Finding and applying palliative care evidence in clinical practice

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CareSearch Project

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General Practitioner component

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Background to CareSearch

• Commonwealth Dept of Health & Ageing initiative – Evidence-Based (Palliative Care) project
  – to develop a repository of “missing” palliative care literature,
  – to make this literature accessible to inform best practice; and
  – to promote evidence-based practice (EBP) in palliative care

• Initially aimed at palliative care providers and researchers

• However, over the last two years CareSearch has been evolving …
Background to CareSearch

• Now aiming at a broader audience
  – All those providing care (GPs, allied health, volunteers etc)
  – All those affected by palliative care (patients and families, friends, neighbours)

• GP webpages released in March 2007, along with webpages for patients, their caregivers, families and friends
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

**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.
General Practitioners and Palliative care

- Most GPs see few palliative care patients each year (median of 5-6 per annum)

- Increasing burden of chronic disease vies for the attention of the GP – palliative care but one issue amongst many
Hierarchy of interest and involvement in palliative medicine amongst GPs, ranging from:

- Those with a particular interest, act as leaders
- Those who are committed - willing to keep up to date
- Those who prefer not to provide palliative care, and may not take advantage of opportunities to increase their skills

Education, Training and Support for General Practitioners in Palliative Care, Department of Health and Ageing, 2004
Aims of the GP webpages

- To support GPs with access to clinical guidance as well as an approach to palliative care
- To provide links to local service providers that encourage interaction and referral
- To give GPs access to good quality patient information which they can use to help meet the information needs of their patients
- To encourage an awareness of the need for evidence based approaches in palliative care
Palliative care for GPs

Quick clinical guidance
- Assessing prognosis
- Pain and symptom management - link to the online Palliative Medicine Handbook
- Effective communication strategies for difficult situations
- Practical skills - ascitic or pleural taps, syringe drivers, medication changes
- Opioid information
- The dying patient and their caregivers
- Palliative care emergencies

Palliative care in practice
- GPs as palliative care providers
- The palliative approach in general practice
- Providing palliative care in aged care facilities
- Further training opportunities for GPs
- Getting help with difficult problems

Your palliative care reference library
- Online Palliative Medicine Handbook
- Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NHMRC)
- Medical Care of Older Persons in Residential Aged Care Facilities (PACGP "Silver Book")
- Pain in Residential Aged Care Facilities: Management Strategies (Australian Pain Society)
- Multicultural palliative care guidelines (Palliative Care Australia)
- Providing culturally appropriate palliative care to indigenous Australians (Department of Health and Ageing)
- Until the chemist opens: palliation from the doctor’s bag (Australian Family Physician article)

Complete list of Patient Resources
Complete list of Assessment Tools

CLINICAL DISCLAIMER: The clinical recommendations in CareSearch are of a general nature and are intended to provide guidance. Health professionals should use their clinical judgement in applying this guidance in the care of individual patients. The information provided on CareSearch is designed to support, not replace, the relationship that exists between a patient/site visitor and her/his physician. While the information contained herein was correct at the date of publication, CareSearch reserves the right to make alterations without prior notice should the need arise. CareSearch is not responsible for the contents of any off-site information.
What can you find in the CareSearch GP webpages?
Quick clinical guidance about palliative care issues

Includes:
- Assessing prognosis
- Practical skills
- Opioid information
- Communication strategies
- Links to a palliative care formulary

…. And more
Quick clinical guidance

Opioid information

Starting an opioid

Opioid analgesics are frequently needed by palliative care patients whose pain does not respond to simple analgesics, weak opioids, and other measures – see the NPS RADAR Prescribing Practice Review on this topic.

Persistent pain should be treated promptly. A high index of suspicion about the presence of pain is needed for patients who are unable to verbalise their experiences.

Morphine, oxycodone or hydromorphone are appropriate strong opioids to start. Caution should be used when initiating analgesia with fentanyl transdermal patches (Durogesic), particularly in the frail opioid naïve patient.

Some analgesics are less suitable for use in palliative care, either because of their ceiling effect, their potential for drug interactions, or other problems. (see Therapeutic Guidelines 2nd edition p102-105) These include:

- Pethidine
- Tramadol (Tramal, Tramadexal, Tramado, Zydol)
- Pentazocine (Drinика, Riotrans, Pentalten, Poizatral)
- Butorphanol (Stadol, Butofan, Poizen, Tryptizol)
PALLIATIVE CARE IN PRACTICE
- GPs as palliative care providers
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FREQUENTLY ASKED QUESTIONS

GP TOOLBAR
- Online Palliative Medicine Handbook
- Translating and Interpreting Service
- Authority Prescribing Evidence-based palliative care reference library

REFERRING TO PALLIATIVE CARE STATE BY STATE
- Australian Capital Territory
- New South Wales
- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia

Switching opioids

Reasons why opioid switching may sometimes be needed include:
- Renal failure
- Adverse effects thought to be due to a particular opioid
- Change in route of administration is required
- Problems with large volumes needing to be given subcutaneously.

Published guidelines for opioid conversion are based on estimates, and there is inter-individual variation. Different conversion factors may be favoured by different clinicians. Clinical judgement should always be used, and doses must be titrated to pain and side effects.

A useful Australian opioid conversion table can be downloaded here.

The IAHPC Manual of Palliative Care provides online guidance on equianalgesic doses and safe management of opioids.

The key to making changes in opioid analgesics is to review carefully and frequently about:
- Whether pain is adequately controlled after the change
- Side effects
- Whether pain is opioid responsive or requires additional pain management strategies.

Opioid non-responsive pain

Pain which is not responding to opioids should be reassessed, as the mechanism of the pain may suggest alternative analgesic strategies. The Palliative Medicine Handbook describes a helpful approach to this issue.
More detailed discussion of the role of GPs in providing palliative care

Includes:

- Sharing care with the palliative care team
- Prescribing difficulties
- Dealing with difficult problems
- Access to further training in palliative care

… And more
Providing 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, and the aged care sector 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 maximize opportunities for a) pain assessment and b) provision of timely feedback to you for medication changes. Review with the nursing supervisor the facility 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 basis.

3. Write orders for PRN medication at intervals of every four hour for short acting medications. If you know that the patient is likely to need frequent PRN medication, write the order as a scheduled regular four hourly order with the extra notation: hold if no pain, or patient may refuse. In a pain crisis it may be necessary to order the FRN dose even more frequently, eg hourly. In this situation the patient must be reviewed regularly until stable.

4. Whenever pain is constant, write an order for a scheduled regular medication, preferably a long-acting medication.

5. Avoid simultaneous orders for multiple opioids. Only one opioid-non-opioid combination product should be prescribed at any one time.

6. Plan ahead, it is common for nursing home residents to have increasing pain related to physical therapy, dressing changes, etc. Write an analgesic order that anticipates painful activity: (e.g.
What else?

→ Links to a library of key references for current palliative care practice
My Evidence-based Palliative Care Reference Library

Peak body: Palliative Care Australia

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

Online reference books

Online Palliative Medicine Handbook (UK)

Online Manual of Palliative Care (International Association of Hospice and Palliative Care)

WHO Cancer Pain Release online journal

Downloadable publications (PDFs)

Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NH&MRC)

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 (MJA)

Medical Care of Older Persons in Residential Aged Care Facilities (RACGP “Silver Book”)

Pain in Residential Aged Care Facilities: Management Strategies (Australian Pain Society)

Guidelines for a Palliative Approach in Residential Aged Care (Department of Health and Ageing)

Multicultural palliative care guidelines (Palliative Care Australia)
What else?

➔ Local referral details for specialist palliative care services
Palliative Care Council of South Australia Inc

Palliative Care Services

Metropolitan

Central Adelaide Palliative Care Service

- Mary Potter Hospice
  89 Strangways Terrace
  NORTH ADELAIDE SA 5006
  (08) 8239 9144
  (Calvary switchboard 08 8239 9100)

- Royal Adelaide Hospital
  North Terrace
  ADELAIDE SA 5000
  (08) 8222 2021
  (RAH switchboard 08 8222 4000)

Lyell McEwin Palliative Care Service
What else?

→ Patient leaflets that can be downloaded
What else?

- Assessment tools for palliative care
  - Pain assessment tools in many languages
  - Other symptom assessment tools
  - Assessing psychosocial distress
  - Assessing delirium
  - Assessing pain in patients with dementia
The dying patient and their caregivers
Palliative care emergencies

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Australian Capital Territory
New South Wales
Northern Territory
Queensland
South Australia
Tasmania
Victoria

Pain assessment

Visual Analogue Scale

Faces pain scale for children

Multilingual versions of a pain assessment tool in 18 languages

Memorial Pain Assessment Card

Abbey Pain scale for assessment of pain in patients with dementia who cannot verbalise

Assessing other symptoms

Memorial Symptom Assessment Scale

Edmonton Symptom Assessment Scale

Delirium

Confusion Assessment Algorithm is a brief, validated tool that screens for delirium

Assessing performance state

The ECOG scale

A modified Karnofsky scale for use in palliative care

Distress

The Distress Thermometer - An online self-assessment tool that patients can complete and print out
As well as other CareSearch information you may be interested in …
Referring your patients to the web-pages which have been specifically developed for palliative care patients, and their caregivers, families and friends
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.
Complicated feelings

You may find that you are experiencing complicated feelings and emotions. This is normal. It is part of what is happening to you.

You may find that you have Good days and Bad days. You will perhaps find that on the good days you will be able to get out and about and feel much like your old self. On other days however, you may not feel up to seeing anyone, will feel emotional and unsure, or just want to sleep or rest. This is something that you won’t have any control over. Generally you will find the best thing is to save your energy for the important things.

Sometimes people will ask ‘Am I going crazy?’ Feeling like this can be horrible. A whole range of feelings and emotions can be experienced by people who are very ill, and that they can often be overwhelming and sometimes take over all other thoughts.

Losing control, being overwhelmed

When you have a serious illness, many things change. Some of these will be out of your control. This can affect how you feel, and can in turn affect how you adjust to the changes that are happening.

All of this can be frustrating, and sometimes overwhelming and scary. This may cause you to have difficulty functioning as normal. While these feelings of losing control and being overwhelmed are not unusual, if you can’t function you can seek help.

Start by talking to your doctor or the visiting nurse. They may be able to organise for you to talk to a social worker or psychologist if you need some professional support.

This may be a time to look at important issues

When a person is very ill they will sometimes say that it makes them focus more on the important things in life, such as spending time with family and friends. You may now decide you want to do the things you always wanted to do. This time can be a very special time, and sometimes good things can come out of a sad situation.
Carers

When someone in your family or one of your friends has an illness that requires palliative care, you may take on the role of carer providing emotional and physical support. As a carer you take on an important role in helping the person with the life limiting illness manage at home and achieve what they see as important in the time they have left.

Caring for someone with a life threatening illness can be exhausting. Looking after yourself physically and emotionally during this time is important, not only for your sake but for the person you are caring for as well.

In these pages you can find more about palliative care and link to quality internet information on some of the diseases and illnesses that may require palliative care. There are also pages and resources that enable you to learn about some of the important caring tasks that you may need to provide.

The pages are not intended to replace the care or advice of your health professionals. They provide a set of resources that may help you learn more and access materials that could help you manage better.

This page was created on 26th March 2007 and is due for review in March 2009.
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
Families and friends

Learning that a family member or a friend has a life limiting illness and can not be cured of their disease can be very difficult and upsetting. It can be hard to know how to help and what to say. Often we do not have much experience in talking about death or in dealing with this important part of life.

There are many things we can do as members of the families, friends, neighbours and colleagues to help support the person with the life limiting illness and their partner or carer.

In these pages you can

- Find out more about **palliative care** and what is likely to happen
- Link to quality **websites and disease information** available on the internet
- Get ideas on **how to help** and **what to say**
- Get information regarding **what to do after death**
- Learn about **different palliative care topics**
- Find out what **state based resources** are available

*This page was created on 26th March 2007 and is due for review in March 2009*
I don't know what to say

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

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

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

It can also be difficult when somebody has died. It is important to acknowledge what has happened and to not try and ignore it. What to do when a friend loses a loved one by Julie Ireland reminds us that friends, neighbours and colleagues can help by talking about the death of someone important to us.

This page was created on 26th March 2007 and is due for review in March 2009.
Talking to children about death

Talking about serious illness

When someone is ill, the whole family is affected. Children will know something is going on. The challenge for adults is to provide children and teenagers with information that is honest, timely and appropriate to their age and situation. Make time to talk with them and listen to what they are asking and what they are saying.

General guidance on talking to children can be found on the Canadian Virtual Hospice and from the help starts here website. The Marie Curie Cancer Centre has information to help children and young people who are experiencing serious illness or loss in the family.

Many of the organisations for specific diseases have section for children that are helpful. It is always important to check out these websites beforehand to see what conversations or questions may follow.

- MND Association of Victoria
- Cancer Council of NSW
- myDR: Dementia
- The Body HIV/AIDS
- MS Australia

Talking about death and dying

If someone with a serious illness is deteriorating, questions from children about death and dying may then follow. It is difficult to know how much information to give children about death, or to know how much they understand. The National Institutes of Health have developed a guide Talking to children about death that provides helpful information on how to talk with children.
Using a web-based education module to extend your knowledge of palliative care
Web based modules by topics:

- General palliative care approach and philosophy
- Pain Management
- Symptom Management
- Communication and end of life decision making
- Nursing issues
- Social work issues
- Aged care issues
- Research issues
Doing a literature search to answer a specific clinical question about palliative care

- CareSearch has preloaded PubMed searches on the website for key areas of palliative care

- These use validated search strategies to filter the literature

- There is also information on the website about how to set up your own search
Validated palliative care search

Palliative care journals offer a wealth of relevant information to the palliative care community. However, because palliative care is such a diverse topic, articles published in the general medical literature can also be relevant. But how can you best search for these?

In order to support evidence based practice in palliative care, a ‘palliative care’ search strategy for use in the general medical literature was developed and validated using an established research methodology. This means that the performance of the search was tested and measured. Professionals with a palliative care background hand searched the Annals of Internal Medicine, The Lancet, BMJ and JAMA from 1990-2001. A medical librarian and researcher then constructed a range of subject searches for use on OVID Medline, and compared the retrieved results with the set of articles already identified through hand searching. The best performing search correctly identified 45.4% of the known palliative care articles (sensitivity), and correctly excluded 99.3% of the irrelevant articles (specificity) in the same journals. The OVID Medline version of this search has since been translated into a PubMed version.

This search strategy is essentially a broad subject search, but it is also a search filter, similar to the methodological filters found on PubMed Clinical Queries. If combined with a more specific subject search using the Boolean Operator ‘AND’, it will filter the initial search and restrict it to those articles which may be relevant to palliative care.

This study now provides a benchmark against which further search refinements can be assessed. In particular, the sensitivity of the search needs to be increased. Whilst improvements to sensitivity were identified using different strategies in the study, these resulted in notable compromises to the overall search performance in terms of specificity and precision. However, until such time as the search is developed further, users of this website may find it a useful starting point when searching the general medical literature.
The first 3 months of the GP webpages
Page views (April 1 – June 30)

- GP Home page 1749
- Opioid information 759
- Effective communication 647
- Assessing prognosis 639
- Practical skills 525
- Pain and symptom management 518
- Palliative approach 480
- Palliative care emergencies 450
- Assessment tools 432
- GPs as palliative care providers 413
- Dying patient 401
- Providing palliative care in aged care facilities 395
- Further training 376
- My palliative care reference library 363
- Getting help 332
- Complete list of patient resources 275

**Total page views** 8754
Some Division weblinks to the GP pages
(the ones we know about)

- Mallee DGP Weekly Fax
- SADI quarterly newsletter
- Quarterly Adelaide Hills Division Newsletter
- Tasmanian GP Atlas (rural general practice on line)
- SA Divisions of General Practice Inc - Weekly News Bulletin
- North East Valley Division of GP - Resources and Downloads
- GP Connections Resource Materials
  - odgp.com
- Mackday Division Of General Practice - Palliative Care
- NSW Central West Division of General Practice Ltd Newsletter
- North West Melbourne Division of General Practice - Friday Facts Newsletter
- Mid North Division of Rural Medicine - Weekly Murmors Newsletter
- Central West Gippsland Division of General Practice
- General Practice Cairns - Northern Exposure Newsletter
- Monash Division of GP
- General Practice South
  - Blue Mountains Division of GP
  - NSW Rural Doctors Network (RDN) newsletter
  - Western Melbourne Division of General Practice website.
- ACTDGP
  - National Divisions in GP
  - The Border Division of GP - educational long weekend
  - 2007 General Practice & Primary Health Care Research Conference (GP
    - Fact sheets)
  - AGPN Forum (Fact sheets in Nov)
  - Border division of GP for all GPs and Practice Staff
  - North West Courier (GP Newsletter)
Applying evidence to practice
CareSearch have balancing expectations

- How to do palliative care in “two clicks” *versus* depth of content and evidence
  - Wish for prescribing information and ‘how to’ *versus* overview and approach
  - Providing evidence *versus* providing the answer
Balancing expectations

• Real world of general practice *versus* the application of a holistic palliative care approach

• Applicability of what we learn in multidisciplinary teams to the private practice GP setting

• Filtered for quality and manageability *versus* “censored”

• Patient led *versus* doctor led
Creating expectations that are difficult for GPs to meet?
Conclusions

• CareSearch is an online source of quality, evidence based information and resources

• Information instantly available when you need it

• CareSearch brokers information on palliative care issues for General Practice
Conclusions

• Web-based information can meet some but not all needs of GPs, and not all GPs will be willing to use it.

• Patients may actually lead this change as they increasingly use the internet – we can help by giving them high quality resources.
New models of interaction and service provision which involve GPs centrally, and which are compatible with the real-world constraints of general practice are needed if we are to ensure that all patients at the end of life can receive the quality of palliative care which our policies mandate.
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In May 2008, CareSearch will become CareSearch *palliative care knowledge network*

More evidence, resources and information at your fingertips.