Same song, different tune…
What we can learn from comparing two palliative care websites
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On behalf of the CareSearch Project
Dr Christine Sanderson has no conflicts of interest to declare.
For CareSearch, Australia

- Jennifer Tieman
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For the Canadian Virtual Hospice

- Harvey Chochinov
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Welcome to the 21st century
Palliative care goes online…

What a website could potentially do (a wish list!)

* **Awareness raising** about palliative care issues – death and dying, advance care planning, what to expect at the end of life, normalising these experiences
* **Providing information** to people *wherever* and *whenever* they need it
* **Always accessible** – always up to date???
* **Communication and interaction** - between patients and clinicians, amongst clinicians, patient to patient
* **Web-based functionality**
* **A giant library** of information and tools
* **Education and training** – a flexible and efficient way to do it
From wish list to reality

.. And some of the steps in between
So you want to have a website! What do you need to consider?

* **Your purpose** – what makes you tick, your main focus
* **Your audience** – who you are speaking to
* **Your voice** – the style and feel of the site
* **Your content** – what goes in, what doesn’t
* **Architecture** - how the information in the site is structured
* **Navigation** – how users find their way around the site
* **Accessibility** – how your audience find their way to the website and use it
* **Quality assurance** – how you will make sure content is of good quality
* **Maintaining currency** – how you will make sure content is up to date
* **Functionality** – any web-based functions you want to use
Two different websites – two different solutions…

CareSearch

&

Canadian Virtual Hospice

In these two talks you will be able to explore the implications of some of these choices for the development of each website, and identify the strengths and the challenges inherent in each approach.
Introducing CareSearch

Funded by the Australian Government to…

Provide a one-stop shop of information and practical resources that serves the needs of all providing palliative care or affected by palliative care through allowing and supporting dynamic interactions between networks of people so that they can develop, share and apply their knowledge to improve palliative care in Australia … supporting the development of evidence, disseminating information that will support the translation of this evidence into practice and prevent duplication of effort around 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.

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

Quick Links
PubMed Topic Searches
GP Hub
Conferences
Indigenous resources
Palliative Dementia Care
COP

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

Proudly linked to:

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

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

CareSearch is an online resource consolidating evidence based and quality information for various groups within the palliative care community. The website has been funded by the Australian Government as part of the National Palliative Care Program.

A series of principles have guided the development of the CareSearch project.

- Evidence from development to application; the knowledge translation cycle
- Multidisciplinary
- Broad concept of palliative care community (those providing and those affected)
- Granularity - many needs, many points of entry, many ways of communicating
- Quality processes - evidence for activity not merely content
- Currency - updatable processes
- Relationship between the print and web page so they can function independently as sources of information.

This project is a work in progress that reflects the changing nature of palliative care needs and practice and the underlying evidence and literature base that supports clinical care and service delivery.
More than just a website

- Databases and information repositories
- Finding evidence: Brokered resources & How to guides
- Evaluated resources and links
- Content pages: Topics for specific users
- Virtual team resources
- News and updates
- Education Options: Links and online
CareSearch: what makes us tick

Our framing philosophy is

*Promoting evidence-based palliative care*

Everything else flows from this.
CareSearch: what makes us tick

so....

- We select our content according to the “best available evidence” criterion
- We collect the “missing palliative care evidence”
- We help people find and access palliative care evidence
- We help people understand and use palliative care evidence
- We use evidence to improve useability and design of the site
- We use what is freely available online – and don’t duplicate – but also specifically write content if it is needed
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.

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.
CareSearch – our audience

- Researchers in palliative care
  - Palliative care clinicians (all the members of the multidisciplinary team employed specifically in palliative care)
  - Non-specialist clinicians (all the health care professionals who need to be able to care for palliative care patients)
  - Palliative care patients
    - Caregivers – families – friends of patients
    - Policy makers, managers of services
      - General community

Overall – those providing care and those receiving care
CareSearch – our *voice*

- We use best available evidence about how to present online information
- Different voices for different audiences
- Different authors – but a team approach for consistency
- Style guides for each section of the site
- Predefined reading levels – different for the *Clinical Practice* pages and the *Patient and Family* pages
The GP pages were developed following a consultation – they told us they wanted “two click access” to information.

Specific concerns of non-specialist palliative care providers were identified.

Links take users who want to know more to deeper levels of information, and to the evidence that informs the pages.

**Opioids and Pain**

**When to start an opioid**

Opioid analgesics are frequently needed by palliative care patients whose pain does not respond to simple analgesics, weak opioids, adequate doses of adjuvants, and other measures. Adjuvants should be continued.

Persistent pain should be treated promptly. A high index of suspicion about the presence of pain is needed in aged patients who are unable to verbalize their experiences, due to dementia, communication problems or reduced level of consciousness.

**TP** - There is now evidence supporting the use of opioids for dyspnoea as safe and effective, both for patients with lung malignancies and those with other primary lung diseases, including COPD.

**About specific opioids**

Morphine, codeine or hydrocodeine are appropriate strong opioids to start. Fentanyl transdermal patches are an option for stable pain, but they are long-acting and take 12–24 hours to full effect, and are therefore often not suitable for initiating analgesia.

Some analgesics are less suitable for use in palliative care, either because of their inappropriate pharmacokinetics, potential for drug interactions, or other problems. Those include:

- Fentanyl
- Dextromethorphan (Capodex, Dijesic, Parodex, Doloxene)
- Dextromoramide
- Pentazocine.
Patient and Family pages have a different readability level to Clinical pages.

Short DVDs present information in audiovisual formats.

Information has been translated into three community languages.
CareSearch – our content

Challenges

• How to shape the content of this huge field – so that we and others can actually find stuff!
• Boundaries – deciding where palliative care begins and ends
• Covers many disciplines, many conditions and problems, many settings of care
• How to determine specifically what is and is not included – quality control, relevance, transparent processes
CareSearch – our *content*

Strategies

• First of all design your site …Structure comes before content!

• The “Hub” concept – grouping together content for specific audiences (eg for GPs & nurses)

• Crosslinks between different sections and layering of content allow users to choose - they can either “go deep” or get a quick summary

• Transitions – give patients / families some warning about what will be covered
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.

**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.

**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 20 May 2009 and is due for review in May 2011.
CareSearch – our content

• One stop shop: CONTENT → RESOURCES → TOOLS … are all linked

• We avoided the “disease by disease” approach – instead…
  – Clinical Practice pages: are structured around a list of symptoms used to routinely assess palliative care patients (the SAS Symptom Assessment Scale - like the ESAS)
  – Patient and Family pages: are structured around the experience of the disease trajectory

• National Advisory Group (NAG) helps make “big picture” decisions about structure and content
CareSearch – our architecture

Granular
Each page can stand alone

Connected
Each page sits within a logical set of content
Links to other relevant parts of the website are on each page

User-driven
Users can jump between pages, or in and out of the site to explore external links
Clinical Practice

Palliative care as a specialist health field draws upon a body of evidence to support its practice. As a multidisciplinary field it uses research from different academic disciplines and research traditions. Some of this work comes from allied medical areas such as oncology or geriatrics. Other knowledge is contributed by disciplines such as psychology, social work and occupational therapy.

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. They are intended to be dynamic being modified as the evidence base evolves.

The pages have been developed following a pragmatic search of multiple literature databases for systematic reviews relevant to the clinical topic. From this basis, the key issues, limitations and contexts for practice have been summarised. Each page also provides links to sources of clinical guidance and ways to find out more.
Delirium

Background
Delirium is defined as a condition of disturbed consciousness, with reduced ability to focus, sustain or shift attention. The DSM 5 diagnostic criteria [1] for delirium require:

- altered cognition or a perceptual disturbance (which is not due to dementia),
- symptoms develop over hours to days and tend to fluctuate during the course of the day, and
- evidence of an etiological cause for the delirium.

Delirium may be:

- hyperactive (presenting with agitation, hyperarousal, and restlessness), or
- hypoactive (presenting with drowsiness, lethargy and reduced levels of arousal), or
- a mixed pattern in which the symptoms fluctuate between hyperactive and hypoactive.

Delirium is often reversible, although there is evidence that in some patients it may be associated with longer term cognitive problems. [3]

Delirium is extremely common in palliative care patients [4] and becomes more frequent towards the end of life, and is associated with a worsening prognosis. [5] The diagnosis is often missed, or may be confused with depression or dementia. Hypoactive delirium in particular is under-diagnosed. [6] Nonetheless, the importance of making the diagnosis is that delirium is a potentially treatable problem, and one which causes serious distress to patients and their families.

Much of the evidence about prognosis and treatment of delirium comes from the aged care and critical care literature. However, the focus of care in these populations is different from that in palliative care, particularly in very advanced disease. [7] In palliative care patients, delirium is frequently multifactorial. The underlying precipitant, though reversible in many instances, may be irreversible in advanced disease, or due to other factors the decision may be made not to pursue active investigation or intervention.
CareSearch – our *navigation*

Multiple navigation strategies

- Double menu
- Search boxes
- Quick links
- Site map

- And of course – many people just use …
  Google …!
CareSearch - *accessibility*

- Open to all
  - No password-protected areas apart from private forums and research databases
- Offline promotion
  - **Direct** - to professionals
  - **Brokered** - to patients and non-professionals
  - **Printed** resources – our own pages, other information
- Search engine optimisation
- WWW3C standards
- Multilingual and multimedia resources
CareSearch DVD's

Health Professionals

- **Volunteers**: Palliative care volunteers speak about their role in a hospice. [Play](#)
- **Aged Care**: Nurses working in Aged Care speak of issues they face. [Play](#)
- **Social Work**: Social workers speak of working with palliative care clients. [Play](#)
- **Rural**: A nurse speaks of issues faced by those living in rural areas. [Play](#)

Finding Evidence

- **Professor David Currow talks of the importance of evidence in palliative care.** [Play](#)

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. [Play](#)
- **Living with a terminal illness**: There are many things to consider whether it be financial, emotional or practical matters. [Play](#)
- **How to care**: When someone is very ill at home, they need help and support to manage. [Play](#)
- **Groups with specific needs**: Death is a reality of life, but the circumstances can vary greatly as different groups have different needs. [Play](#)
- **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. [Play](#)
CareSearch – our **quality assurance processes**

- Content map overviewed and approved by National Advisory Group
- Internal and external reviews of all content before uploading
- Review cycles – 2 years, but more frequent in rapidly changing clinical areas
- Research projects
- Evaluation (formative and summative) including useability studies
CareSearch – maintaining currency

• Updating content – the two year cycle requires dedicated staffing and resources
• Search boxes on each page which link to PubMed searches using the palliative care filter
  → Users can stay up to date with a single click
• Collection of systematic reviews – continually being added to
• News from the field … “What’s New”
Constipation

Constipation is a frequent complaint in the general community, and more common in palliative care patients. [1-2] Chronic constipation is one of the most frequent side effects of opioids, and occurs in 40 – 70% of patients treated for cancer pain with oral morphine. [3] However other causes of constipation should also be sought and addressed.

An assessment of constipation in the palliative context needs to address opioid induced bowel dysfunction. Other possible contributing factors include:

- Medications – 5-HT3 antagonists, anticholinergics, iron, some antihypertensives
- Decreased oral intake, alterations in diet
- Metabolic abnormalities (eg. hypercalcaemia, uraemia, hypothyroidism, hypokalaemia, diabetes)
- Decreased mobility, weakness
- Obstruction
- Nervous system disorders, demyelinating disease, or peripheral neuropathy.
PubMed Topic Searches

Follow these links to run real-time PubMed searches. They give you a broad entry point into the relevant English, palliative care related literature. When you select a topic, different search options will be provided.

Patient problems
- Airway Obstruction
- Anoxia
- Anxiety
- Appetite
- Artificial Nutrition
- Bereavement
- Bowel Obstruction
- Cachexia (Weight Loss)
- Constipation
- Cough
- Delirium
- Depression
- Dysphagia
- Dyspnoea
- Existential Distress
- Fatigue
- Haemoptysis
- Nausea
- Pain
- Prognosis
- Respiratory Secretions
- Sexuality
- Sleeping Problems
- Suffering
- Vomiting

Specific groups
- Aged
- Aged Care Facilities
- Careers (all)
- Careers (young)
- Dementia
- Disabled
- Homeless
- Indigenous Health
- Multicultural
- Paediatrics
- Rural & Remote Health

Issues relating to care & treatment
- Advance Care Planning
- Advance Directives
- Audit
- Complementary Therapies
- Dignity
- Euthanasia
- Family Distress
- Models of Service Delivery
- Multi-disciplinary Teams
- Palliative Sedation
- Patient Education
- Professional Burnout
- Quality of Life
- Resuscitation Orders
- Social Support
- Spirituality
- Terminal Care
- Volunteering

Health Professionals
- General Practitioners
CareSearch – *our functionalities*

- Research Data Management System
- Databases
- Palliative care filter – which drives the PubMed topic searches and can also be used independently
- Professional Connect

... and more coming
The Research Data Management System

Supports multisite clinical trials, audits, and palliative care research.
Some of the things we decided *not* to do

- **Online chat**
  - Duty of care, follow up, provision of clinical advice online
  - Staffing of the website not adequate to support this function

- **Provide a formulary or make direct clinical recommendations**
  - Duplication of existing resources
  - Medicolegal concerns
  - Different local practices and clinical settings of care
  - Evidence gaps

→ **Alternative:** we provide links to online guidelines or other high quality resources

- **“Disease by disease” approach to content**
  - Unable to be “encyclopaedic”
Some of the things that have worked well…

• Specifically building sections of the site for GPs, and for patients and families
• The online newsletter for nurses – focuses on “how to use CareSearch”
• Intensively promoting the use of the search capacity by clinicians, students, researchers (“Caresearching…”)
• Collecting web-based educational resources
• The branding and identifiability of the site (credible – reliable – accessible information)
So – how are we doing?
# Usage Patterns

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What lies ahead:
knowledge translation research areas

- Filters: Palliative care, heart failure
- Online communication: eHealth literacy, consumer search, readability
- ICT evaluation: Formative, summative
- Translational tools: Carer toolkit,
- Online learning
CareSearch would like to thank the many people who contribute their time and expertise to the project including members of the National Advisory Group and the Knowledge Network Management Group.

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

www.caresearch.com.au
And I would personally like to thank the fantastic CareSearch team, especially Jennifer Tieman

www.caresearch.com.au
The Knowledge Challenge

The application of what we know already will have a bigger impact on health and disease than any drug or technology likely to be introduced in the next decade

Muir Gray 2005
And now…

… its over to the Canadians!