.

### Do you need help now?
- Contact numbers if you need help now.
About palliative care

• Includes:
  – What palliative care is and how to access it
  – That it is not just for those with a cancer diagnosis
  – That having information can help to make better decisions
About Palliative Care

Palliative care is provided when an illness cannot be cured. Palliative care is appropriate even in the early stages of an illness when someone is having active treatment. It is about supporting people to live well while they manage their illness. It is not just about cancer.

Many health professionals help with palliative care. Palliative care can be provided at home, in residential aged care facilities and in hospitals and hospices.

Patients, family carers and friends can find information on many topics in this section including:

- What is palliative care
- Referring to palliative care
- Who provides palliative care
- It's not just cancer
- Why information matters
Living with Illness

- It takes into account some of the issues that those who have a life-limiting illness have to face, such as:
  - Finances
  - Work
  - Difficult emotional challenges
Living With Illness

When someone has a serious illness there are things to consider. This could be for the person who has the illness or for those around them.

This could mean thinking about quality of life and what is important now. Whether someone continues to work, how things are likely to change and how to prepare for them is important. There is information here that can help in making informed choices.

Topics in this section look at:

- Planning for the future
- Financial matters
- Continuing to work
- Changes over time
- Emotional challenges
- Communication
- Symptoms
- Complementary therapies

This page was created on 26 May 2009 and is due for review in May 2011.
How to Care

• People can find themselves in a situation where they are involved in looking after someone

• People do not often identify themselves as a ‘carer’ but rather – ‘his wife’ or ‘her neighbour’

• Not many people know what is involved or how to go about it
How To Care

Many people have never looked after someone who is seriously ill. It can be a bit overwhelming. They describe needing information and resources to help in managing daily life. This could be in relation to managing medications or accessing transport. It could be sorting out finances or getting support for themselves.

There is information here that can help with the caring role. Topics covered include:

- Looking after someone
- Looking after yourself as a carer
- Getting help
- Managing medications
- Practical information and resources
- Managing daily life
- How to help families

Return to For Patients and Families home page

This page was created on 26 May 2009 and is due for review in May 2011.
At the End

- As the end of a person’s illness approaches, some patients will want to know what is ahead and the majority of carers certainly will.

- This information can be confronting and some people will never read it, but it useful to know it is there.
At The End

There are many things that can be done in preparation as someone approaches the last few weeks and days of their life. Access to accurate information can be very helpful at this time.

People vary in their knowledge, understanding and beliefs in regard to death and dying. They also differ in what they want to know. Each individual should be as informed, or not, as they want to be. For many, knowing what to expect can help take some of the fear and anxiety away. For others, having too much information provides more things to worry about.

Information can be found here on:

- Place of care and place of death
- Preparing for the end and end of life decisions
- Caring issues at this time
- Changes around the time of death.

Return to For Patients and Families home page
Bereavement, grief and loss

- Information can be found here for the carers, families and communities left behind when someone dies
Bereavement, Grief and Loss

It is often quite a shock when someone dies, even when it is an expected death after a long illness. The death of that person can change things forever.

Those who are bereaved will react differently to the loss. For some it can take a long time to recover. Each individual will react differently when someone dies and there is no right or wrong way to grieve.

There is information and resources on these pages that may be of help during this time. Topics include:

- Grief and sadness
- Children and grief and loss
- Loss of a child
- Grief and loss resources
- Remembering and recovering

Return to For Patients and Families home page

This page was created on 26 May 2009 and is due for review in May 2011.
Specific Groups

- A population health approach has been taken to these pages with information provided for those who may not have equitable access to services and to care.

- Particular groups such as the homeless, prisoners and the intellectually disabled have different care needs.

- Information is provided here that may help them.
Specific Groups

Australia is made up of people with many different backgrounds. One in four Australians were born overseas. Indigenous Australians make up 2.4% of Australia’s population and 1.5% of Australians are 85 years or older.

When someone in the family or your community has a serious life limiting illness, they will need support and care. The amount and type of support needed varies from person to person. People living with a terminal illness may require different types of care and support depending on their disease, where they live, or other characteristics such as age or culture.

These pages provide information on resources and issues for particular groups within Australia. There is specific information for health professionals on the needs of these groups in the clinical practice pages.
Finding out More

• These pages provide information on how consumers can be more informed

• It includes facts on how to judge the quality of information and how to use it in decision making

• There is also information on how research contributes
Finding Out More

It is always helpful to become more informed about what is happening to you. There are many good quality resources that can help you find out more. The CareSearch Finding Services section has links to quality websites related to specific conditions and diseases and to many groups and organisations.

However, you may also want to find more detailed information on a specific topic or issue. The following pages can help you:

- Find good information sources and databases.
- Assess the quality of information and sites on the web.
- Think about how to use this information.
- Learn more about research.

Return to For Patients and Families home page

This page was created on 30 April 2008 and is due for review in April 2010.
Print Resources

- There are many resources available within the ‘For patients and Families’ section and here many of them are in a print-ready format
Print Resources

Sometimes it can be helpful to have some information that can be read later or given to friends and family members. All pages in the For Patients and Families section are print ready. By clicking on the printer icon, the webpage will be formatted for printing.

As well the following resources are available on the web and can be printed off. Think about what resources could help now. Over time as needs change, other printed materials may be helpful. Some of these resources are from other countries. You should always think about how useful the information is to your particular needs.

Advance care planning

> [Advance care planning guide](#) (Select State or Territory of interest then download the guide)
  Booklet from Respecting Patients Choices website

Bereavement Grief and Loss

> [Now what? Understanding grief](#)
  Booklet from Palliative Care Australia
> [Are you needing help after someone has died?](#)
  From CentreLink Summary of relevant services and other useful information
> [Bereavement Allowance Payment Rates](#)
  From Centrelink

Carers

> [Resources for carers](#)
  A pamphlet from Palliative Care Victoria
> [Rights and responsibilities in caring for a family member](#)
  Information sheet for carers from Carers Victoria
> [Practical caring: At the end of life](#)
  Fact sheet for carers from CareSearch
> [Safety at Home](#)
CareSearch: Making it easier to find Free Full Text Articles
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
PubMed Searches
GP Hub
Conferences
Nurses[HUB]

VPCNPC

Proudly linked to:

Flinders University
HealthInsite

This site complies with the HONcode standard for trustworthy health information: verify here.

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

This page was created on 26 May 2008. This website was last updated on 19 November 2010
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
  - For patients, families and community
Evidence Based Practice

• Applying what is known to practice
  – Need to have the evidence first to then make decisions around applicability to your situation
  – The range of disciplines involved in palliative care can mean searching many databases or journals (eg, CINAHL or PsycINFO)
  – Finding the article does not necessarily mean you can access it
Evidence Based Practice

- Finding relevant FREE full text (FFT) articles that you can read and/or download is not always easy

- CareSearch has made this a more straightforward process

- Follow the simple steps here

- FFT articles do limit search results but are something that can be read there and then
Finding Evidence

• Go to the Finding Evidence section of CareSearch

• There is a PubMed Topic Searches Page
  – Over 60 pre-written searches are available
  – Choose your area of interest (eg, Dementia)
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.
Palliative Care PubMed Searches

The links on this page provide an easy and reliable way to find the relevant palliative care literature in English. Each link runs an immediate search of PubMed and all searches are automatically updated as new articles are added to the database.

CareSearch search filters

Palliative care
This search uses a palliative care filter developed by CareSearch. It retrieves all English language articles of relevance to palliative care within PubMed.

Heart failure
This search uses a heart failure filter developed by CareSearch. It retrieves all English language articles of relevance to heart failure within PubMed. Searches based on specific heart failure issues are also available.

Palliative care: specific issue searches
These links make it possible to search on specific palliative care issues such as bereavement and dyspnea. Each search combines MeSH terms and textwords describing the topic with the CareSearch palliative care filter. Results are limited to the English language palliative care literature.

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Dementia: An acquired organic mental disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The dysfunction is multifaceted and involves memory, behavior, personality, judgment, attention, spatial relations, language, abstract thought, and other executive functions. The intellectual decline is usually progressive, and initially spares the level of consciousness (Source: MeSH Thesaurus).

To choose another topic, go back to Palliative Care PubMed Searches

This page was created on 30 April 2008
Last reviewed 3 May 2010
Finding Evidence

- Free Full text/Strongest Evidence
  - this will search in real time and provide articles available as FFT on randomised controlled trials or systematic reviews on palliative care and dementia.
Dementia: An acquired organic mental disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The dysfunction is multifaceted and involves memory, behavior, personality, judgment, attention, spatial relations, language, abstract thought, and other executive functions. The intellectual decline is usually progressive, and initially spares the level of consciousness (Source: MeSH Thesaurus).

To choose another topic, go back to Palliative Care PubMed Searches.
Palliative care for the elderly--developing a curriculum for nursing and medical students.

Just JM, Schulz C, Bongartz M, Schnell MW.
PMID: 20954885 [PubMed - indexed for MEDLINE] [PubMed - in process]
Free PMC Article
Free text
Related citations

Dying with dementia: what we know after more than a decade of research.

van der Steen JT
PMID: 204343 [PubMed - in process]
Free Article
Related citations

Patient preferences for future care--how can Advance Care Planning become embedded into dementia care: a study protocol.

BMC Geriatr. 2010 Jan 12;10.2.
Free PMC Article
Free text
Related citations

Epidemiological pathology of dementia: attributable-risks at death in the Medical Research Council Cognitive Function and Ageing Study.

Matthews FE, Brayne C, Lowe J, McKeith I, Wharton SB, Ince P.
Free PMC Article
Free text
Related citations

The clinical course of advanced dementia.

Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Pigrocco LG, Volcker L, Givens JL, Hamel MB.
Free PMC Article
Free text
Related citations

Free PMC Article
Free text
Related citations
Patient preferences for future care--how can Advance Care Planning become embedded into dementia care: a study protocol.

Institute of Health and Society, Newcastle University, Newcastle upon Tyne NE2 4DA, UK. a.r.obinson@ncl.ac.uk

Abstract

BACKGROUND: People living with a long term condition may wish to be able to plan ahead, so that if in future they cannot make decisions, their wishes about their care will be known; this process is termed Advance Care Planning (ACP). In dementia, guidance stipulates that ACP discussions should take place whilst the person still has capacity to make decisions. However there is a lack of evidence on the effectiveness of ACP in influencing patient choice and resource use. The aims of this study are to determine the effectiveness of ACP in dementia care, identify the factors which facilitate the process in practice and provide a better understanding of the views and experiences of key stakeholders in order to inform clinical practice.

METHODS/DESIGN: The four phase project comprises a systematic review (Phase 1) and a series of qualitative studies (Phases 2 and 3), with data collection via focus groups and individual interviews with relevant stakeholders including people with dementia and their carers, health and social care professionals and represented by voluntary organisations and the legal profession. The conduct of the systematic review will follow current best practice guidance. In phases 2 and 3, focus groups will be employed to explore the perspectives of the professionals; individual interviews will be carried out with people with dementia and their carers. Data from Phases 1, 2 and 3 will be synthesised in a series of study workshops to develop draft guidelines and educational tools for implementing ACP in practice (Phase 4).

DISCUSSION: In the UK, there is little published research on the effectiveness of ACP, despite its introduction into policy. This study was designed to explore in greater depth how ACP can best be carried out in routine practice. It affords the opportunity to develop both a theoretical and practical understanding of an area in which both patients and professionals may find emotionally challenging. Importantly the study will also develop practical tools, which are grounded in practice, for all relevant stakeholders to enable the facilitation of timely and sensitive ACP discussions.
Patient preferences for future care - how can Advance Care Planning become embedded into dementia care: a study protocol

Louise Robinson¹, Claire Bamford¹, Fiona Beyer¹, Alexa Clark², Claire Dickinson¹, Charlotte Emmet³, Catherine Exley¹, Julian Hughes⁴, Lesley Robson², Nikki Rousseau¹

Abstract

Background: People living with a long term condition may wish to be able to plan ahead, so that if in future they cannot make decisions, their wishes about their care will be known; this process is termed Advance Care Planning
Finding Evidence

- Free Full text/Everything
  - this will search in real time and provide articles available as FFT on everything available on palliative care and dementia.
Dementia: An acquired organic mental disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The dysfunction is multifaceted and involves memory, behavior, personality, judgment, attention, spatial relations, language, abstract thought, and other executive functions. The intellectual decline is usually progressive, and initially spares the level of consciousness (Source: MoSH Thesaurus).

To choose another topic, go back to Palliative Care PubMed Searches.
Results: 1 to 20 of 161

1. Early Alzheimer's disease.
   Lavelle L, Robinson DJ, O'Shea D.
   Related citations

2. Palliative care for the elderly—developing a curriculum for nursing and medical students.
   Just JM, Schulz C, Bongartz M, Schnell MW.
   Related citations

3. Dying with dementia: what we know after more than a decade of research.
   van der Steen JT.
   Related citations

4. Making decisions for people with dementia who lack capacity; qualitative study of family carers in UK.
   BMJ. 2010 Aug 18;341:c4184. doi: 10.1136/bmj.c4184.
   Related citations

5. The BELFRAIL (BFC80+) study: a population-based prospective cohort study of the very elderly in Belgium.
   Related citations

   Mole SE, Williams RE.
   Related citations

7. Development of an efficient therapeutic agent for Alzheimer's disease: design and synthesis of dual inhibitors of acetylcholinesterase and serotonin
   Related citations
Finding Evidence

• All citations/Everything
  – this will search in real time and provide all abstracts available on everything available on palliative care and dementia
  – i.e. these are not free full text
Dementia PubMed Search

Select one search option for your chosen search topic.

**Free full text only** (likely to reduce the number of results)
- Strongest evidence (systematic reviews or randomised controlled trials)
- Everything

**All citations**
- Strongest evidence (systematic reviews or randomised controlled trials)
- Everything
- Last 3 months only

Dementia: An acquired organic mental disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The dysfunction is multifaceted and involves memory, behavior, personality, judgment, attention, spatial relations, language, abstract thought, and other executive functions. The intellectual decline is usually progressive, and initially spares the level of consciousness (Source: MeSH Thesaurus).

To choose another topic, go back to Palliative Care PubMed Searches

This page was created on 30 April 2008
Last reviewed 3 May 2010
Results: 1 to 20 of 1322

1. Palliative care for the geriatric patient in Europe: Survey describing the services, policies, legislation, and associations.
   Z Gerontol Geriatr. 2010 Nov 20. [Epub ahead of print]
   PMID: 21035931 [PubMed - as supplied by publisher]
   Related citations

   Ersek M, Polissar N, Neradilek MB.
   J Pain Symptom Manage. 2010 Nov 19. [Epub ahead of print]
   PMID: 21004018 [PubMed - as supplied by publisher]
   Related citations

3. Advance care plans for CPR or mechanical ventilation in patients with dementia.
   Westenhaver TF, Krassa TJ, Bonner GJ, Wilkie DJ.
   Nurse Pract. 2010 Dec;35(12):33-42
   PMID: 21088502 [PubMed - in process]
   Related citations

4. Electroconvulsive Therapy in Palliative Care.
   Rasmussen KG, Richardson JW.
   Am J Hosp Palliat Care. 2010 Nov 17. [Epub ahead of print]
   PMID: 21087947 [PubMed - as supplied by publisher]
   Related citations

5. Quality of Life in Nursing Home Residents with Advanced Dementia.
   Cordner Z, Blass DM, Rabins PV, Black BS.
   PMID: 21054329 [PubMed - as supplied by publisher]
   Related citations

   PMID: 21054292 [PubMed - in process]
   Related citations

7. Treatment of Alzheimer disease and prognosis of dementia: time to translate research to results.
   Yaffe K.
Finding Evidence

• All citations/ Everything
  – This just shows that requesting only FFT narrows the results you will retrieve
  – However, if you do not have access to a database then at least being able to have the choice of reading 161 articles is better than not being able to read anything at all
Finding and using CareSearch promotional materials

This event is part of the Quality Use of CareSearch Project

CareSearch is funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program.
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.
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
- PubMed Searches
- GP Hub
- Conferences
- Nurses[HUB]

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

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

This page was created on 26 May 2008. This website was last updated on 19 November 2010.
Using CareSearch materials

- There are a few project resources that may be of interest.
Project Resources

Various resources and materials are produced as part of the project. They enable users to find out more about what is happening and how to use the website more effectively. They also provide a record of the promotional and research activities of the project.

The materials being produced as part of the project will be available here.

This page was created on 20 May 2008
Last updated 26 May 2008
Promotional Resources

We have a variety of information pieces available for the palliative care community. All enquiries regarding our promotional materials can be directed to Natasha Schembri via email at natasha.schembri@flinders.edu.au.

# means the item has been printed and can be ordered. Please use the order form (web pdf) or Fax or send to CareSearch and we will post the information to you.

Brochures and fact sheets for patients carers and families

General Resources

> Caregivers Fact Sheet
> CareSearch promotional poster
> For Patients, Carers, Families and Friends # [Brochure]
> CareSearch web details # [Bookmark]
> Helping Carers and Families # [Magnetic List]

End of Life Series: Brochures and Fact Sheets

> Why information matters # [Brochure]
> Why information matters [Fact sheet]
> Communication # [Brochure]
> Communication [Fact sheet]
Promotional Resources

We have a variety of information places available for the palliative care community. All enquiries regarding our promotional materials can be directed to Natasha Schembri via email at natasha.schembri@finders.edu.au.

# means the item has been printed and can be ordered. Please use the order form [order form 18%b.pdf](https://example.com/order_form.pdf) Fax or send to CareSearch and we will post the information to you.

Brochures and fact sheets for patients, carers and families

General Resources

- Caregivers Fact Sheet
- CareSearch promotional poster
- For Patients, Carers, Families and Friends # [Brochure]
- CareSearch web details # [Bookmark]
- Helping Carers and Families # [Magnetic List]

End of Life Series: Brochures and Fact Sheets

- Why information matters # [Brochure]
- Why information matters [Fact sheet]
- Communication # [Brochure]
- Communication [Fact sheet]
- Living with a terminal illness # [Brochure]
- Living with a terminal illness [Fact sheet]
- How to care # [Brochure]
- How to care [Fact sheet]
- Groups with specific needs # [Brochure]
- Groups with specific needs [Fact sheet]
- At the end # [Brochure]
- At the end [Fact sheet]
- Bereavement, grief and loss # [Brochure]
- Bereavement, grief and loss [Fact sheet]
- End of Life brochure packet
Brochures and fact sheets for health professionals

General Resources

- For health professionals # [Fact sheet]
- CareSearch GP Bookmark # [Bookmark]
- Helping health professionals # [Magnetic list]
- Supporting health professionals providing care at the end of life (rural and remote) [Fact sheet]

Nurses Resources

- Nurses Hub Fact Sheet
- Nurses Promotional Poster

Profession Specific Fact Sheets

- Caregivers Fact Sheet
- Supporting those working in residential aged care
- Allied Health Fact Sheet
- CareSearch: Helping GPs with one of their most important roles
- Resources for pastoral care workers and chaplains
- CareSearch: Resources for pharmacists
- Volunteers Fact Sheet
- Resources for medical students

Clinical Issues Fact Sheets

- Resources for palliative medicine
- Resources for paediatric palliative care
- Pain resources
Project and website resources

Specific CareSearch resources

- CareSearch Research Data management System [Fact sheet]
- First anniversary newsletter [Newsletter]
- Understanding palliative care: An A to Z of CareSearch [Fact sheet]
- What is Professional Connect [Fact sheet]
- About the Palliative Care Filter [Fact sheet]
- Order form

Getting the most out of CareSearch Fact sheets

- 10 things you need to know #
- Page icons #
- Finding your way around CareSearch #
- Structure of the website #
- Favourites and shortcuts #
- Six steps to information and evidence #

This page was created in June 2007
Last updated 03 November 2019
CareSearch DVDs

About CareSearch

Understanding CareSearch: Dr Christine Sanderson explains what CareSearch is and how it can be used.
Finding Evidence: Professor David Currow talks of the importance of evidence in palliative care.
Introduction to CareSearch: Overview of the website for the general community.

Health Professionals

Aged Care: Nurses working in Aged Care speak of issues they face.
PCIAA Perspective: An interview with Dr John Rosenberg.
Rural: A nurse speaks of issues faced by those living in rural areas.
Social Work: Social workers speak of working with palliative care clients.
Volunteers: Palliative care volunteers speak about their role in a hospice.

For Patients and Families

About palliative care: Palliative care helps those with an illness that cannot be cured by managing symptoms as well as providing emotional and spiritual support.

Living with a terminal illness: There are many things to consider whether it be financial, emotional or practical matters.

How to care: When someone is very ill at home, they need help and support to manage.

Groups with specific needs: Death is a reality of life, but the circumstances can vary greatly as different groups have different needs.

At the end: Many people have little or no prior experience of dying and death. As much as possible, people like to have choice at the end of life.
Using CareSearch materials

- All resources can be ordered / printed and used to:
  - Inform colleagues in education sessions
  - Display posters (e.g., nurses hub) in staff areas
  - Display consumer information in waiting areas / foyers
  - Hand consumer brochures to community members or families so that they can find out more
  - Use consumer brochures to initiate conversations
Making your life easier: Computers and the internet
Computers and the Internet

- Not everyone is familiar with computers

- Not everyone is comfortable using computers

- Not everyone knows how to effectively search the internet
  - Shortcuts are always useful
  - The following hints may help to make life easier
CareSearch

• The following options are often found on websites and can make life easier when navigating
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?on the community?on the literature?

Quick Links
PubMed Topic Searches
GP Hub
Conferences
Indigenous Resources
Victorian Palliative Care Nurse Practitioner Collaborative

What is Palliative Care
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch

Proudly linked to:

Flinders University
HealthInsite

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

This site complies with the HONcode standard for trustworthy health information: verify here.

This page was created on 26 May 2008. This website was last updated on 27 August 2010.

Accessibility | Credits | Terms & Conditions | Site Map
Site Map

What is Palliative Care

> Understanding Palliative Care
  - Caring in the Community
  - Death and Dying in Australia
  - Preferred Place of Death
  - Providing Palliative Care in Australia
  - Specific Populations
  - Volunteers

> National Palliative Care Program
  - APRAC
  - Caring Communities Program
  - COP-D1: Palliative Dementia Care
  - ComPAC
  - Dementia Care Dialogues
  - Indigenous Palliative Care Project
  - Knowledge Network Project
  - Local Palliative Care Grants
  - NHMRC Round Three
  - National Standards Assessment Program
  - PaCCSC
  - Palliative Care Curriculum for Undergraduates (PCC4U)
  - Palliative Care for People at Home
  - Palliative Care Medicines Working Group
  - Palliative Care Needs Assessment Framework
  - Palliative Care Outcomes Collaborative (PCOC)
  - Palliative Care Trial
Living With Illness

When someone has a serious illness there are things to consider. This could be for the person who has the illness or for those around them.

This could mean thinking about quality of life and what is important now. Whether someone continues to work, how things are likely to change and how to prepare for them is important. There is information here that can help in making informed choices.

Topics in this section look at:

- Planning for the future
- Financial matters
- Continuing to work
- Changes over time
- Emotional challenges
- Communication
- Symptoms
- Complementary therapies

This page was created on 26 May 2009 and is due for review in May 2011.
Advance Care Planning

Advance care planning means supporting people to think about, and plan for, their wishes as they approach the end of life. Advance care planning encourages people to:

- consider the kind of care that is in keeping with their values, and their wishes about their own life and death
- talk to their health care providers about their concerns about the dying process, to seek information to help them make decisions about their future care, and to review possible scenarios related to their own situation
- talk to their families and/or friends about these matters
- identify a proxy decision-maker
- address other matters to do with their death, such as organ donation, wills, funerals and so on.

Advance care planning is based on the ethical and legal principle of autonomy – that violating patients' autonomy by disregarding their wishes may constitute a legal offence. In Australia, the legal framework and terminology surrounding advance care planning varies between states. Link to Legislative framework in Australia.
Reducing Evidence-Practice Gaps

Reducing evidence-practice gaps is a complex task that requires input from many different groups including researchers, clinicians, consumers and policy makers. The National Institute of Clinical Studies is an institute of the National Health and Medical Research Council with a specific focus on how to improve healthcare by closing gaps between the best available evidence and real world practice.

For palliative care as for other disciplines, reducing evidence-practice gaps presumes the existence of relevant evidence. This forms the base against which current practice is assessed and change programs initiated if needed. Within palliative care, the literature is beginning to report about implementation and moving evidence into practice. [3-7]

Finding out more

> Taking action locally: Eight steps to putting cancer guidelines into practice
  Melbourne Australia National Institute of Clinical Studies 2006
> Keenan Research Centre – Research Programs: Joint Program in Knowledge Translation
> Introduction to KT and the KT Clearinghouse
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This page was created on 26 May 2008
Last updated on 16 June 2010
Continuing Professional Development

- Find university courses, short courses, web-based learning modules (education)

- Get the latest evidence to support your study
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<td>Ian Anderson_Continuing_Education_Program in End-of-Life Care</td>
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<td>National Association of Social Workers Web Ed</td>
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<td>Thinking and planning ahead: learning from each other: a volunteer training programme about Advance Care Planning</td>
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<td>Can meet needs</td>
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<td>Cleveland Clinic Center for Continuing Education</td>
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<td>Multidisciplinary Training in Psycho-Oncology</td>
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<td>National Association of Social Workers Web Ed</td>
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