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CareSearch: A resource to support palliative care

Deb Rawlings, CareSearch Project

PC Victoria
Oct 2008

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

Flinders UNIVERSITY

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www.caresearch.com.au

Jennifer Tieman, Deb Rawlings

Australian Knowledge Network Project

Department of Palliative & Supportive Services

Flinders University,

South Australia

Evidence based approach

- An evidence based approach is one that looks to the evidence to answer clinical and service related questions, using the best available evidence to do so

- Role of evidence
  - Providing care
    Best practice; handling new or different care needs
  - Receiving care
    Understanding what is happening; empowering in choices
  - Policy makers
    Helping in planning and allocating resources; population health issues

Issues in generating evidence

- Research infrastructure and capacity still developing
- Attitudes to research in vulnerable populations
- Technical considerations
- Defining and measuring appropriate outcomes

Issues in finding evidence

- Multiple databases
- Size of literature base
- Searching for palliative is complex
- “Missing” literature

Issues in using evidence

- Characteristics of the evidence
- Characteristics of the user
- Characteristics of the organisation /system
- Recipients

CareSearch and evidence

- Identifies and enables access to evidence relevant to palliative care
- Encourages use of evidence
- Used evidence in the design and development of the resource
- Contributes to the evidence base through project research

Searching for Information

- Google
  - ‘Palliative care’ = 4.7 million results
  - 298,000 pages from Australia
- What will you find?
- Of what quality?

CareSearch *palliative care knowledge network*

- **A website that enables access to information and resources**
  - For health professionals involved with palliative care as their major role, or as part of their health care role
  - AND for patients, families and community

Quality processes

- All materials on the website are developed and reviewed by Australian health professionals
  - to ensure that they relate to palliative care
  - that they are trustworthy and reflect the best available evidence
  - Where possible the evidence relates to rigorous research work.



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Logout | Contact CareSearch

Search

Welcome to CareSearch. CareSearch is an online resource of palliative care information and evidence. All materials included in this website are reviewed for quality and relevance.

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

Quick Links
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Introduction to CareSearch
Audio Version

Proudly linked to:

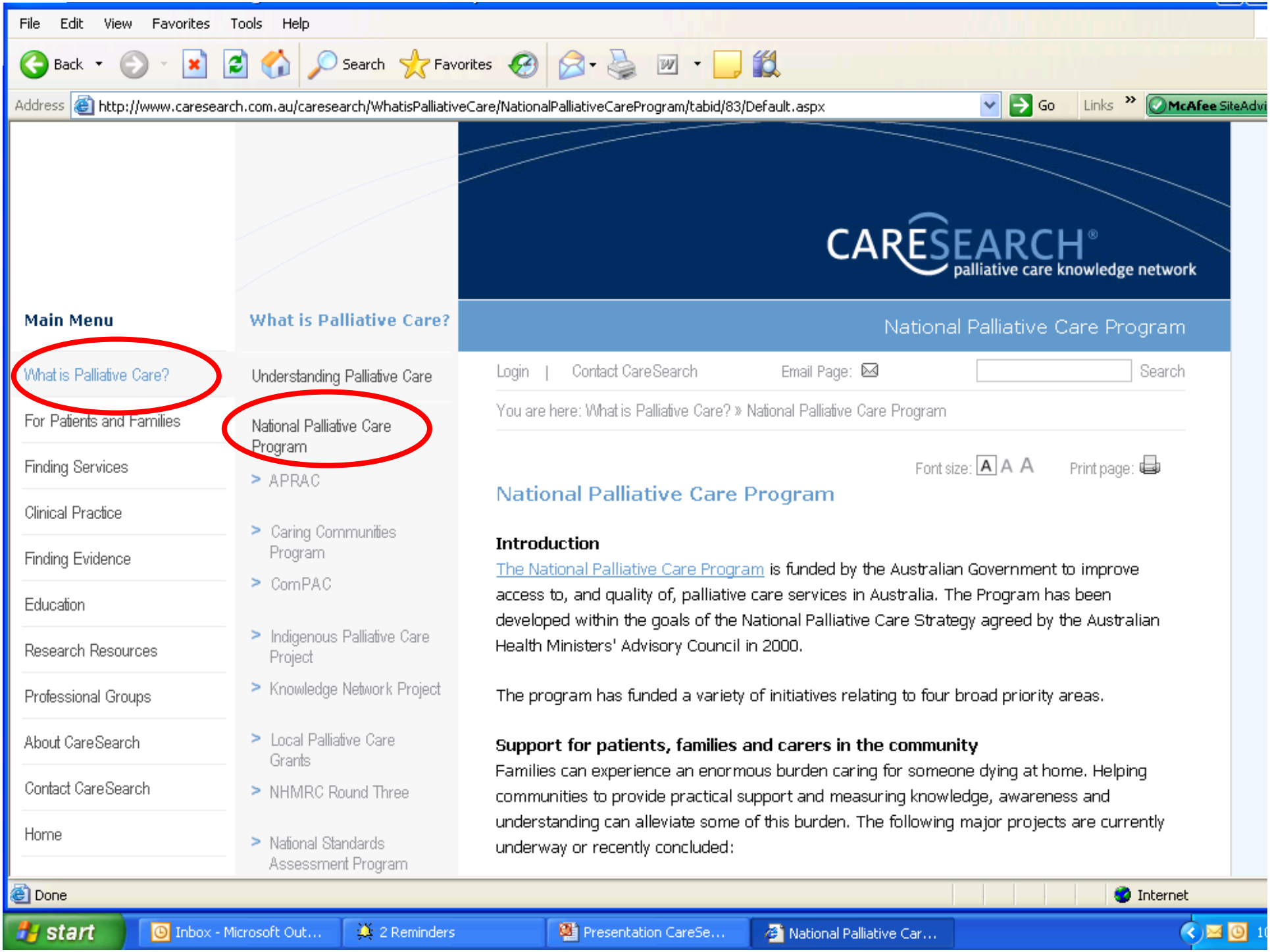
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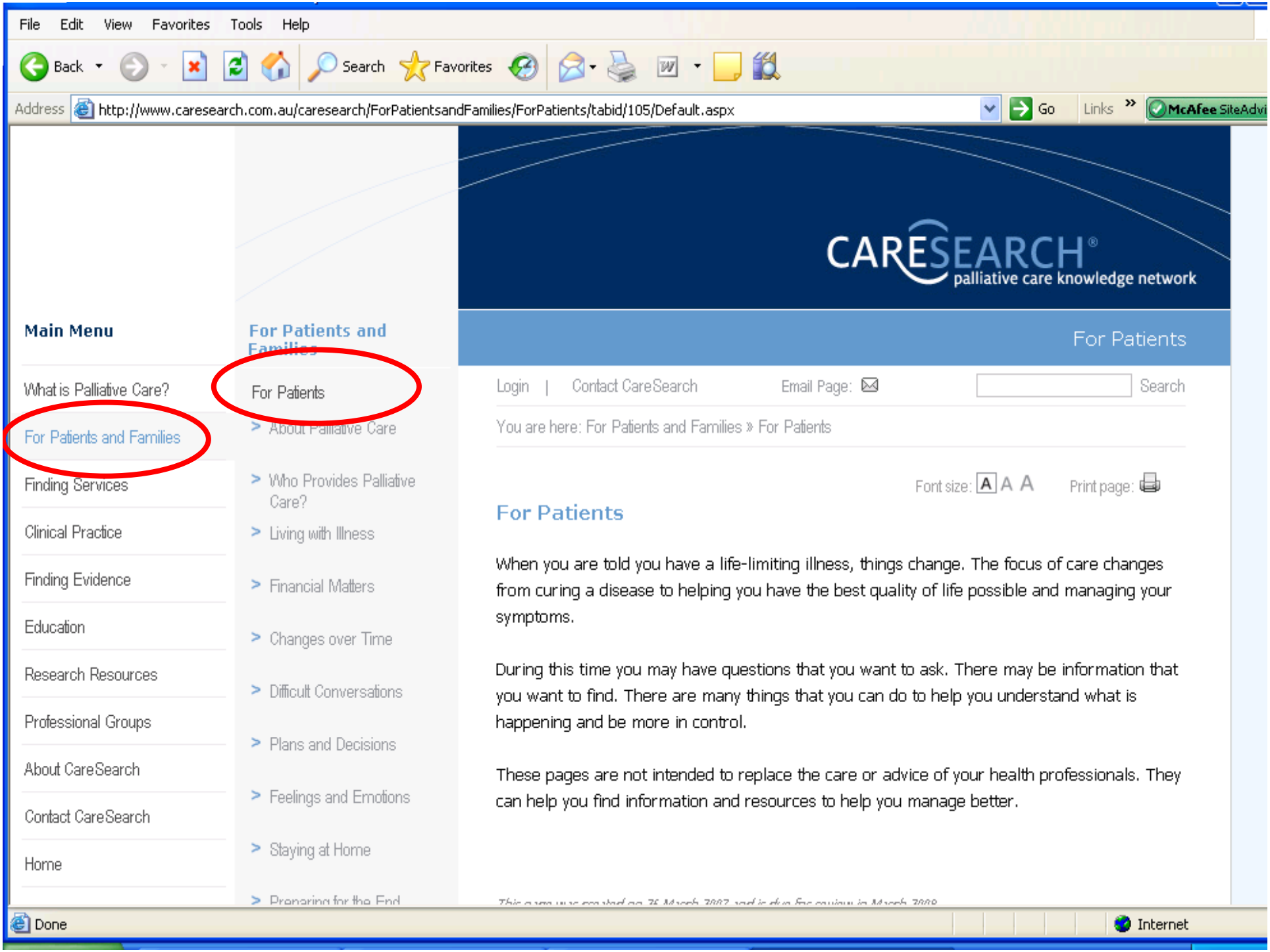
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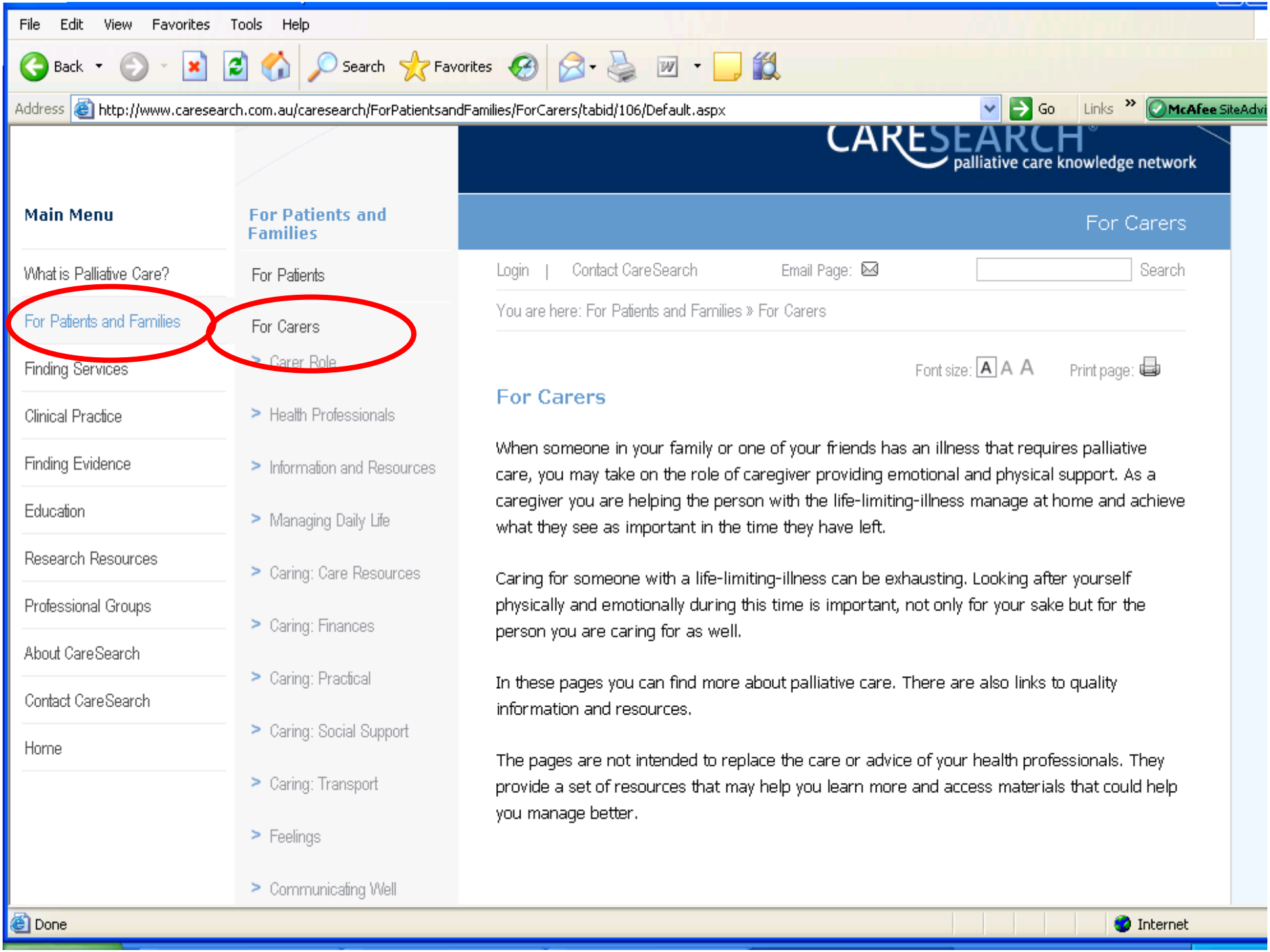
HEALTH *Insite*

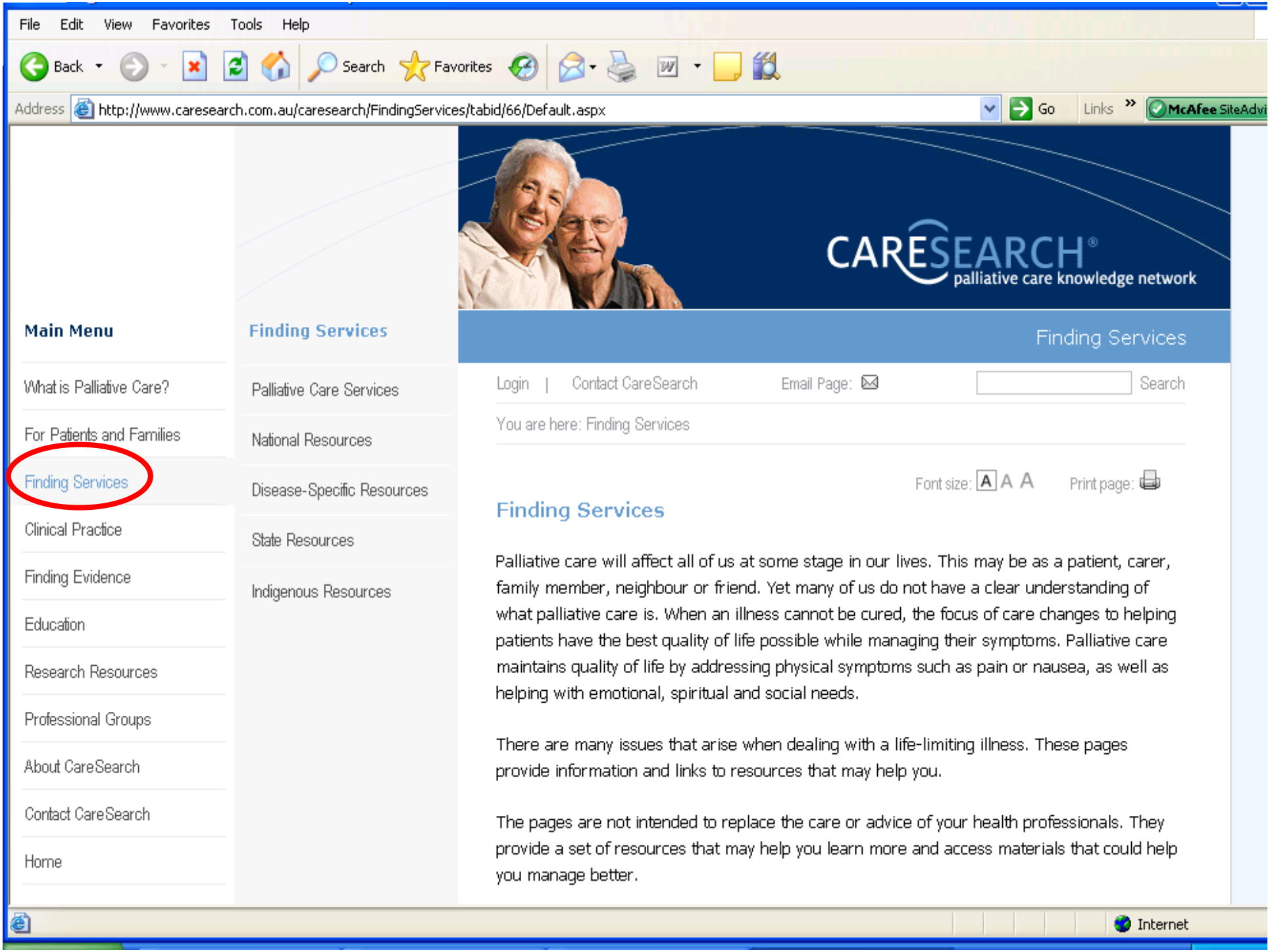
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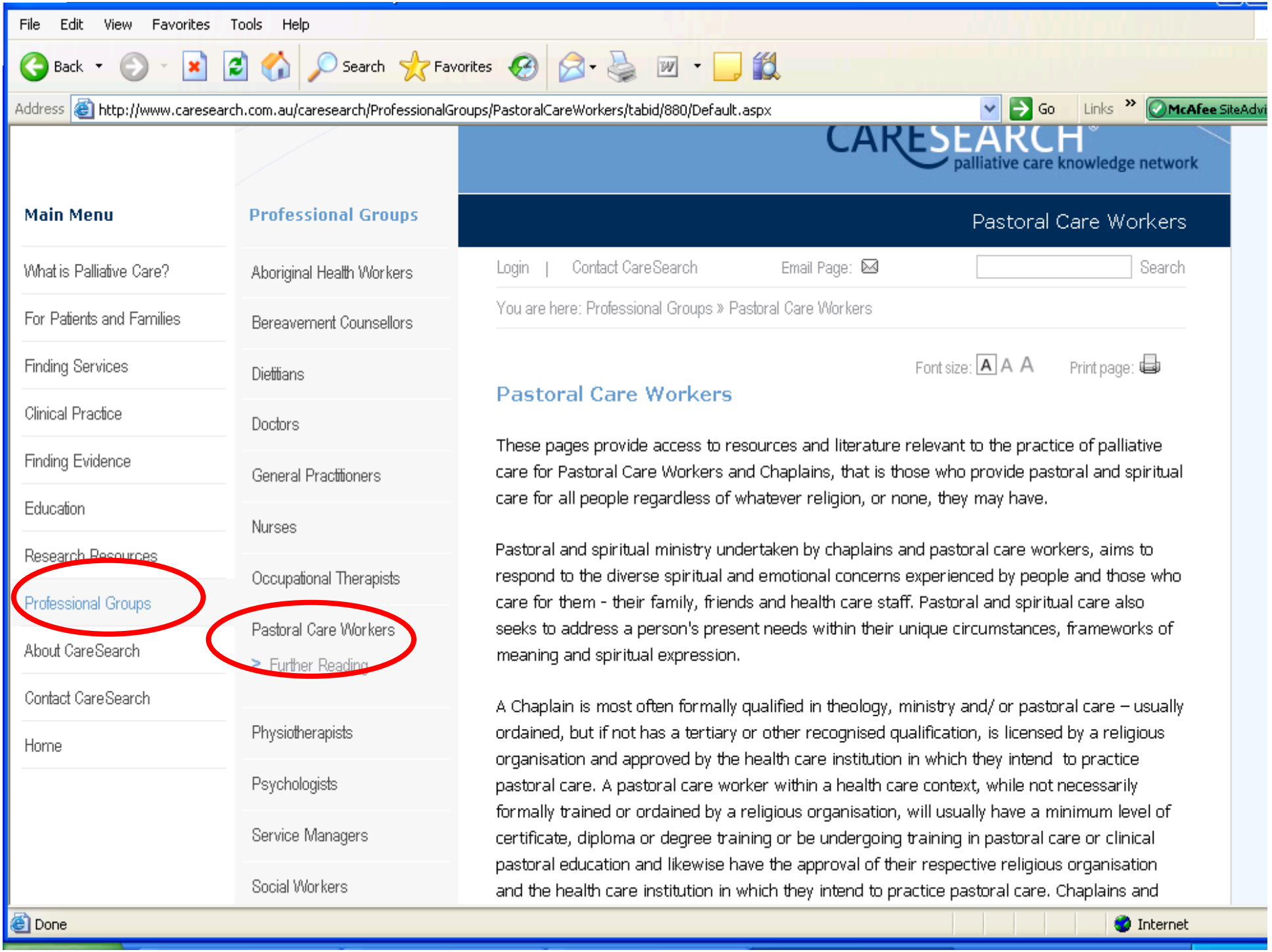
This page was last updated on 26 May 2008


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National Palliative Care Program
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National Palliative Care Program
Introduction
The National Palliative Care Program is funded by the Australian Government to improve access to, and quality of, palliative care services in Australia. The Program has been developed within the goals of the National Palliative Care Strategy agreed by the Australian Health Ministers' Advisory Council in 2000.
The program has funded a variety of initiatives relating to four broad priority areas.
Support for patients, families and carers in the community
Families can experience an enormous burden caring for someone dying at home. Helping communities to provide practical support and measuring knowledge, awareness and understanding can alleviate some of this burden. The following major projects are currently underway or recently concluded:
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2 Reminders
Presentation CareSe...
National Palliative Car...


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> Financial Matters
> Changes over Time
> Difficult Conversations
> Plans and Decisions
> Feelings and Emotions
> Staying at Home
> Preparing for the End
For Patients
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For Patients
When you are told you have a life-limiting illness, things change. The focus of care changes from curing a disease to helping you have the best quality of life possible and managing your symptoms.
During this time you may have questions that you want to ask. There may be information that you want to find. There are many things that you can do to help you understand what is happening and be more in control.
These pages are not intended to replace the care or advice of your health professionals. They can help you find information and resources to help you manage better.
Done
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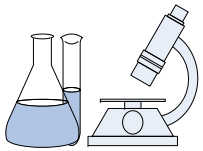

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For Carers
When someone in your family or one of your friends has an illness that requires palliative care, you may take on the role of caregiver providing emotional and physical support. As a caregiver you are helping the person with the life-limiting-illness manage at home and achieve what they see as important in the time they have left.
Caring for someone with a life-limiting-illness can be exhausting. Looking after yourself physically and emotionally during this time is important, not only for your sake but for the person you are caring for as well.
In these pages you can find more about palliative care. There are also links to quality information and resources.
The pages are not intended to replace the care or advice of your health professionals. They provide a set of resources that may help you learn more and access materials that could help you manage better.
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Finding Services
Palliative care will affect all of us at some stage in our lives. This may be as a patient, carer, family member, neighbour or friend. Yet many of us do not have a clear understanding of 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.
There are many issues that arise when dealing with a life-limiting illness. These pages provide information and links to resources that may help you.
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.
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Pastoral Care Workers
These pages provide access to resources and literature relevant to the practice of palliative care for Pastoral Care Workers and Chaplains, that is those who provide pastoral and spiritual care for all people regardless of whatever religion, or none, they may have.
Pastoral and spiritual ministry undertaken by chaplains and pastoral care workers, aims to respond to the diverse spiritual and emotional concerns experienced by people and those who care for them - their family, friends and health care staff. Pastoral and spiritual care also seeks to address a person's present needs within their unique circumstances, frameworks of meaning and spiritual expression.
A Chaplain is most often formally qualified in theology, ministry and/ or pastoral care – usually ordained, but if not has a tertiary or other recognised qualification, is licensed by a religious organisation and approved by the health care institution in which they intend to practice pastoral care. A pastoral care worker within a health care context, while not necessarily formally trained or ordained by a religious organisation, will usually have a minimum level of certificate, diploma or degree training or be undergoing training in pastoral care or clinical pastoral education and likewise have the approval of their respective religious organisation and the health care institution in which they intend to practice pastoral care. Chaplains and
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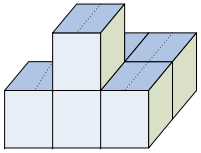
More than just a website



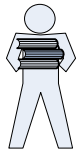
Research Data
Management System



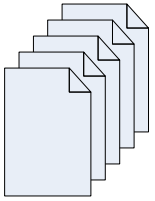
Evaluated resources and links



Databases and
information repositories



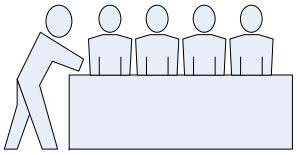
Finding evidence:
Brokered resources
& How to guides



Content pages:
Topics for specific users



News and updates



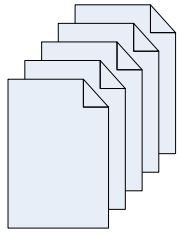
Virtual team resources



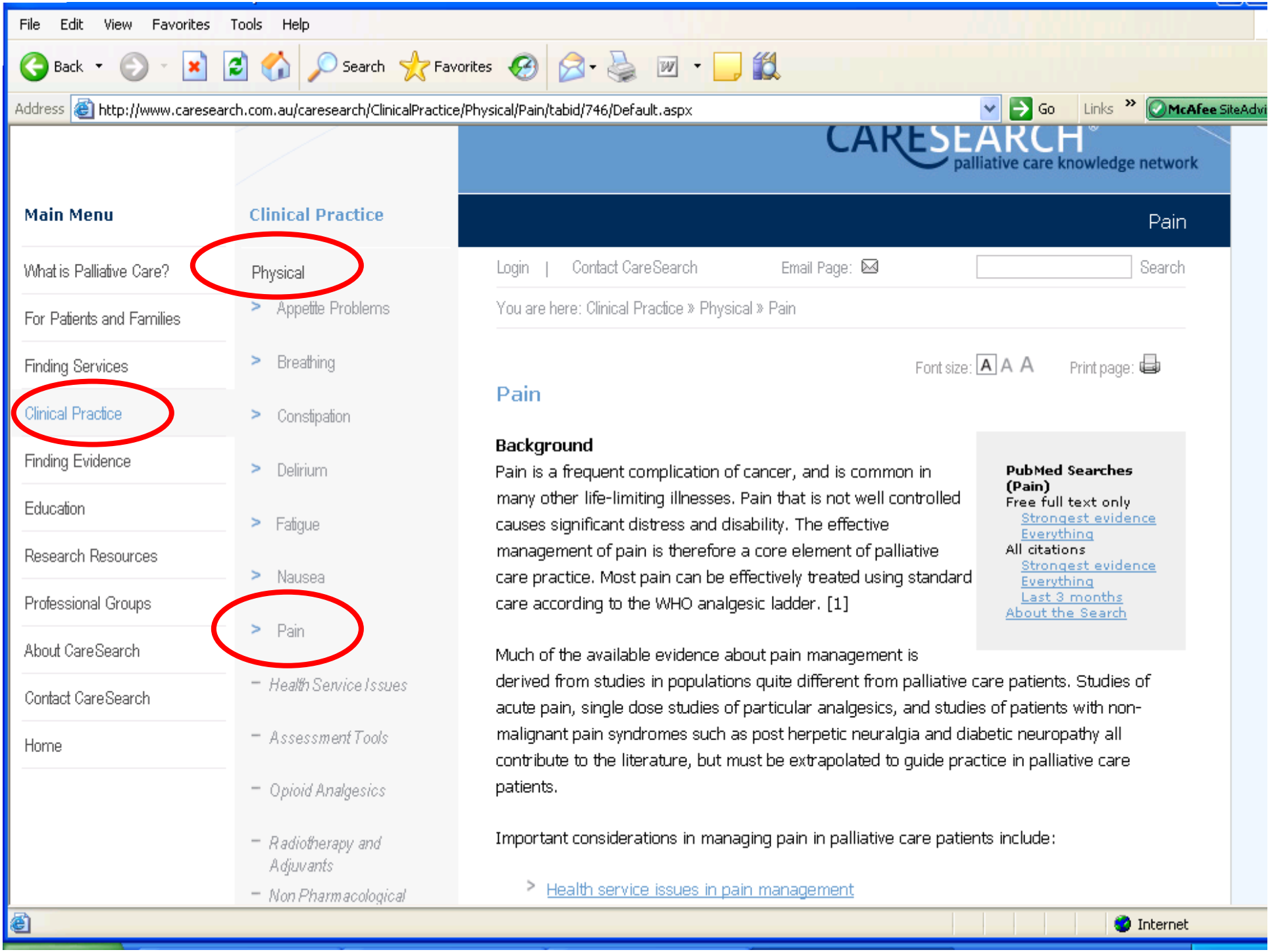
Education Options:
Links and online

Content Pages

- Specifically written content on palliative care topics
- Sections for consumers and for health professionals
- National Palliative Care Program
  - *PCOC*
  - *ComPAC*
  - *Caring communities projects*
  - *Local Palliative Care Grants projects*



Content pages:
Topics for specific users

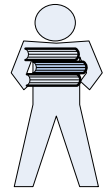

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Radiotherapy and Adjuvants
Non Pharmacological
Pain
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You are here: Clinical Practice » Physical » Pain
Font size: A A A Print page:
Pain
Background
Pain is a frequent complication of cancer, and is common in many other life-limiting illnesses. Pain that is not well controlled causes significant distress and disability. The effective management of pain is therefore a core element of palliative care practice. Most pain can be effectively treated using standard care according to the WHO analgesic ladder. [1]
PubMed Searches (Pain)
Free full text only
Strongest evidence
Everything
All citations
Strongest evidence
Everything
Last 3 months
About the Search
Much of the available evidence about pain management is derived from studies in populations quite different from palliative care patients. Studies of acute pain, single dose studies of particular analgesics, and studies of patients with non-malignant pain syndromes such as post herpetic neuralgia and diabetic neuropathy all contribute to the literature, but must be extrapolated to guide practice in palliative care patients.
Important considerations in managing pain in palliative care patients include:
Health service issues in pain management
Internet

Clinical applications

- Improve patient outcomes through treatment and practice
- Patient and carer support
- Facilitate evidence-based practice

Finding evidence

- Evidence based information about palliative care topics in web pages
- Section within the website on how to find evidence
- Automated brokered access to PubMed
- Access to databases contributing literature, research



Finding evidence:
Brokered resources
& How to guides

PubMed Topic Searches

- PubMed has over 17 million citations that go back to the 1950's. Narrowing your search to one relevant topic can be difficult and time-consuming
  - 50+ topic searches available
  - Weblinks to saved searches on pages
  - English, palliative care related literature
  - 5 search options per topic (eg, free full text)
  - Quick, real time (always current)
  - Designed to find highest level of evidence
  - Embed evidence and expertise into one click

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Clinical Practice

Physical

- > Appetite Problems
- > Breathing
- > Constipation
- > Fatigue
- > Nausea
- > Pain
- > Sleeping Problems

Psychological, Social, Spiritual

Patient Considerations

Professional Considerations

Service Issues

Specific Populations

Fatigue

PubMed Searches (Fatigue)
Free full text only
Strongest evidence
Everything
All citations
Strongest evidence
Everything
Last 3 months
About these searches

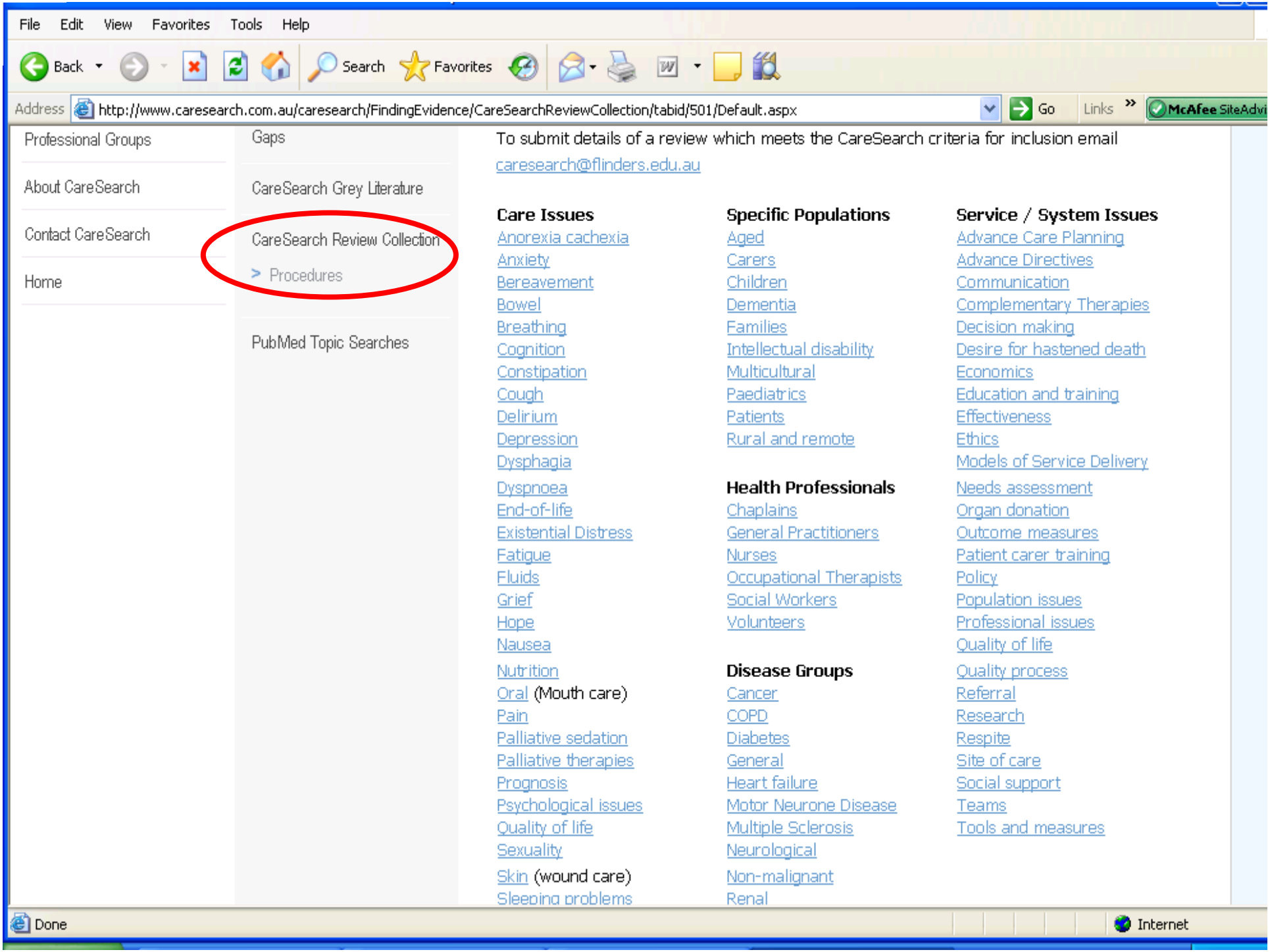
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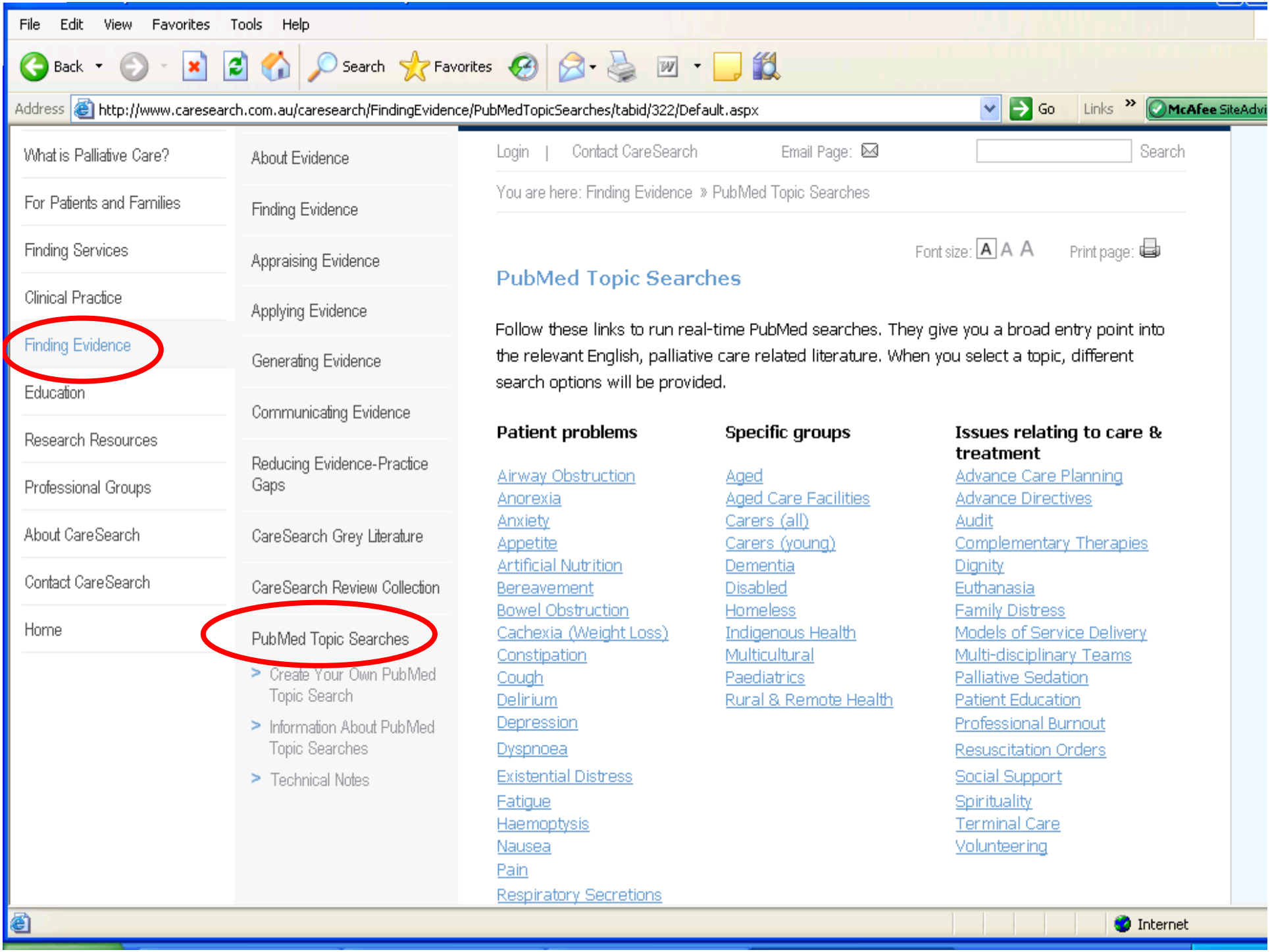
Fatigue is an extremely common problem amongst palliative care patients and causes significant distress, but our understanding of its natural history and causes is still evolving. [1] A systematic review of symptoms in patients with advanced cancer indicated that over half of the patients studied experienced 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.

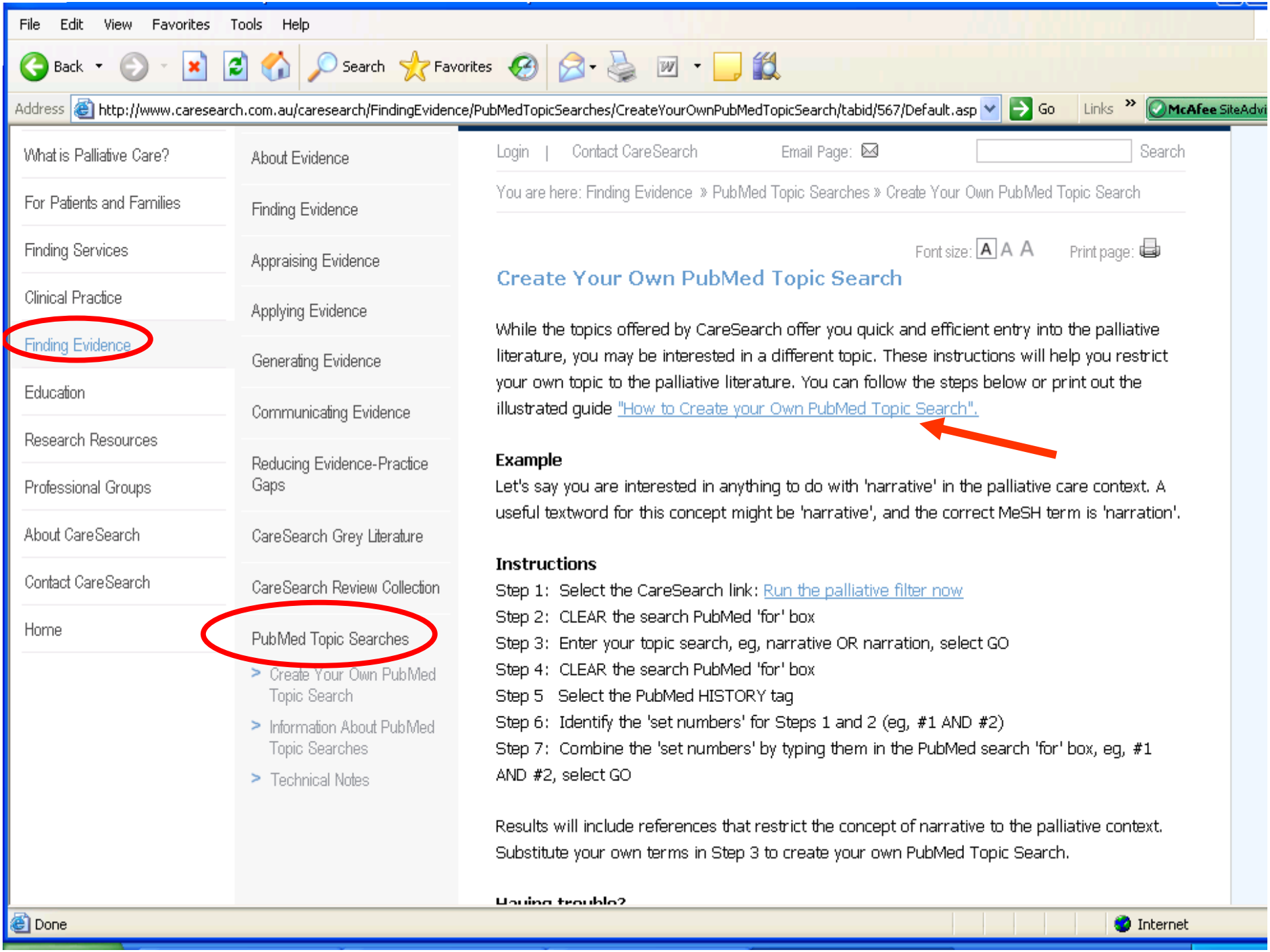
Fatigue: the palliative context

- > Advanced cancer
- > End stage chronic disease
- > HIV-AIDS

Important contributing factors

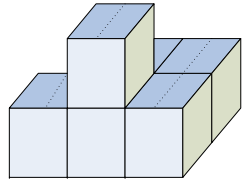

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Existential Distress
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CareSearch Review Collection
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PubMed Topic Searches
Follow these links to run real-time PubMed searches. They give you a broad 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
Anorexia
Anxiety
Appetite
Artificial Nutrition
Bereavement
Bowel Obstruction
Cachexia (Weight Loss)
Constipation
Cough
Delirium
Depression
Dyspnoea
Existential Distress
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Haemoptysis
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Carers (all)
Carers (young)
Dementia
Disabled
Homeless
Indigenous Health
Multicultural
Paediatrics
Rural & Remote Health
Issues relating to care & treatment
Advance Care Planning
Advance Directives
Audit
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Euthanasia
Family Distress
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Terminal Care
Volunteering
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> Create Your Own PubMed Topic Search
> Information About PubMed Topic Searches
> Technical Notes
Login | Contact CareSearch Email Page: Search
You are here: Finding Evidence » PubMed Topic Searches » Create Your Own PubMed Topic Search
Font size: A A A Print page:
Create Your Own PubMed Topic Search
While the topics offered by CareSearch offer you quick and efficient entry into the palliative literature, you may be interested in a different topic. These instructions will help you restrict your own topic to the palliative literature. You can follow the steps below or print out the illustrated guide "How to Create your Own PubMed Topic Search".
Example
Let's say you are interested in anything to do with 'narrative' in the palliative care context. A useful textword for this concept might be 'narrative', and the correct MeSH term is 'narration'.
Instructions
Step 1: Select the CareSearch link: Run the palliative filter now
Step 2: CLEAR the search PubMed 'for' box
Step 3: Enter your topic search, eg, narrative OR narration, select GO
Step 4: CLEAR the search PubMed 'for' box
Step 5 Select the PubMed HISTORY tag
Step 6: Identify the 'set numbers' for Steps 1 and 2 (eg, #1 AND #2)
Step 7: Combine the 'set numbers' by typing them in the PubMed search 'for' box, eg, #1 AND #2, select GO
Results will include references that restrict the concept of narrative to the palliative context. Substitute your own terms in Step 3 to create your own PubMed Topic Search.
Done
Internet

Databases

- CareSearch Grey Literature
  - *National conferences*
- Research Studies Register
  - *Current NPCPC projects*
- CareSearch Review Collection



Databases and
information repositories

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CARESEARCH®
palliative care knowledge network

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Research Resources

- Conducting Research in Palliative Care
- Grants
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- Research Data Management System

Research Resources

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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.

Done Internet

Links and Resources

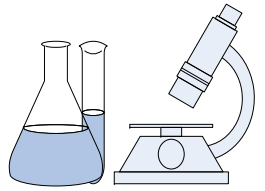
- Connecting to more
- Page hyperlinks
- Summary sets of resources
    - Finding services
    - State information
    - Disease resources
    - Indigenous
- Finding out more
- Evaluated for quality and relevance



Evaluated resources and links

Research Data Management System

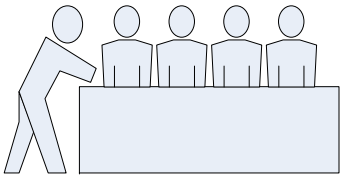
- Online design of data collection forms and surveys
- Data entry from anywhere in the world
- Audit trials and central management
- Statistical analysis and reporting
- Export to Excel, Access and SPSS
  - *PaCCSC*



Research Data
Management System

Virtual Team Resources

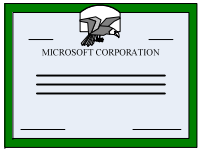
- Project pages restricted by password to team members
- Password protected forums
- Ability to hold skype type meetings
- Ability to hold documents in web
  - *Rural Palliative Care Program*
  - *OT Aust Oncology /Palliative care SIG*



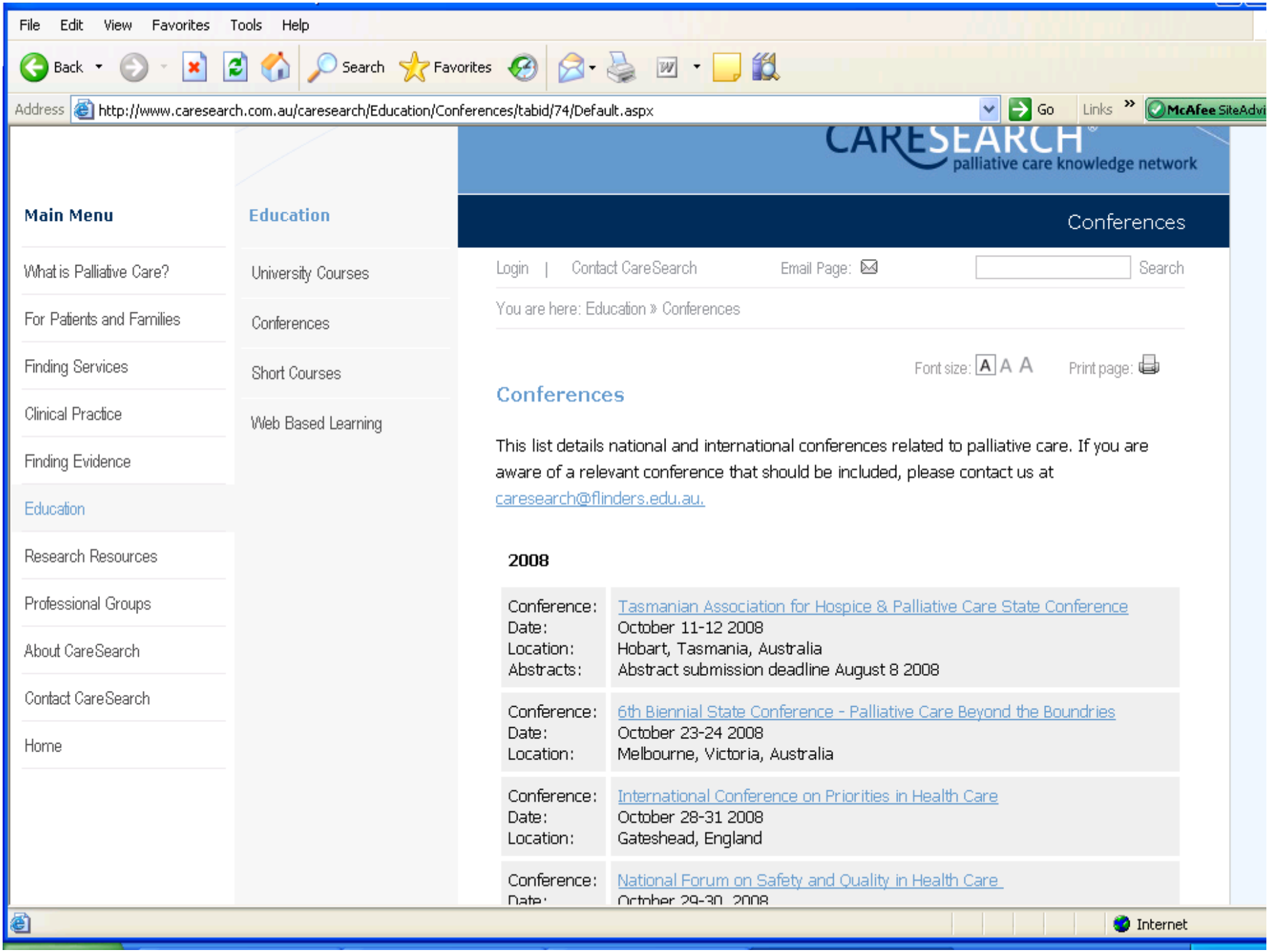
Virtual team resources

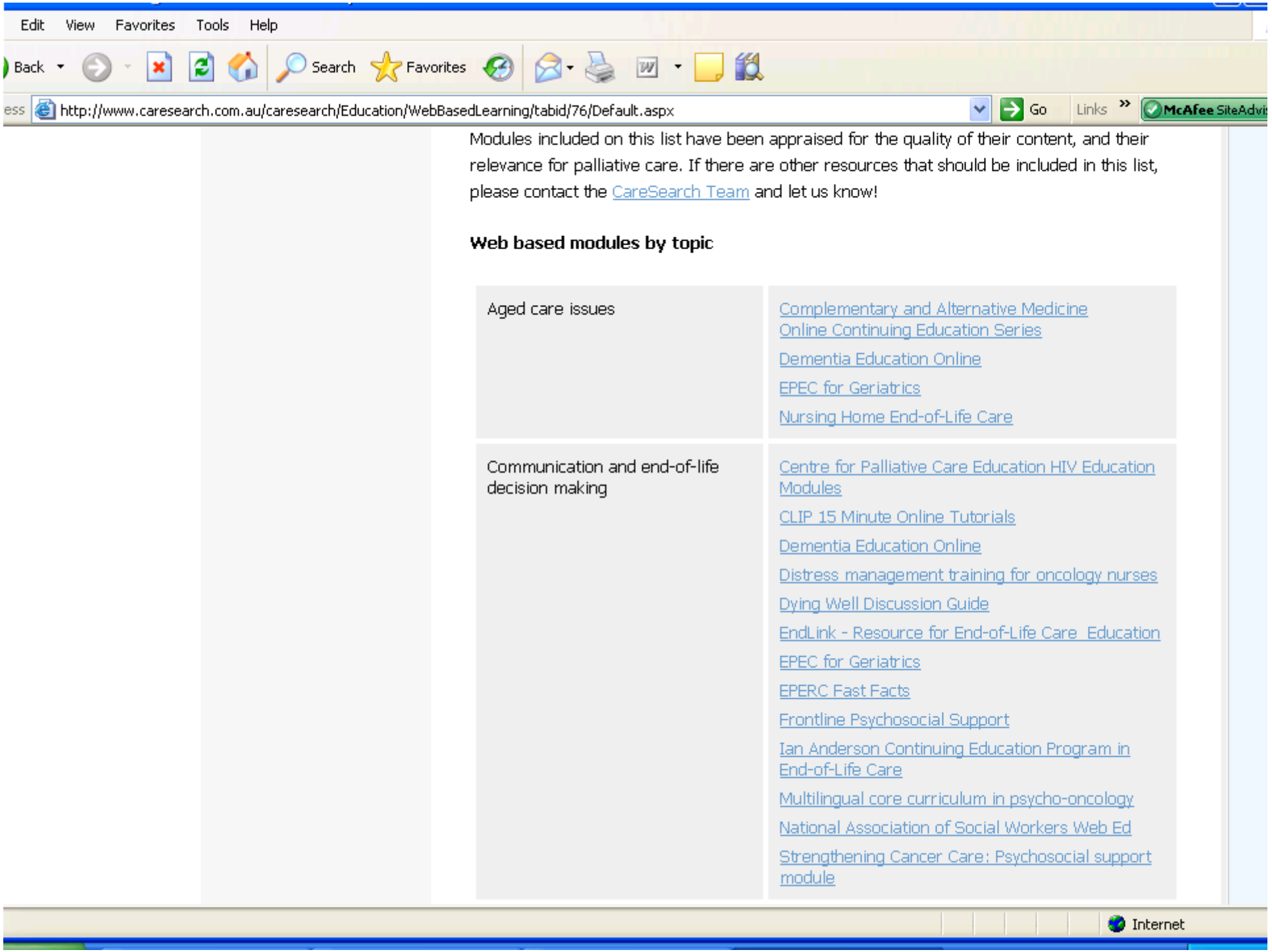
Education Options

- Information and Links
  - Short courses
  - Conferences
  - Formal training
- Web based learning
- Quality checked



Education Options:
Links and online


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Conferences
This list details national and international conferences related to palliative care. If you are aware of a relevant conference that should be included, please contact us at caresearch@flinders.edu.au.
2008
Conference: Tasmanian Association for Hospice & Palliative Care State Conference
Date: October 11-12 2008
Location: Hobart, Tasmania, Australia
Abstracts: Abstract submission deadline August 8 2008
Conference: 6th Biennial State Conference - Palliative Care Beyond the Boundries
Date: October 23-24 2008
Location: Melbourne, Victoria, Australia
Conference: International Conference on Priorities in Health Care
Date: October 28-31 2008
Location: Gateshead, England
Conference: National Forum on Safety and Quality in Health Care
Date: October 29-30 2008
Internet


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Modules included on this list have been appraised for the quality of their content, and their relevance for palliative care. If there are other resources that should be included in this list, please contact the CareSearch Team and let us know!
Web based modules by topic
Aged care issues
Complementary and Alternative Medicine Online Continuing Education Series
Dementia Education Online
EPEC for Geriatrics
Nursing Home End-of-Life Care
Communication and end-of-life decision making
Centre for Palliative Care Education HIV Education Modules
CLIP 15 Minute Online Tutorials
Dementia Education Online
Distress management training for oncology nurses
Dying Well Discussion Guide
EndLink - Resource for End-of-Life Care Education
EPEC for Geriatrics
EPERC Fast Facts
Frontline Psychosocial Support
Ian Anderson Continuing Education Program in End-of-Life Care
Multilingual core curriculum in psycho-oncology
National Association of Social Workers Web Ed
Strengthening Cancer Care: Psychosocial support module
Internet

News and Updates

- What's new on CareSearch
- What's new in the community
- What's new in literature
- @CARESEARCH
- Register for page alerts



News and updates

…and finally…

" Information is a source of learning. But unless it is organized, processed, and available to the right people in a format for decision making, it is a burden, not a benefit."

William Pollard

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