

CareSearch is a website that has been developed to help patients and their families find quality information about palliative care. Pages can be downloaded or printed to read later. You can find these pages at www.caresearch.com.au in the Patient-Family section.



WHY INFORMATION MATTERS AT THE END OF LIFE BROCHURE SERIES: 1

Further information:

CareSearch is an online resource funded by the Department of Health and Ageing to help patients and their families find helpful information about palliative care. There are over 600 pages in the website and over 100 have been written specifically for patients, family members and others in the community. These pages include links to other quality web resources and provide information on state and national services and organisations.

It is free to use and available now at
www.caresearch.com.au



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2. CareSearch is managed by Palliative and Supportive Services, Flinders University.

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AT THE END OF LIFE

In Australia, around 130,000 people die each year and many of these are expected deaths. For people living with a terminal illness and for their families, there are many things to think about and plan for.

FINDING INFORMATION

There are many places to find information about palliative care. Doctors and nurses are an important source. Community Health Services, councils and libraries can help in identifying local services and organisations. Organisations such as Palliative Care Australia and Carers Australia will also be useful.

The internet is also increasingly being used to find health information. Web users need to use common sense when judging the value of what they find. Look for sites that have been checked by agencies such as Health Insite or HONCode. Use of these logos indicates the site has met their quality criteria.

INFORMATION NEEDS

Patients and carers can have many information needs. They may want information about the illness, about managing symptoms or about resources and services. Information on financial matters and on providing care in the home may also be important.

Patients and families can differ in how much information they want. Some want to learn as much as possible. Others prefer less information and only as needed. The amount and type of information wanted may vary over time, as a condition continues or changes.

HOW INFORMATION CAN HELP

Information can help patients and carers:

- > know what services are available
- > understand care options now and into the future
- > feel more capable of making decisions
- > feel more able to cope and less anxious
- > be more confident about asking questions

Patients, carers and family members can sometimes be reluctant to ask questions during appointments. They may also have trouble remembering everything they have been told.

Printed information and trustworthy websites are available to support patients and their families.

USING INFORMATION

Information and resources can be used to keep track of what is happening and how things are changing. Finding out that other people have similar experiences or feelings can be reassuring. Discussing information found on the web or from other sources with the health care team is useful. They may be able to provide comments or suggest other information and resources. Summarising the information and writing a short list of questions for future discussion can be helpful.

CareSearch is a trustworthy website that has information about palliative care.

