



An Australian Government Initiative



# Dementia Resource Guide

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# Dementia Resource Guide

## Hello

*I am someone you know. I am an ordinary person who has had my share of ups and downs over my busy lifetime. I have a few aches and pains now and maybe I'm slowing down a bit too. Recently it seems I have also developed dementia and this is creating some new issues for both my family and I.*

*We have shared many special times together and although I may not be able to recall your name you are still a part of me and who I am.*

*Perhaps you haven't known me for long. We may have just met and it takes me a while to learn who you are. Likewise you may not know how I have lived my life, what I value and what makes me laugh or cry.*

*You might sometimes get frustrated with me as I can no longer think as clearly as I used to and I have difficulty telling you how I feel. But I'm still a person; I still need you to treat me with respect and dignity. I can still feel pain, discomfort, loneliness and embarrassment. All I ask is that you stand beside me and try to look at my world from my perspective.*

*There are many questions you may have, so to help you help me, this resource guide has been developed to assist us both on this journey we are on.*

### **About this Guide**

This Guide has been developed to help people care for those who have dementia. The Guide supports a holistic approach that considers the social, emotional, physical and spiritual needs of the person with dementia and those around them.

Perhaps your employment involves working with people who have dementia. You will find many topics that will be relevant. You may also find it useful for locating information to give to family members and friends caring for someone who has dementia.

Perhaps you are a relative or friend of someone who has dementia. Particular sections you may find helpful are *Caring for families and carers* and *Support services*. If you have difficulty using this Guide it might be worth discussing it with your doctor, a community service provider or someone at a residential care facility.

Rather than reading from cover to cover, this Guide is a resource that can be referred to when you sense a new issue emerging. It has a section on how to use the Guide as well as a contents page and glossary. There is also a website where you can directly access many of the resources that are available on the Internet: [www.health.gov.au/dementia](http://www.health.gov.au/dementia)

# Dementia Resource Guide

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# Dementia Resource Guide

## Welcome

In 2006 approximately 190,000 people in Australia had dementia with 81% of these over the age of 75 years<sup>1</sup>. The impact of dementia on the community prompted the Australian Government to make dementia a National Health Priority, and the Australian Government Department of Health and Ageing funded the development of the Dementia Resource Guide.

The Guide aims to improve care and quality of life for people with dementia by recommending resources, tools, guidelines and best practice principles. A research team at the National Ageing Research Institute (NARI) developed the Guide and reviewed over 700 resources to determine the best available.

The target audience includes people with dementia, family members and carers and staff and volunteers in residential care, community care and hospital settings.

The Guide was developed in consultation with people with dementia, their carers and families, the peak bodies that represent them, service providers and dementia experts.

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<sup>1</sup> Australian Institute of Health and Welfare. (2007). *Dementia in Australia: a national data analysis and development*. Canberra.

# Dementia Resource Guide

## Authors and acknowledgements

### **Authors**

The National Ageing Research Institute (NARI) was contracted to develop the Dementia Resource Guide by the Australian Government Department of Health and Ageing. Members of the NARI project team were:

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Personal stories developed by Ella McEwan.

### **Reference group**

An expert reference group provided advice to the project team on all aspects of the development of the Dementia Resource Guide. Members of the expert reference group included the project team, as well as:

- Marion Davidson and Michael Rodda (Australian Government Department of Health and Ageing)
- Judy Basile (MECWA)
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- Virginia Moore (Brightwater Group)
- Judith Mulcahy (representing Carers Australia)
- Jack Sach (representing Alzheimer's Australia)
- Delys Sargeant (Council on the Ageing).

### **Pilot agencies**

A draft version of the Guide was piloted across Australia in regional and metropolitan areas, and residential, community and health care settings. The authors would like to thank staff, volunteers, clients, and family members from the following sites for their participation:

- Amity Group (Amity at Bonbeach), Victoria
- Bega Valley Meals on Wheels Co-operative, New South Wales
- Fronditha Care Inc. (Templestowe), Victoria
- Frontier Services (Rocky Ridge), Northern Territory
- The Hammond Group (The Pines), New South Wales
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- Royal District Nursing Service of South Australia Inc. (The Research Unit, RDNS Central), South Australia
- Southern Cross Care (Frank Prendergast House), Western Australia
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- Spiritus Care Services (St John's Home for Men), Queensland.

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- People with dementia and their families and carers who participated in focus group discussions
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- People who submitted feedback on the draft website
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- Chris Croyden for editing
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# Dementia Resource Guide

## Is this Guide for me?

The Dementia Resource Guide is intended for a broad audience. The Guide should be useful for anyone providing care for a person with dementia. The Guide may also be useful for those seeking information about memory problems and dementia. For more information on the process of evaluating the resources included in the Guide, please refer to the *Appendices*.

The Guide promotes a partnership approach to caring for people with dementia. While it may be suitable to target a specific audience such as people living with dementia or staff in a particular work environment, this Guide aims to remove such distinctions and can be used by anyone involved in the care of a person with dementia. Everyone involved in dementia care will have different needs and should therefore have access to a broad range of information. Although the Guide contains a lot of information it is designed for use as a resource to refer to as needed, rather than read from front to back.

A small number of sections are for specific audiences. *Caring for families and carers* outlines recommendations and resources specifically for families and carers. *Caring for service providers* outlines those specifically for service providers. *Practice guidelines* focuses on a broad range of dementia topics to assist service providers provide care and develop policies within their service.

# Dementia Resource Guide

## How to use

The Guide includes 17 sections covering different dementia topics. For each there is a summary page of text covering the main issues and key recommendations on that topic. Following the text is a list of recommended resources for further reading.

For each recommended resource a description of the resource and details for accessing the resource are provided. A series of symbols have been used to indicate the depth of information in the resource, whether the resource is available in different languages, and the target setting of the resource (Refer to *Explanation of symbols*).

The Guide is intended to be utilised as a reference as particular issues arise, rather than to be read from front to back.

### **Use by service providers**

Service providers may choose to use the Dementia Resource Guide

- As a training supplement
- For quality improvement purposes
- For involving clients, families and carers in promoting quality dementia care.

Identifying areas of dementia care to focus on is best achieved through group discussions involving staff and volunteers as well as clients, families and carers. Gaining insight from the users of a service is important for identifying areas in need of improvement.

Once key issues have been identified group brainstorming is a useful strategy. At this stage the Dementia Resource Guide could be a reference tool for identifying new strategies for improving care. When a specific topic has been identified, the summary page and list of resources recommended on that topic could be printed and distributed to staff to review. Staff could discuss strategies and suggestions to reflect on their own practice and identify areas where they may need to improve.

During group discussions an action plan could be written outlining

- The issue to be addressed
- Actions to address the issue
- Resources needed to assist implementing the action (information from the Guide may be relevant here)
- People responsible for carrying out action
- Anticipated timelines.






Further meetings will be required to reflect on the action plan and its effectiveness. If the actions have not been useful in addressing the issue this can be discussed and new actions developed for implementation.





# Dementia Resource Guide

## Explanation of symbols

As the Dementia Resource Guide includes a large range of resources, a set of symbols has been used to highlight some of the features of resources. This should make it easier to find resources that might be shorter or provide more detail, or for resources designed for a particular setting or group.

### Symbols

<p style="text-align: center;"><b>Light reading</b></p> <p>One book indicates light reading such as a resource that provides a brief/general overview of a topic. Fact sheets, brochures and posters would usually be included in this category of resources.</p>	
<p style="text-align: center;"><b>Medium level resource</b></p> <p>Two books indicate a medium level resource. These resources will usually be more in-depth than fact sheets and posters, but less in-depth than books or reports. They may include audiovisual materials such as DVDs and cassettes.</p>	
<p style="text-align: center;"><b>In depth, detailed resource</b></p> <p>Three books indicate a heavy resource in terms of the depth of information. These resources will usually provide a fairly in-depth amount of information in the form of a comprehensive resource, book or report.</p>	
<p style="text-align: center;"><b>Community</b></p> <p>The 'C' symbol represents resources that have been designed for people living in their own home and for community services provided in the home or in a community venue. These resources may or may not be applicable to other settings.</p>	
<p style="text-align: center;"><b>Hospital</b></p> <p>The 'H' symbol represents resources that have been designed specifically for health care settings (hospitals). These resources may or may not be applicable to other settings.</p>	

<p style="text-align: center;"><b>Residential Care</b></p> <p>The ‘R’ represents resources that have been designed specifically for residential aged care services, such as high and low level residential care facilities (also known as nursing homes and hostels). These resources may or may not be applicable to other settings.</p>	
<p style="text-align: center;"><b>General</b></p> <p>The ‘G’ represents resources that were not designed for any specific setting, but may be applicable across community, health care, and residential care settings.</p>	
<p style="text-align: center;"><b>Aboriginal and Torres Strait Islander</b></p> <p>Resources primarily designed for Aboriginal or Torres Strait Islander people, or for providing information to care for people with dementia from Aboriginal and Torres Strait Islander communities.</p>	
<p style="text-align: center;"><b>Culturally and Linguistically Diverse (CALD)</b></p> <p>Resources primarily designed for people from one or more Culturally and Linguistically Diverse (CALD) backgrounds. This indicates that the resource is either targeted to a specific CALD group, or is aimed at providing information for people with dementia from a CALD background, or is available in a language other than English.</p>	
<p style="text-align: center;"><b>Glossary terms</b></p> <p>Key terms defined in the glossary are underlined throughout the Guide.</p>	<p><u>Underlined text</u></p>

# Dementia Resource Guide

## Disclaimer

### ***Provision of Education and Research Information Only - Always Seek Professional Advice***

This Dementia Resource Guide was developed for the Australian Government Department of Health and Ageing to disseminate dementia care information free of charge for the benefit of the public. This Guide is not a substitute for independent professional advice. Nothing contained in this Guide is intended to be used as medical or legal advice and is not intended to be used to diagnose, treat, cure or prevent any disease, nor should it be used for therapeutic purposes or as a substitute for your own health professional's advice. The Australian Government Department of Health and Ageing does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information contained in this Guide.

### ***Quality of Information - Always Check the Information***

The Australian Government Department of Health and Ageing makes every effort to ensure the quality of the information available in this Guide. However the Australian Government Department of Health and Ageing cannot guarantee and assumes no legal liability or responsibility for the accuracy, currency or completeness of the information.

### ***Recommended Resources and Web Sites***

This Guide contains information for accessing resources developed by agencies external to the Australian Government Department of Health and Ageing. The Australian Government Department of Health and Ageing takes reasonable care in selecting these resources.

Web sites have been included for your convenience and do not constitute endorsement of material at those sites, or any associated organisation, product or service. We make every effort to ensure that links on this site are kept up to date.

It is the responsibility of the user to make their own decisions about the accuracy, currency, reliability and correctness of information contained in external resources and web sites. The Australian Government Department of Health and Ageing does not accept responsibility for information on any external resource or web site.

Resources and web sites in this Guide should not be taken to be an endorsement or a recommendation of any third party products or services offered by virtue of any information, material or content linked from or to this resource or site. Users of web sites provided by this Guide are responsible for being aware of which organisation is hosting the site they visit.

Views or recommendations provided in external resources or web sites do not necessarily reflect those of the Australian Government.

***Security of the Dementia Resource Guide***

Users should be aware that the World Wide Web is an insecure public network that gives rise to a potential risk that a user's transactions are viewed, intercepted or modified by third parties or that files which the user downloads may contain computer viruses or other defects.

The Australian Government accepts no liability for any interference with or damage to a user's computer system, software or data occurring in connection with this Guide. Users are encouraged to take appropriate and adequate precautions to ensure that any web sites accessed are free of viruses or other contamination that may interfere with or damage the user's computer system, software or data.

***Images***

Models used for illustration purposes only.