

Helping Patients and Families at the End of Life

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

Palliative Care

- Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
- Palliative care encompasses not only the patient but the carer and family as well.

Palliative Care

- Palliative care will affect most people at some stage whether as a patient, carer, family member, neighbour or friend
- Patients and carers are often unprepared for living with illness or for the care giving experience
- Extended family and communities also have questions and require information

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)

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.

Online Resources

- In this age of technology, the internet is increasingly becoming an important source of information for patients (Penson et al, 2002)
- We need to be ready for this

For Patients and Families

- Good quality information can help with decision making
- Why CareSearch and not Google?
 - Palliative Care = 10.9 million results
 - Pages from Australia = 685,000
 - What will you find? Of what quality?

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

For Patients and Families

- Information in this section has been sourced and written differently to the other pages
 - This section has been built upon evidence from the published literature
 - But also based on searches for relevant tools and resources accessible through the web
 - Readability scores have been recorded on all pages to ensure they are targeted at the right level

National Advisory Group

- The CareSearch National Advisory Group oversees the development of resources such as these:
 - Carers Australia
 - Consumer Health Forum
 - Cochrane Consumer Network



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

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What is Palliative Care



For Patients and Families



Finding Services



Clinical Practice



Finding Evidence



Education



Research Resources



Professional Groups



About CareSearch

Proudly linked to:



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



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For Patients and Families

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

About Palliative Care

What is palliative care and why is it important?

Living with Illness

Information on living with illness, and changes over time.

How to Care

Information on the practical things that can help daily life.

At the End

What happens when someone is nearing the end of life?

Bereavement, Grief, Loss

Information on how to manage after someone has died.

Groups with Specific Needs

Some groups have specific needs such as older or homeless people.

Finding Out More

Learn more about how to search for quality information.

Do you need help now?

Contact numbers if you need help now.

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

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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



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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](#)

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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



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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](#)

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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

Carers

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



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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](#)
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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.](#)

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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

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At The End

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

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



[At the End DVD](#)
[Ελληνικά](#) / [Italiano](#) / [广东](#)

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.](#)

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Bereavement, Grief and Loss

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



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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.](#)

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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

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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](#)
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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

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Finding Out More

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



[Finding out More DVD](#)
[Ελληνικά](#) / [Italiano](#) / [广东](#)


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.

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*Last updated 26 May 2008**

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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

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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 is information that can be helpful to families
- The 'Finding Services' Section contains information on Palliative Care services, National and Disease-specific resources, and Indigenous 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, and where to access equipment and supplies or transport schemes



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For Patients
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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
[Address Health Direct](#)

Summary

- The CareSearch website has developed a section to help patients and their families find quality information about palliative care
- Clinicians can also safely recommend this information, or can print pages to read later or to help initiate difficult conversations

For Patients and Families

- Good quality information can help with decision making
- It helps if you know where to access information even if you don't want to read it right now
- Pages can be printed and shared with others
 - to help discuss issues or
 - for those without a computer

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