

Why Information Matters: At the End of Life

In Australia, around 160,000 people die each year. Many of these are expected deaths because of age or illness. For people living with a terminal illness and for their families, there are many things to think about and plan for.

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.

Information needs

Patients and carers can have different information needs. These can include information about the illness, about managing the patient and their symptoms and 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.

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 increasingly being used to find health information. Web users need to use their common sense to judge the quality of information 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.

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 also 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 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 Patients, Carers and Family section.

