



# Providing Quality Information for Patients

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## Introduction

Relevant and trustworthy information can help palliative care patients when making choices and decisions. People may seek different information depending upon their experience, their understanding and their circumstance. [1-2] For example, patients and carers may want different information at different stages of the disease trajectory.

Health professionals cannot always be available to answer queries, and they may not be accessible to all members of the extended family. So, health consumers may look for information from other sources. Increasingly, patients and families are turning to the Internet for health information. [3-4]

CareSearch is funded by the Department of Health and Ageing as part of the National Palliative Care Program. It provides evidence-based information and resources for those providing palliative care and for those affected by the need for palliative care, namely, patients, carers, their family and friends.

## Methods

The development of the content and structure of the CareSearch website has been overseen by a National Advisory Group with representatives from consumer oriented organisations such as Cancer Voices, Cochrane Consumer Network, Australian Centre for Grief & Bereavement, Carers Australia, Consumer Health Forum and the Respecting Patient Choices Program.

A major web section consolidates information and resources for patients, carers and family members. Quality processes are in place to ensure that information is trustworthy, evidence-based and relates to palliative care. All information is peer reviewed. Where possible, Australian resources are used.

Readability scales ensure pages are targeted at the reading skills of the general community.

Short videos and information in languages other than English are also available.



## Role of Health Professionals

Nurses will need to be aware of relevant online resources suitable to the needs of their patients and recognise and adapt to the technologies that their patients are using. [4-5] Further, they may have a role in assisting patients and families in making use of new technologies. Carers appear to be much more likely to use or try technology if a health professional involved with the patient and carer explains that the technology would be helpful. [6]



## Patient and Carer Resources

**For Patients and Family** provides information on the many issues that patients and their families will need to consider. The section has over 100 pages dealing with:

*About Palliative Care:* Describes what it is, who provides it and how to access it.

*Living With Illness:* Looks at planning for the future, work and financial issues and changes over time.

*How to Care:* Deals with what is involved in looking after someone and managing daily life.

*At the End:* Helps in preparing for the end and being aware of changes around the time of death.

*Bereavement, Grief & Loss:* Provides information on grief and sadness, loss of a child, and remembering and recovering.

*Specific Groups:* Recognises the diversity in the population with information for particular groups such as the intellectually disabled, people living alone, or those who are homeless.

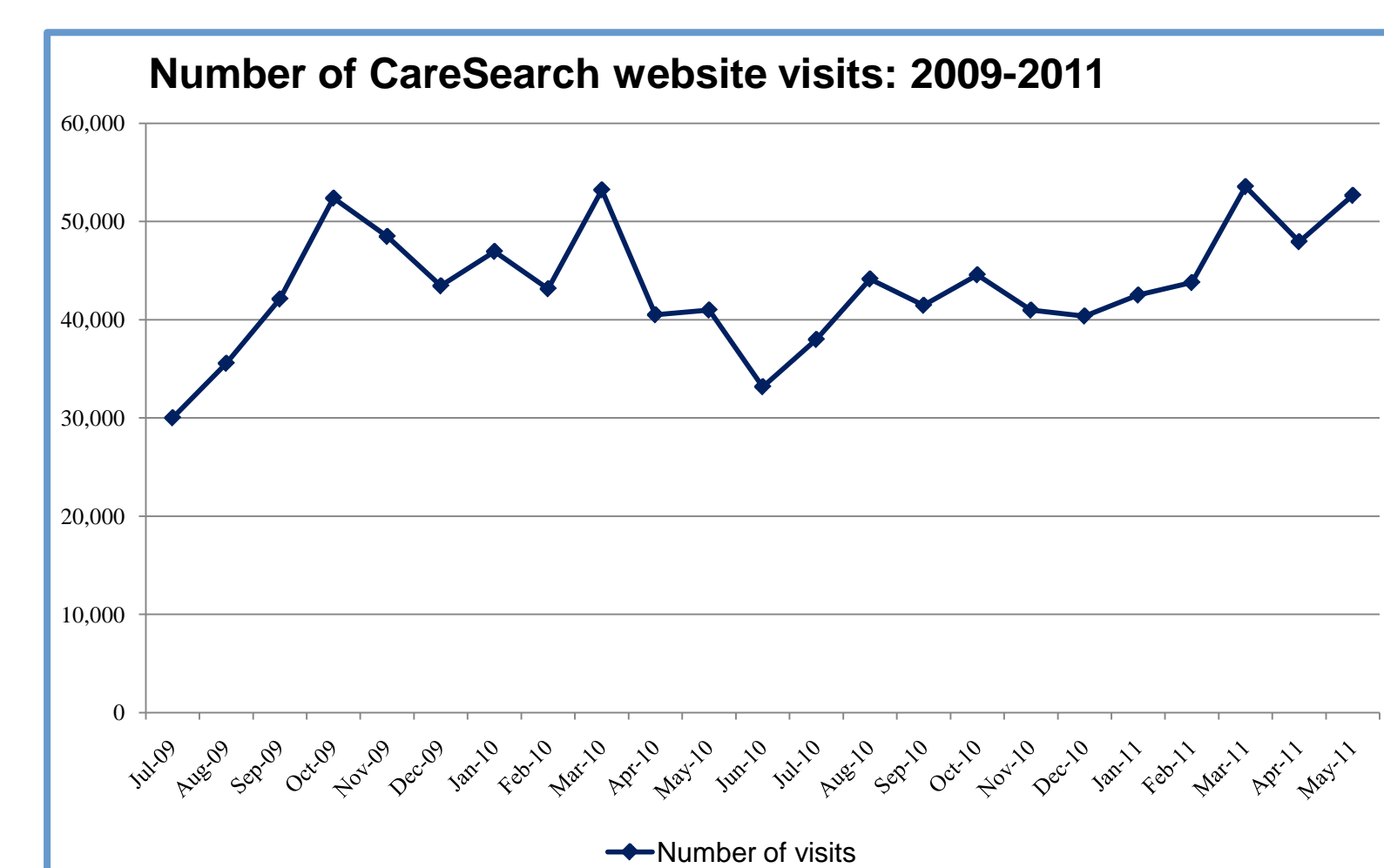
*Finding Out More:* Helps consumers judge the quality of information they might find on the web.

*Life, Hope and Reality:* A new section specifically about living with advanced cancer.

Pages are print-ready and downloadable. All sections have links to other online sites and to tools, leaflets and materials that can be printed or emailed to the patient or their family.

## Results

Each month there are over 30,000 visits to the CareSearch website. Monthly visits from July 2009 to June 2011 are shown in the graph below.



In 2010-2011, there were over three million page views of all CareSearch pages. In the same year, there over 230,000 views of pages held in the For Patients and Families section. In 2010, over 40,000 free print resources were ordered by health professionals to disseminate to patients and families. The number of resources being ordered is growing with many palliative care services and oncology wards providing brochures to patients and their families to help them find trustworthy, evidence-based materials on the web.



## Conclusion

Having trustworthy information can help to understand options, informing patients in decision making. CareSearch aims to provide relevant, timely information in a variety of formats to help improve the knowledge and confidence of patients.

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### References

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1. CareSearch is funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program.
2. CareSearch is managed by the Department of Palliative and Supportive Services, Flinders University.