CARESEARCH®
palliative care knowledge network

Palliative Care Resources ‘For Patients and Families’

Deb Rawlings

PCCSA Volunteers Conference
October 2012

CareSearch is funded by the Australian Government Department of Health and Ageing.

Flinders UNIVERSITY

Palliative Care

- Palliative care will affect most people at some stage whether as a patient, carer, family member, neighbour or friend.
- Many people find themselves in the position of providing care for someone who is terminally ill. They may do this regularly or intermittently.

Palliative Care

- In the last year of their lives, those with a terminal illness will spend the majority of their time at home under the care of their GP, community nurses and palliative care services.
- Volunteers have a vital role to play in supporting patients and / or those who are in caregiving roles.

Palliative Care

- Patients and carers are often unprepared for living with illness or for the care giving experience
- Extended family and communities also have questions and require information
- Carers may need help for the person they are looking after, or they may be looking for help and support for themselves or other family members.

Palliative Care

- The ‘For patients and Families’ section was developed to help empower and inform consumers, helping them to understand what is happening and to be aware of care considerations and choices
- Authors such as Thielemann (2000) identify three sets of needs: relating to the patient’s illness, physical caring skills and community resources.

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)

Wilkes L, White K and O'Riordan L. Empowerment through information: supporting rural families of oncology patients in palliative care (2000) Aust J Rural Health 8, 41-6

Timely information

- Good quality information can help with decision making

- “Appropriate and timely information can make the difference between a positive care giving experience and a distressing one” (Dunbrack, 2005).

Dunbrack, J., (2005). *The information needs of informal caregivers involved in providing support to a critically ill loved one: A synthesis report prepared for Health Canada. O*ttawa, ON: Health Canada

Carers

- Carers come in all shapes and sizes, but are not always identified as such
  - Husband, wife, neighbour, friend

- Carers may be ill themselves
- The patient and carer may have different GPs
  - Potentially unaware of home situation

Online Resources

- In this age of technology, the internet is increasingly becoming an important source of information for patients (Penson et al, 2002)
- As a disease progresses, carers have an increased need to know what is going to happen

Penson RT, Benson RC, Parles K, Chabner BA, Lynch TJ (2002) Virtual Connections: Internet Health Care *The Oncologist* 7: 555-568

WWW

- Internet use in Australia is growing
- In 2011 there were 10.9 million Internet subscribers
- 80% of internet users look for health information on the internet*

* http://pewinternet.org/Reports/2011/HealthTopics.aspx

For Patients and Families

- There is an estimated 1 billion Google searches each day (ABS, 2011)

- Why not Google?
  - Palliative Care = 10.9 million results
  - Pages from Australia = 685,000

  - What will you find? Of what Quality?

Australian Bureau of Statistics, *Internet Activity, Australia*, June 2011

Dr. Google Misdiagnoses 25% of Women, 50% Wrongly Self-Medicate

Women who face unexplained health problems are almost twice as likely to check online before going to the doctor, according to a new study which also revealed that one in four British women has misdiagnosed themselves on the internet.

BY CHRISTINE HSU | APRIL 18, 2012

7 Text Size

Women who face unexplained health problems are almost twice as likely to check online before going to the doctor, according to a new study which also revealed that one in four British women has misdiagnosed themselves on the internet.

After checking for their unexplained medical problems on the internet, it was also found tha half of the 1,000 women in the study would then buy a product they think will cure their illness.



'Dr. Google' is now the first port of call for women with genuine health concerns, even though it rarely gives an accurate diagnosis, according to experts.

Health Information on the net

- The Web is an unregulated environment.
- If you can access the internet, you can create a website.
- Anyone can put any information on the web
- There is no requirement to maintain a website, the information may be outdated, it could be moved or removed without notice

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 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.



CARESEARCH®
palliative care knowledge network

CareSearch, *palliative care knowledge network*

Login | 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?

Not sure where to start?
Commonly sought information
Nurses[HUB]
GP pages
Life, Hope and Reality

COMING SOON: Residential Aged Care resource hub!
More information available here.

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

HEALTH*Insite*

HON code CERTIFIED 05/2012

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.

This website was last updated on 24 September 2012

Accessibility | Credits | Terms & Conditions | Site Map

Website

www.caresearch.com.au

CareSearch

- CareSearch has:
  - information and resources for those caring for someone who is terminally ill
  - reviewed the evidence for supporting carers for health professionals
  - access to materials produced in several major projects relating to carers of those with terminal illnesses

For Patients and Families

- Information in this section has been sourced and written differently to the other pages
  - built upon evidence from the published literature
  - 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

National Advisory Group

- The CareSearch National Advisory Group oversees the development. The NAG includes representatives from:
  - Carers Australia
  - Consumer Health Forum
  - Cochrane Consumer Network
  - Carer Respite Centre

Page Review 2012

- The pages are currently being reviewed and updated
- An advisory group is helping the page author to undertake this
  - Content, resources update
  - Lowering readability scores
  - Adding further images, DVD’s



CARESEARCH®
palliative care knowledge network

CareSearch, *palliative care knowledge network*

Login | 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
PubMed Searches
GP Hub
Conferences
Nurses[HUB]

VPCNPC

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

HEALTH *Insite*

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

Accessibility | Credits | Terms & Conditions | Site Map



CARESEARCH®
palliative care knowledge network

For Patients and Families

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families

Font size: A A A Print page:

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
- At The End
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
- Print Resources
- DO YOU NEED HELP NOW?

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

Back to top Print page:

Show Bag / Envelopes

- Includes :
  - Brochures that explain what is in each section of the patient and carer section
  - Can be handed out
  - People can read the brochure and then go online for other information
  - Can be ordered free of charge

Website

For Patients and Families

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

CARESEARCH®
palliative care knowledge network

About Palliative Care

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » About Palliative Care

Font size: A A A Print page:

Main Menu

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

For Patients and Families

- About Palliative Care
  - > What is Palliative Care
  - > Referring to Palliative Care
  - > It's Not Just Cancer
  - > Who Provides Palliative Care
  - > Why Information Matters
- Living With Illness
- How To Care
- At The End
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
- Print Resources
- DO YOU NEED HELP NOW?

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.



About palliative care DVD
Ελληνικά / Italiano / 广东

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

Return to For Patients and Families home page

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

Back to top Print page:

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

CARESEARCH
palliative care knowledge network

Living With Illness

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » Living With Illness

Font size: A A A Print page:

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
  - > Planning For The Future
  - > Financial Matters
  - > Continuing To Work
  - > Changes Over Time
  - > Emotional Challenges
  - > Why Is Communication Important
  - > Symptoms
  - > Complementary Therapies
- How To Care
- At The End
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
- Print Resources
- DO YOU NEED HELP NOW?

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.



Living with Illness DVD
Ελληνικά / Italiano / 广东

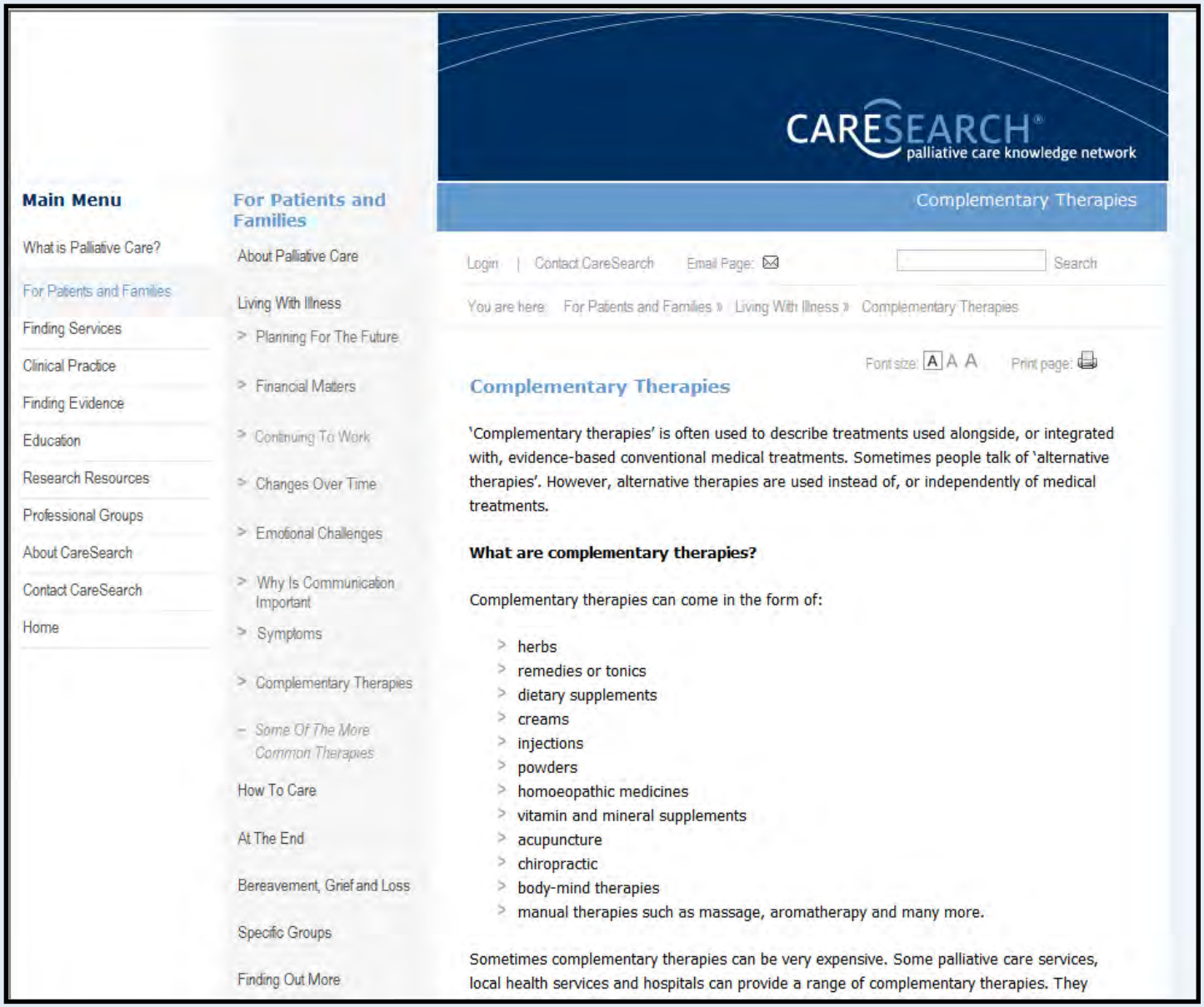
Topics in this section look at:

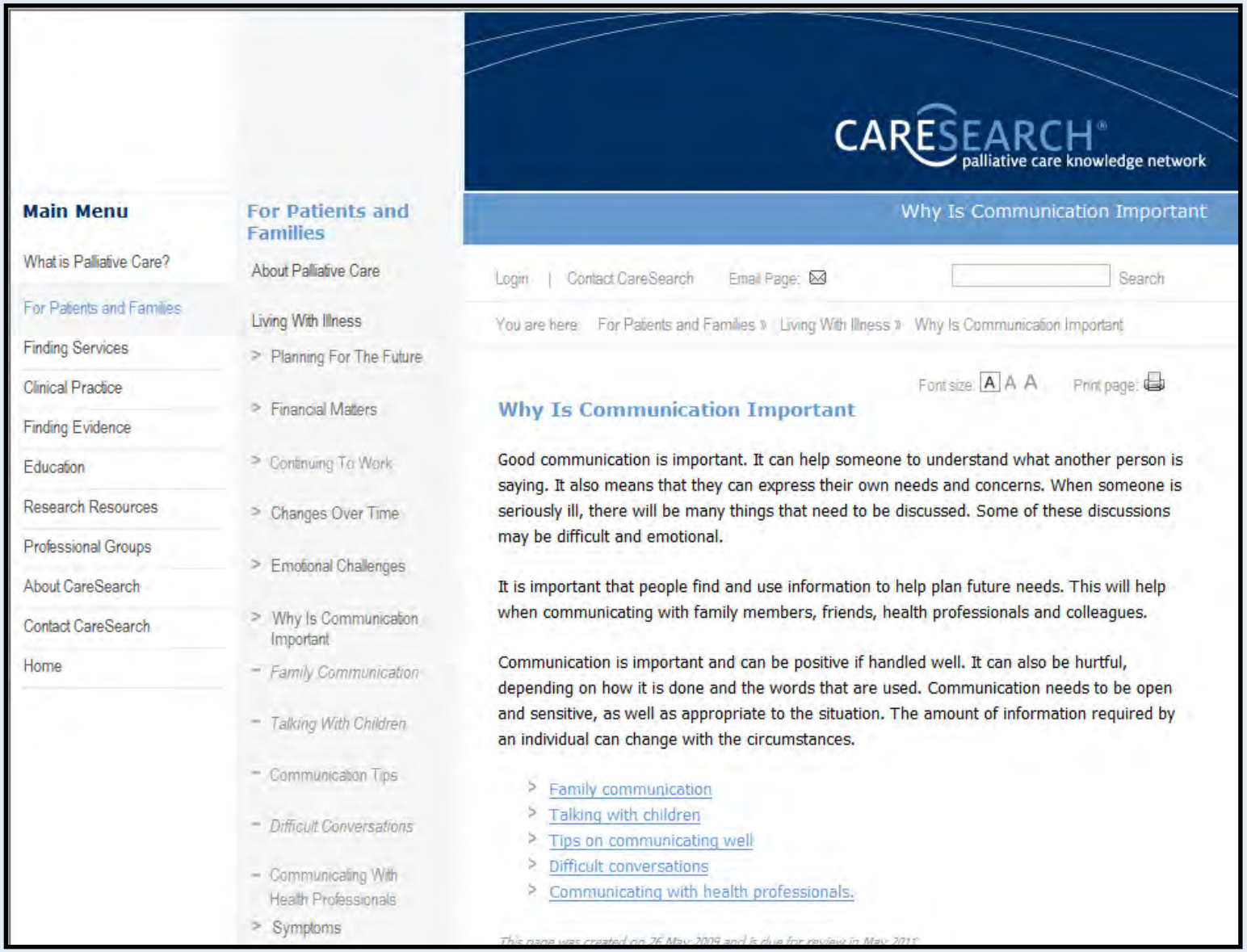
- Planning for the future
- Financial matters
- Continuing to work
- Changes over time
- Emotional challenges
- Communication
- Symptoms
- Complementary therapies

Return to For Patients and Families home page

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

Back to top Print page:


CARESEARCH
palliative care knowledge network
Complementary Therapies
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
> Planning For The Future
> Financial Matters
> Continuing To Work
> Changes Over Time
> Emotional Challenges
> Why Is Communication Important
> Symptoms
> Complementary Therapies
– Some Of The More Common Therapies
How To Care
At The End
Bereavement, Grief and Loss
Specific Groups
Finding Out More
Login | Contact CareSearch Email Page: Search
You are here: For Patients and Families » Living With Illness » Complementary Therapies
Font size: A A A Print page:
Complementary Therapies
'Complementary therapies' is often used to describe treatments used alongside, or integrated with, evidence-based conventional medical treatments. Sometimes people talk of 'alternative therapies'. However, alternative therapies are used instead of, or independently of medical treatments.
What are complementary therapies?
Complementary therapies can come in the form of:
> herbs
> remedies or tonics
> dietary supplements
> creams
> injections
> powders
> homoeopathic medicines
> vitamin and mineral supplements
> acupuncture
> chiropractic
> body-mind therapies
> manual therapies such as massage, aromatherapy and many more.
Sometimes complementary therapies can be very expensive. Some palliative care services, local health services and hospitals can provide a range of complementary therapies. They


CARESEARCH
palliative care knowledge network
Why Is Communication Important
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
> Planning For The Future
> Financial Matters
> Continuing To Work
> Changes Over Time
> Emotional Challenges
> Why Is Communication Important
– Family Communication
– Talking With Children
– Communication Tips
– Difficult Conversations
– Communicating With Health Professionals
> Symptoms
Login | Contact CareSearch Email Page: Search
You are here: For Patients and Families » Living With Illness » Why Is Communication Important
Font size: A A A Print page:
Why Is Communication Important
Good communication is important. It can help someone to understand what another person is saying. It also means that they can express their own needs and concerns. When someone is seriously ill, there will be many things that need to be discussed. Some of these discussions may be difficult and emotional.
It is important that people find and use information to help plan future needs. This will help when communicating with family members, friends, health professionals and colleagues.
Communication is important and can be positive if handled well. It can also be hurtful, depending on how it is done and the words that are used. Communication needs to be open and sensitive, as well as appropriate to the situation. The amount of information required by an individual can change with the circumstances.
> Family communication
> Talking with children
> Tips on communicating well
> Difficult conversations
> Communicating with health professionals.
This page was created on 26 May 2009 and is due for review in May 2015

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’ ‘her neighbour’
- Not many people know what is involved or how to go about it

CARESEARCH®
palliative care knowledge network

How To Care

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » How To Care

Font size: A A A Print page:

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
  - > Looking After Someone
  - > Practical Caring Resources
  - > How To Help Families
  - > Children Provide Care Too
- At The End
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
- Print Resources
- DO YOU NEED HELP NOW?

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.



How to Care DVD
Ελληνικά / Italiano / 广东

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.

CARESEARCH®
palliative care knowledge network

At The End

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » At The End

Font size: A A A Print page:

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
- At The End
  - > Place of Care, Place of Death
  - > Preparing For The End
  - > Caring At The End
  - > Changes At The Time of Death
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
- Print Resources
- DO YOU NEED HELP NOW?

At The End



At the End DVD
Ελληνικά / Italiano / 广东

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

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

Back to top Print page:

Bereavement, Grief and Loss

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

CARESEARCH®
palliative care knowledge network

Bereavement, Grief and Loss

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » Bereavement, Grief and Loss

Font size: A A A Print page

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
- At The End
- Bereavement, Grief and Loss
  - > Grief and Sadness
  - > Grief and Loss Resources
  - > Children and Grief and Loss
  - > Loss of a Child
  - > Remembering and Recovering
- Specific Groups
- Finding Out More
- Print Resources
- DO YOU NEED HELP NOW?

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.



Bereavement Grief and Loss DVD
Ελληνικά / Italiano / 广东

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

Back to top Print page:

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

CARESEARCH®
palliative care knowledge network

Specific Groups

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » Specific Groups

Font size: A A A Print page

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
- At The End
- Bereavement, Grief and Loss
- Specific Groups
  - > Homelessness
  - > Indigenous
  - > Intellectually Disabled
  - > Gay, Lesbian, Bisexual and Transgender
  - > Living Alone
  - > Multicultural
  - > Older People
  - > Paediatrics
  - > People with Dementia

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.

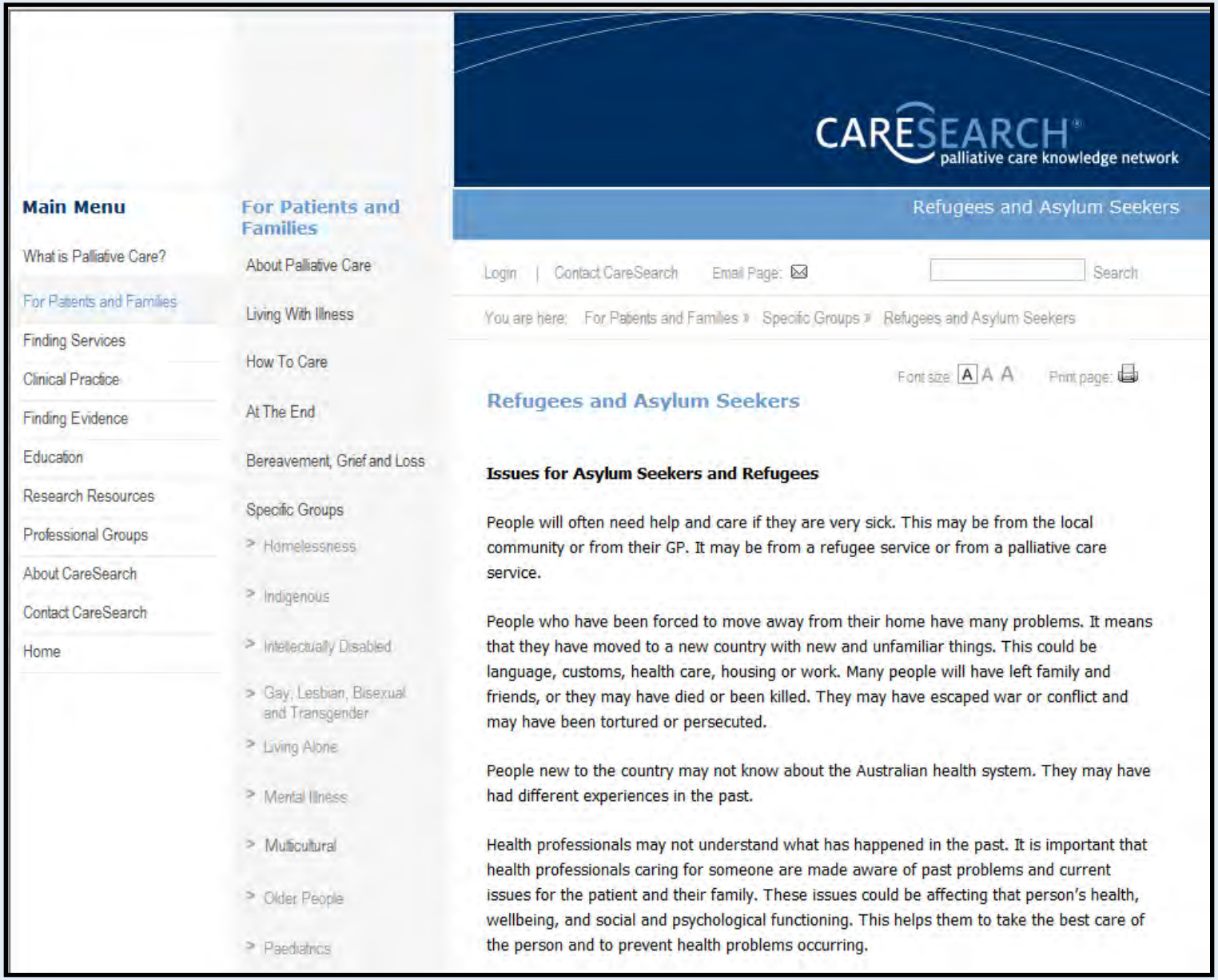
When someone in the family or your community has a serious life limiting illness, they will need support and care. The amount and type of support needed varies from person to person. People living with a terminal illness may require different types of care and support depending on their disease, where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



Groups with specific needs DVD
Ελληνικά / Italiano / 广东

Return to For Patients and Families home page


CARESEARCH
palliative care knowledge network
Refugees and Asylum Seekers
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
How To Care
At The End
Bereavement, Grief and Loss
Specific Groups
Homelessness
Indigenous
Intellectually Disabled
Gay, Lesbian, Bisexual and Transgender
Living Alone
Mental Illness
Multicultural
Older People
Paediatrics
Login | Contact CareSearch Email Page:
Search
You are here: For Patients and Families » Specific Groups » Refugees and Asylum Seekers
Font size: A A A
Print page:
Refugees and Asylum Seekers
Issues for Asylum Seekers and Refugees
People will often need help and care if they are very sick. This may be from the local community or from their GP. It may be from a refugee service or from a palliative care service.
People who have been forced to move away from their home have many problems. It means that they have moved to a new country with new and unfamiliar things. This could be language, customs, health care, housing or work. Many people will have left family and friends, or they may have died or been killed. They may have escaped war or conflict and may have been tortured or persecuted.
People new to the country may not know about the Australian health system. They may have had different experiences in the past.
Health professionals may not understand what has happened in the past. It is important that health professionals caring for someone are made aware of past problems and current issues for the patient and their family. These issues could be affecting that person's health, wellbeing, and social and psychological functioning. This helps them to take the best care of the person and to prevent health problems occurring.

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

CARESEARCH®
palliative care knowledge network

Finding Out More

Login | Contact CareSearch Email Page: Search

You are here: For Patients and Families » Finding Out More

Font size: A A A Print page:

Main Menu

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

For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
- At The End
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
  - > Sources of Information
  - > Is it Trustworthy?
  - > Using Information
  - > How Research Contributes
- Print Resources
- DO YOU NEED HELP NOW?

Finding Out More



Finding out More DVD
Ελληνικά / Italiano / 广东

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:

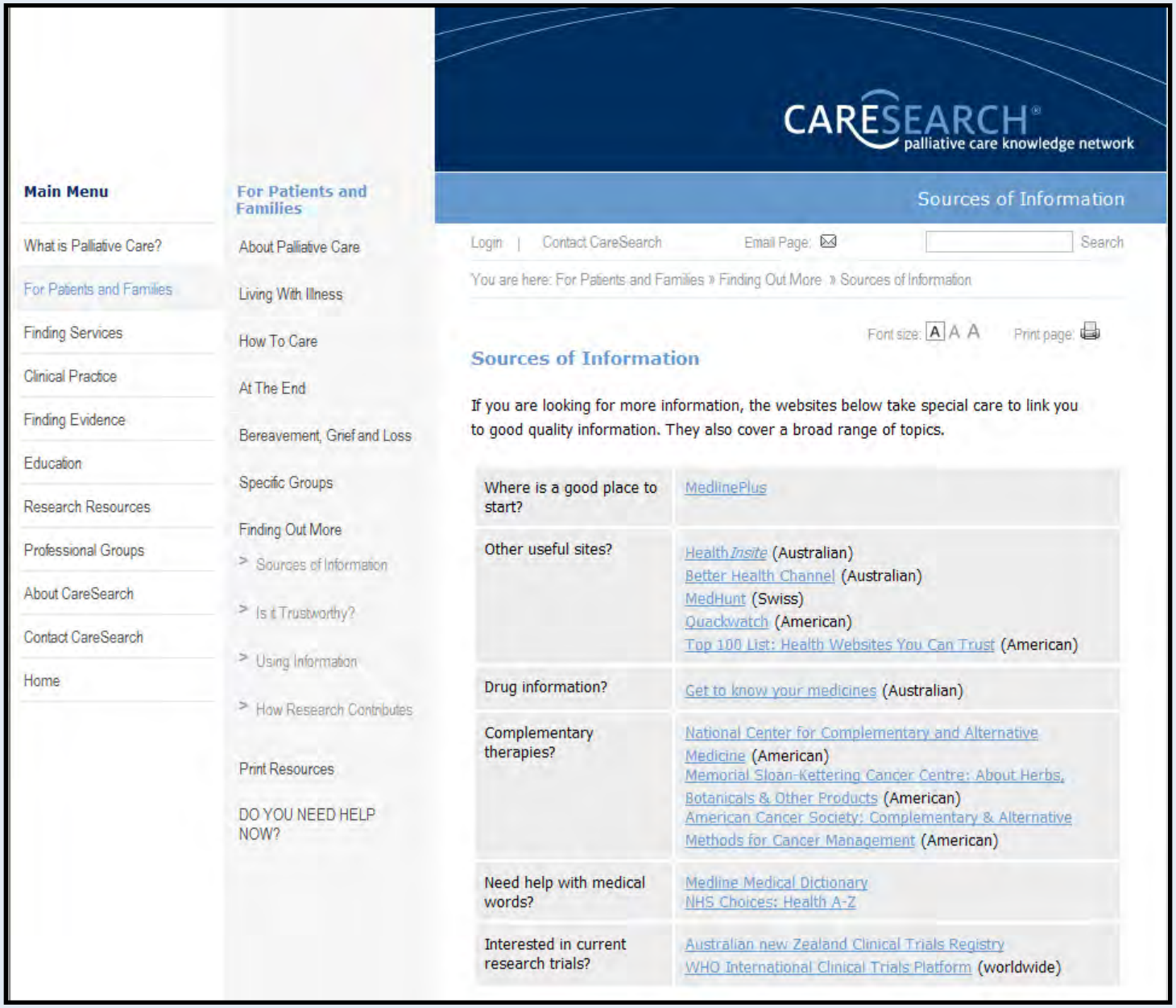
- Find good information sources and databases
- Assess the quality of information and sites on the web
- Think about how to use this information
- Learn more about research.

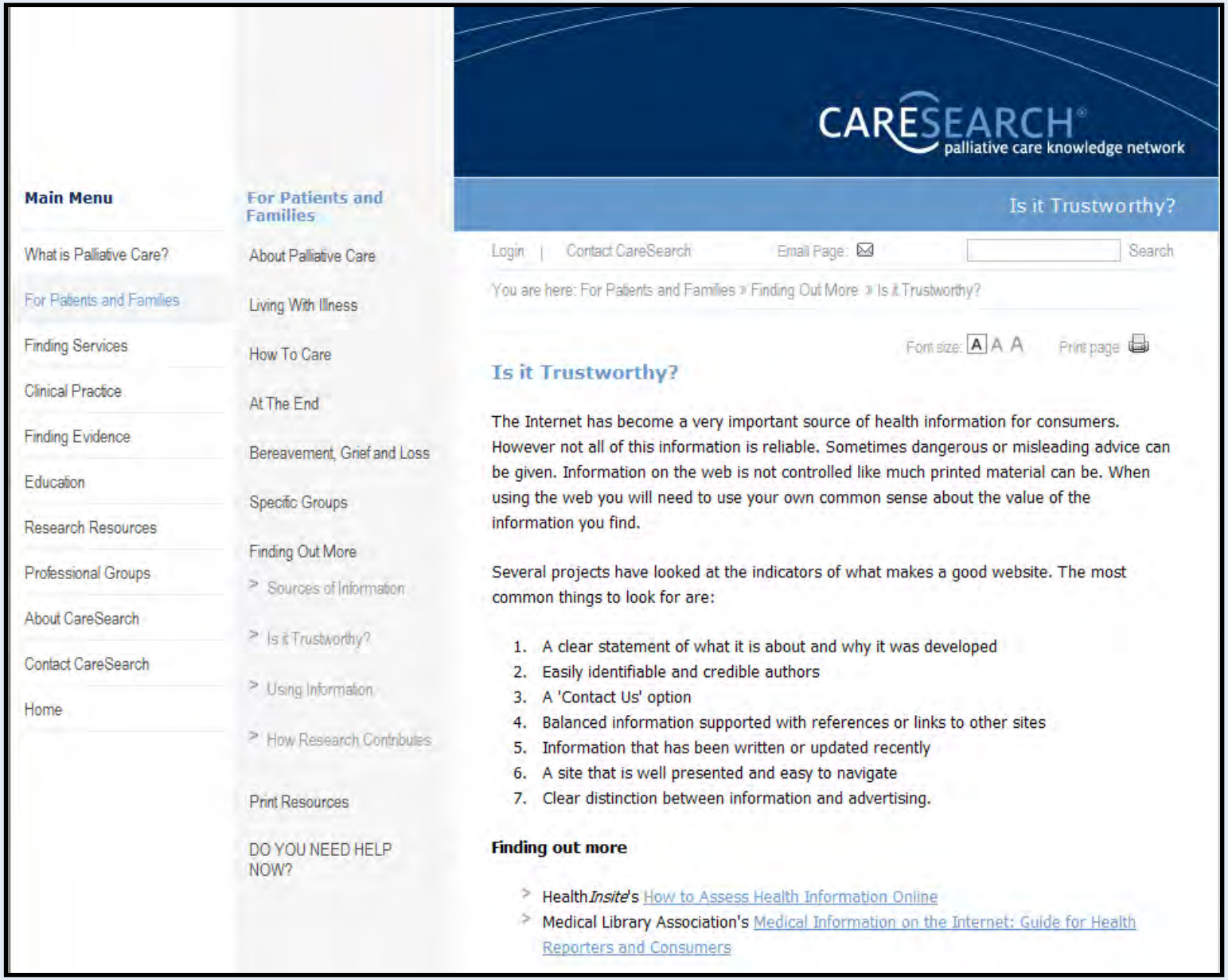
Return to For Patients and Families home page

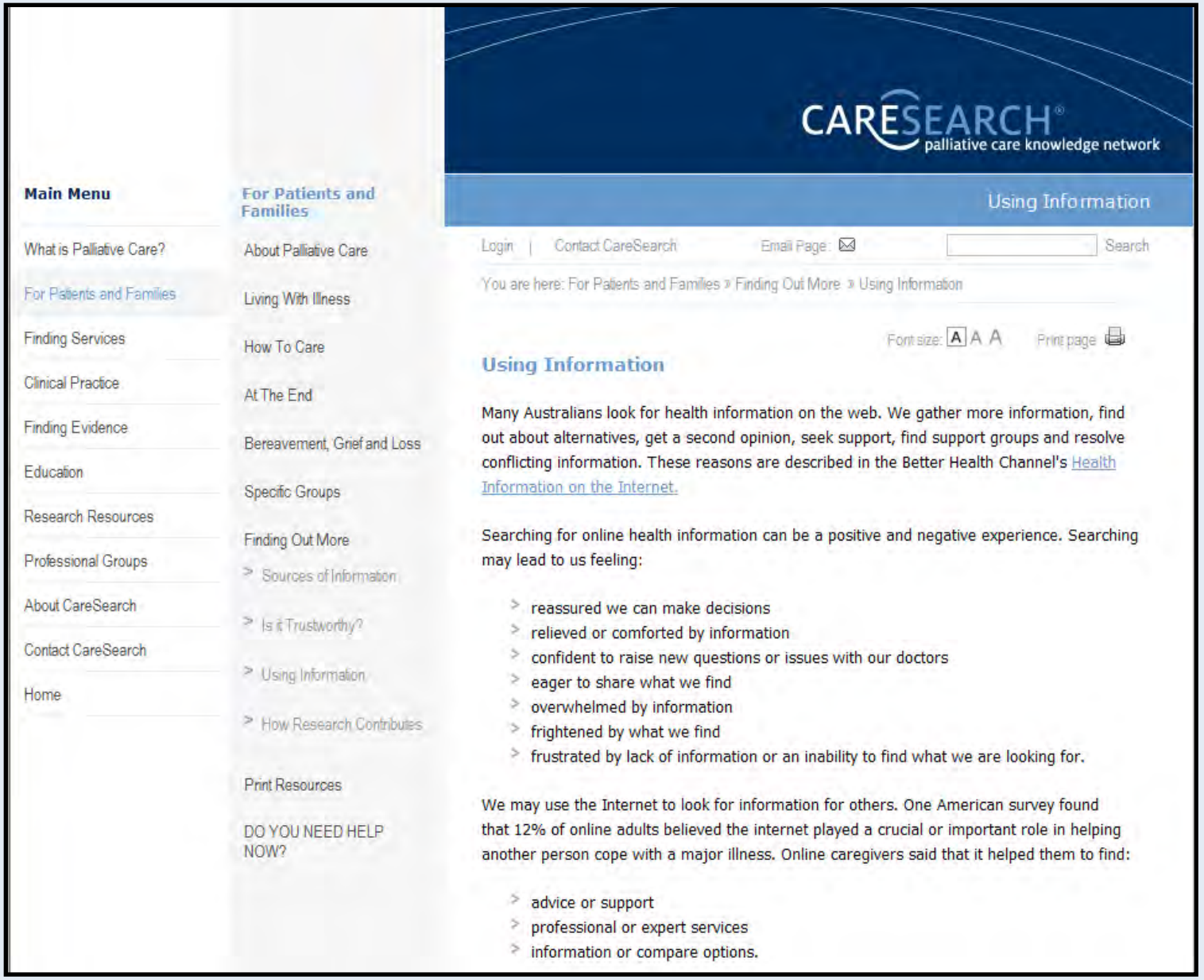
This page was created on 30 April 2008 and is due for review in April 2010.
*Last updated 26 May 2008**

Back to top Print page:

Accessibility | Credits | Terms & Conditions | Site Map


CARESEARCH
palliative care knowledge network
Sources of Information
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
How To Care
At The End
Bereavement, Grief and Loss
Specific Groups
Finding Out More
> Sources of Information
> Is it Trustworthy?
> Using Information
> How Research Contributes
Print Resources
DO YOU NEED HELP NOW?
Login | Contact CareSearch
Email Page:
Search
You are here: For Patients and Families » Finding Out More » Sources of Information
Font size: A A A
Print page:
Sources of Information
If you are looking for more information, the websites below take special care to link you to good quality information. They also cover a broad range of topics.
Where is a good place to start?
MedlinePlus
Other useful sites?
HealthInsite (Australian)
Better Health Channel (Australian)
MedHunt (Swiss)
Quackwatch (American)
Top 100 List: Health Websites You Can Trust (American)
Drug information?
Get to know your medicines (Australian)
Complementary therapies?
National Center for Complementary and Alternative Medicine (American)
Memorial Sloan-Kettering Cancer Centre: About Herbs, Botanicals & Other Products (American)
American Cancer Society: Complementary & Alternative Methods for Cancer Management (American)
Need help with medical words?
Medline Medical Dictionary
NHS Choices: Health A-Z
Interested in current research trials?
Australian new Zealand Clinical Trials Registry
WHO International Clinical Trials Platform (worldwide)


CARESEARCH®
palliative care knowledge network
Is it Trustworthy?
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
How To Care
At The End
Bereavement, Grief and Loss
Specific Groups
Finding Out More
Sources of Information
Is it Trustworthy?
Using Information
How Research Contributes
Print Resources
DO YOU NEED HELP NOW?
Login | Contact CareSearch Email Page: Search
You are here: For Patients and Families » Finding Out More » Is it Trustworthy?
Font size: A A A Print page
Is it Trustworthy?
The Internet has become a very important source of health information for consumers. However not all of this information is reliable. Sometimes dangerous or misleading advice can be given. Information on the web is not controlled like much printed material can be. When using the web you will need to use your own common sense about the value of the information you find.
Several projects have looked at the indicators of what makes a good website. The most common things to look for are:
1. A clear statement of what it is about and why it was developed
2. Easily identifiable and credible authors
3. A 'Contact Us' option
4. Balanced information supported with references or links to other sites
5. Information that has been written or updated recently
6. A site that is well presented and easy to navigate
7. Clear distinction between information and advertising.
Finding out more
HealthInsite's How to Assess Health Information Online
Medical Library Association's Medical Information on the Internet: Guide for Health Reporters and Consumers



CARESEARCH®
palliative care knowledge network

Using Information

Login | Contact CareSearch Email Page Search

You are here: For Patients and Families » Finding Out More » Using Information

Font size: A A A Print page

Using Information

Many Australians look for health information on the web. We gather more information, find out about alternatives, get a second opinion, seek support, find support groups and resolve conflicting information. These reasons are described in the Better Health Channel's Health Information on the Internet.

Searching for online health information can be a positive and negative experience. Searching may lead to us feeling:

- reassured we can make decisions
- relieved or comforted by information
- confident to raise new questions or issues with our doctors
- eager to share what we find
- overwhelmed by information
- frightened by what we find
- frustrated by lack of information or an inability to find what we are looking for.

We may use the Internet to look for information for others. One American survey found that 12% of online adults believed the internet played a crucial or important role in helping another person cope with a major illness. Online caregivers said that it helped them to find:

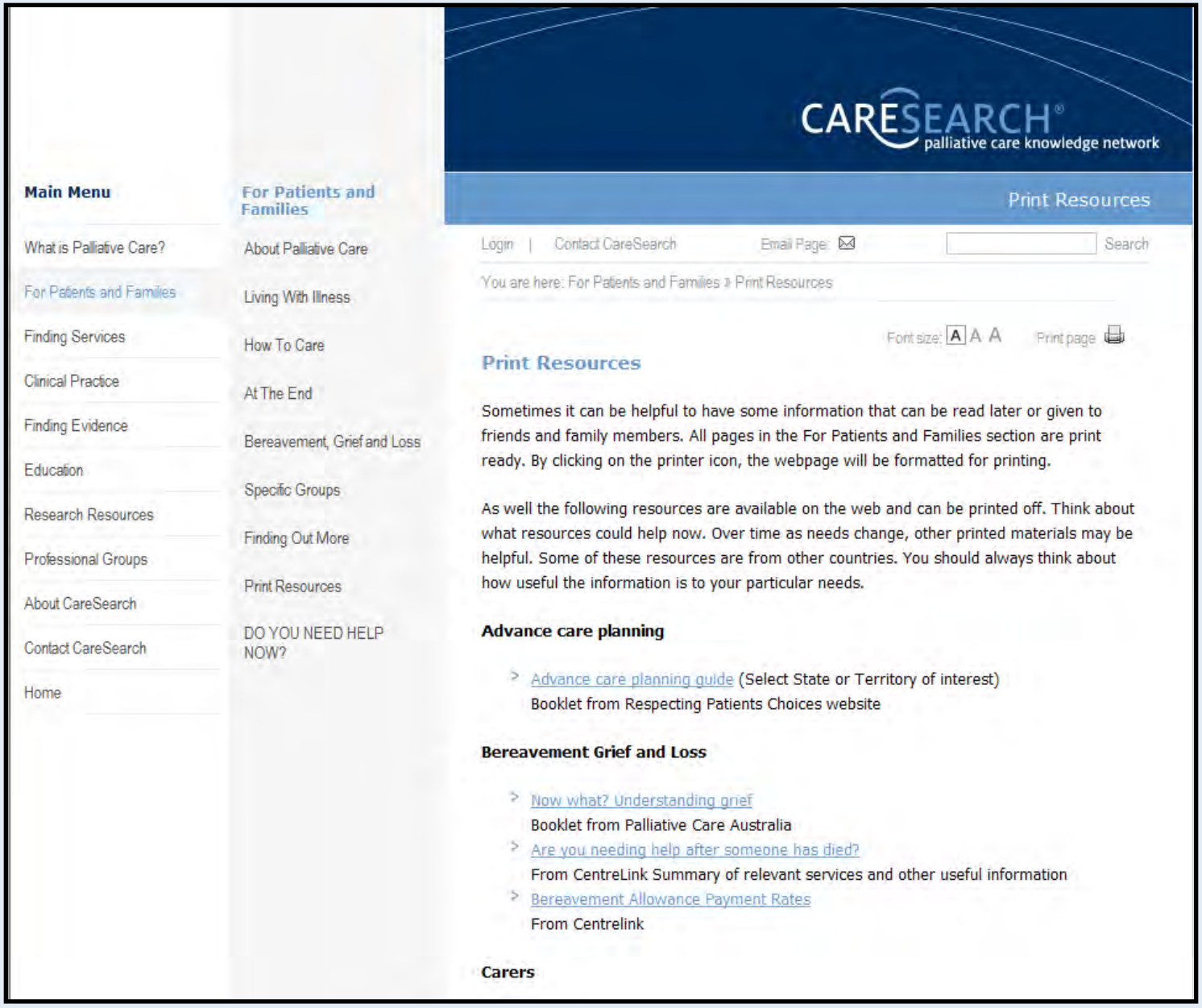
- advice or support
- professional or expert services
- information or compare options.

Main Menu

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

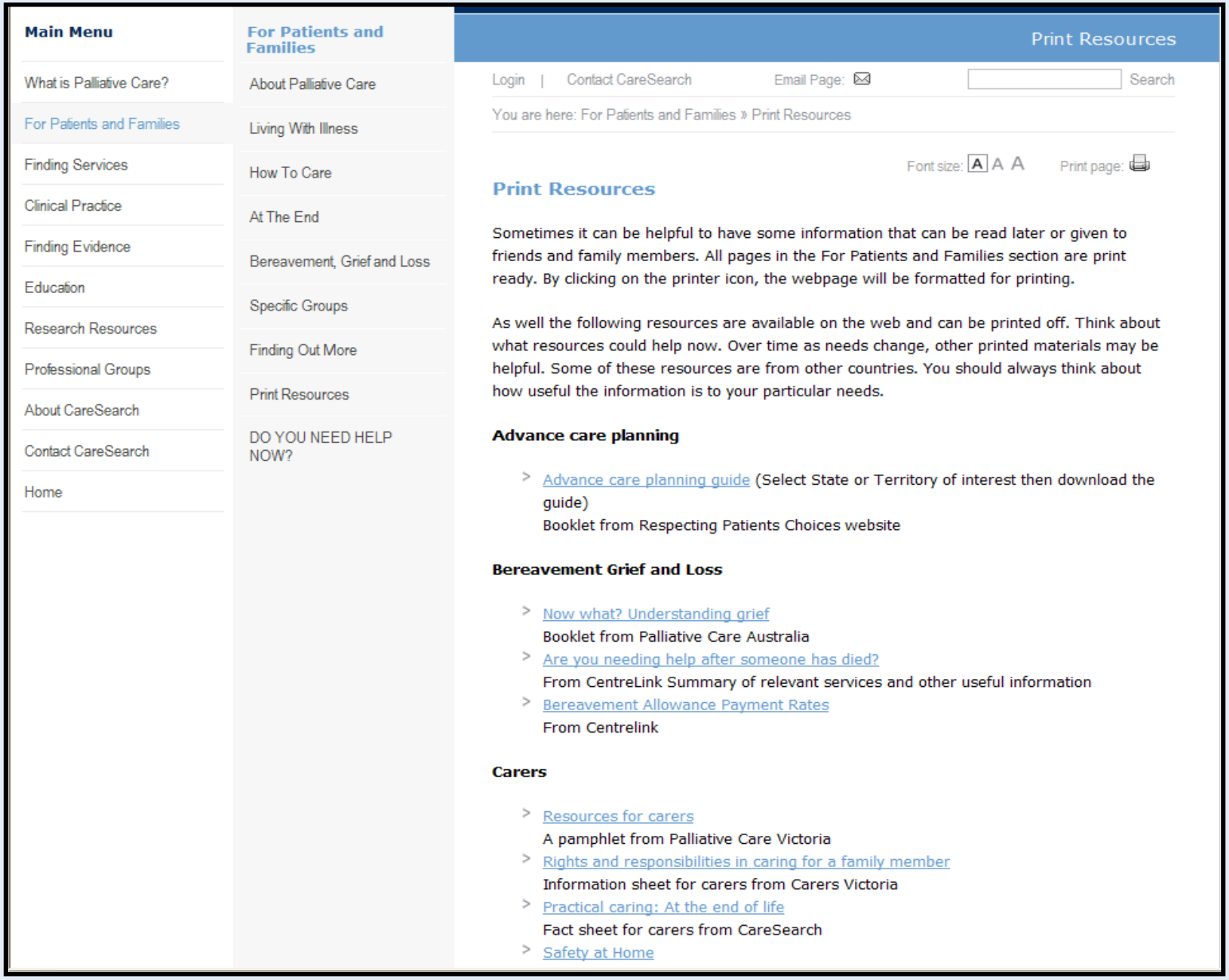
For Patients and Families

- About Palliative Care
- Living With Illness
- How To Care
- At The End
- Bereavement, Grief and Loss
- Specific Groups
- Finding Out More
  - Sources of Information
  - Is it Trustworthy?
  - Using Information
  - How Research Contributes
- Print Resources
- DO YOU NEED HELP NOW?


CARESEARCH
palliative care knowledge network
Print Resources
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
How To Care
At The End
Bereavement, Grief and Loss
Specific Groups
Finding Out More
Print Resources
DO YOU NEED HELP NOW?
Login | Contact CareSearch
Email Page:
Search
You are here: For Patients and Families » Print Resources
Font size: A A A
Print page
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)
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

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


Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
For Patients and Families
About Palliative Care
Living With Illness
How To Care
At The End
Bereavement, Grief and Loss
Specific Groups
Finding Out More
Print Resources
DO YOU NEED HELP NOW?
Print Resources
Login | Contact CareSearch Email Page: Search
You are here: For Patients and Families » Print Resources
Font size: A A A Print page:
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

Other relevant resources

- Also within the website are information that can be helpful to families
- The Finding Services Section contains information on:
  - Palliative Care services
  - National and Disease-specific resources
  - State based Resources
  - Indigenous resources

Other relevant resources

State Based Resources

- There is a page for every State and Territory containing useful information on local resources
- This includes practical things such as:
  - support groups
  - financial assistance
  - resources to support carers
  - where to access equipment and supplies or transport schemes.



CARESEARCH®
palliative care knowledge network

CareSearch, *palliative care knowledge network*

Login | 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
PubMed Topic Searches
GP Hub
Conferences
Indigenous resources
Palliative Dementia Care
COP

CareSearch DVDs

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

HEALTH *Insite*

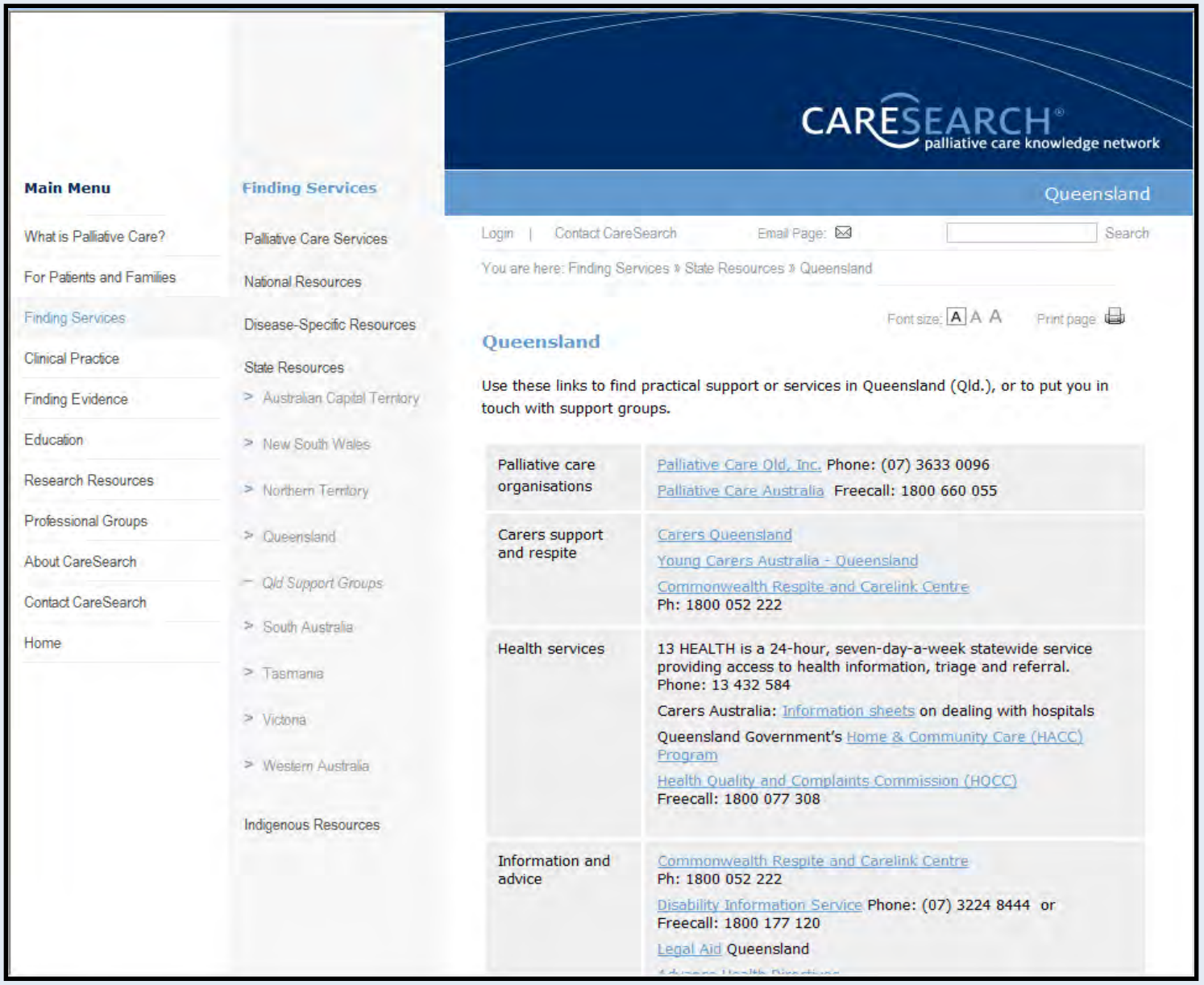
HON CODE CERTIFIED 11/2009

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 16 August 2010

Accessibility | Credits | Terms & Conditions | Site Map


CARESEARCH
palliative care knowledge network
Queensland
Main Menu
What is Palliative Care?
For Patients and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch
Contact CareSearch
Home
Finding Services
Palliative Care Services
National Resources
Disease-Specific Resources
State Resources
> Australian Capital Territory
> New South Wales
> Northern Territory
> Queensland
– Qld Support Groups
> South Australia
> Tasmania
> Victoria
> Western Australia
Indigenous Resources
Login | Contact CareSearch
Email Page:
Search
You are here: Finding Services » State Resources » Queensland
Font size: A A A
Print page
Queensland
Use these links to find practical support or services in Queensland (Qld.), or to put you in touch with support groups.
Palliative care organisations
Palliative Care Qld, Inc. Phone: (07) 3633 0096
Palliative Care Australia Freecall: 1800 660 055
Carers support and respite
Carers Queensland
Young Carers Australia - Queensland
Commonwealth Respite and Carelink Centre
Ph: 1800 052 222
Health services
13 HEALTH is a 24-hour, seven-day-a-week statewide service providing access to health information, triage and referral.
Phone: 13 432 584
Carers Australia: Information sheets on dealing with hospitals
Queensland Government's Home & Community Care (HACC) Program
Health Quality and Complaints Commission (HQCC)
Freecall: 1800 077 308
Information and advice
Commonwealth Respite and Carelink Centre
Ph: 1800 052 222
Disability Information Service Phone: (07) 3224 8444 or
Freecall: 1800 177 120
Legal Aid Queensland

Other relevant resources

Life, Hope, Reality

- An online version of a booklet, created for those living with advanced cancer.
- It draws on many information resources that already exist, including those available from the Cancer Councils in each state.
- For Patients and Families / Specific Groups / Living with Advanced Cancer

Life, Hope & Reality

Life, Hope and Reality provides information for people with advanced cancer, their families, caregivers and friends.

Life, Hope and Reality was developed and written by Afaf Girgis, Claire Johnson, and Sylvie Lambert with funding from the NHMRC and Cancer Council NSW.



Please provide feedback on Life, Hope and Reality

- Introduction

The sections look at the following issues:

- Physical Needs
- Emotional Needs
- Social Needs
- Lifestyle
- Finances
- End of Life
- The People Who Care
- Palliative Care
- Useful Assessment Tools
- Glossary

HMRI

Cancer Council New South Wales

Flinders University

The University of Newcastle Australia

Other relevant resources

Finding Evidence

- A Systematic Review Collection on Volunteers
- A PubMed Topic Search on Volunteering
- A Professional Groups page on Volunteers in Palliative Care

Summary

- CareSearch provides information to help patients and their families find quality information about palliative care
- Good quality information can help in making better decisions
- It helps if you know where the information is even if you don’t want to read it right now
- Anyone can safely recommend this information. It is free to access and available 24 hours a day

CARESEARCH®
palliative care knowledge network

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.

www.caresearch.com.au