GUIDING
PERSON-CENTRED
DEMENTIA CARE
IN THE
COMMUNITY
Valuing people: An organisational resource enabling a person-centred approach (the Resource) is made up of both the Valuing People website and this book. It has been developed by Alzheimer’s Australia to assist community care providers to achieve excellence in person-centred care. It does this by providing a Framework of person-centred principles that supports an organisation self-assessment process.

The Framework underpins the overall approach of the Resource and its accompanying tools and materials. It consists of five guiding VALUEs that describe the aspects of person-centred care that are important for people living in the community. Each value is defined by Elements and Actions that illustrate the behaviours and activities that can help you to ensure a person-centred approach to care. They are building blocks to think about and share with others throughout your organisation that can be used to guide the development of innovative ways to address consumer, staff and organisational needs.

The self-assessment process has been created to gauge the degree to which consumers, their carers, staff and organisational leaders believe community agencies engage in person-centred practices.

The assessment is made up of five different Organisational Self-Assessment Tools (OSATs) that can be completed on the Valuing People website.

As part of ongoing consultation, the assessment can help community agencies build upon their existing strengths and focus on opportunities for improvement as they strive to provide person-centred care to the people they serve.

For those organisations that have already developed a service model that seeks to promote person-centred care, this is not intended to replace it. Rather it will assist you to determine how well these principles are being applied across your service initiatives.

Organisational structures, policies and practices play an important part in whether or not person-centred support approaches are successful. Kitwood proposed that to provide care that is person-centred, staff need to be afforded the same level of person-centredness within their working environment that the organisation strives to provide to the people they serve. The Resource takes the same standpoint.

The content of the Resource is drawn from:
- a comprehensive review of published research and other literature about person-centred care approaches
- the experience of people living with dementia and their carers
- the experience of Australian service providers, academics, professionals, change agents and policy makers.

The Resource starts from a place where a substantial amount of learning, thinking and action about person-centred care has already taken place and brings this together to assist community care providers, people living with dementia and those who support them.

The Resource is not a manual but rather an organisation improvement resource. It is intended to assist you as a service provider to:
- further your understanding of how person-centred care can promote and facilitate quality support
- facilitate conversations about person-centred care with consumers and staff
- identify current practice and processes that are already consistent with person-centred philosophy so you can sustain these
- understand what it is you have already achieved and what you need to do to become more person-centred
- focus on practices that are important to support the move towards person-centred care.
### Guiding VALUES

<table>
<thead>
<tr>
<th>Valuing people</th>
<th>Autonomy</th>
<th>Life experience</th>
<th>Understanding relationships</th>
<th>Environments</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Valuing people icon" /></td>
<td><img src="image2.png" alt="Autonomy icon" /></td>
<td><img src="image3.png" alt="Life experience icon" /></td>
<td><img src="image4.png" alt="Understanding relationships icon" /></td>
<td><img src="image5.png" alt="Environments icon" /></td>
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#### Elements

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</thead>
<tbody>
<tr>
<td>2. Listening to each other</td>
<td>2. Balancing rights, risks and responsibilities</td>
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<td>2. Community connections</td>
<td>2. Responsive support</td>
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#### Actions

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WHY SHOULD YOU USE THE RESOURCE?

Quality of care is an individual experience for consumers and all those involved in providing support.

It requires an understanding of the experience of care from different perspectives to facilitate the development and delivery of services to meet the needs of people and those who care for them. This is the foundation of the Resource and organisation assessment process.

The Resource introduces person-centred care in the community from the point of view of organisational culture change. It provides information and guidance to help plan the necessary steps for undertaking quality improvement activities and embark on a journey of organisational change. It is suitable to use if your organisation is:

- just starting to think about opportunities for improvement
- looking to refresh a waning commitment
- wanting to identify areas of existing good practice
- wanting to ensure that an established person-centred culture is sustained over time.

The assessment process is a practical mechanism for organisations wanting to become more person-centred. It serves as a precursor to quality improvement efforts. It is an iterative process rather than an isolated event that can become a part of organisational planning cycles. It will help you to:

- describe what person-centred dementia support looks like for your organisation
- facilitate conversations about person-centred care with your consumers and staff
- identify current practice and processes that are consistent with person-centred care so they can be sustained
- identify practice and processes that you would like to strengthen
- prioritise and plan the way forward.

The Resource has been developed to be consistent with the Community Common Care Standards and may assist you in your reporting requirements.

If you have chosen to undertake the assessment process there is no requirement to report or share your results, although you may choose to celebrate and share what you are doing well.

It is important that you provide feedback to those you have surveyed.
Australia is experiencing a demographic shift with a rapid increase in the number of older Australians. The population aged 65 years and over is projected to increase from 3.2 million at 30 June 2012 to between 5.7 million and 5.8 million in 2031. As a result of population ageing, we are also facing a rapid increase in the number of people who have dementia. Currently there are more than 320,000 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050.

The increasing number of older Australians and those who have a chronic illness such as dementia will have a major impact on both the health and aged care systems. As with most people, those living with dementia want to remain independent and in control of how and where they live, with assistance from informal carers and community care programs.

The community care system is an important and growing element of aged care services in Australia that makes a tangible difference to the quality of life for many older people. Community expectations of support in the home are changing and require services to be accessible, responsive and flexible to meet diverse needs and preferences.

Person-centred approaches to support will help you to achieve this and more. They make a significant difference not only to the people you support and your staff but also to how your organisation operates and prospers.

Person-centred approaches:
• allow consumers and their carers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and how and when they are delivered
• support staff to value and seek to know the people they care for, to understand their experience and to support them to retain as much independence and dignity as possible
• result in happier staff who want to stay in your organisation
• mean that organisations are well placed to provide culturally appropriate responses
• enhance an organisation’s reputation and standing
• provide the foundation for delivering Consumer Directed Care.

The Resource is suitable for organisations that are supporting people living in their own homes. It is intended primarily for services who are seeking to achieve excellence in person-centred support including providers of:
• Home Care Packages Program
• Home and Community Care (HACC) Program
• Respite care provided in the home.

Person-centred approaches can achieve significant outcomes for individuals and are relevant to all people receiving support from community care services. Best results will be achieved in situations where there is an established relationship between the service provider and consumer and when care is planned and delivered on a regular basis.
Person-centred care is a philosophical approach to service development and service delivery that sees services provided in a way that is respectful of, and responsive to, the preferences, needs and values of people and those who care for them.

Person-centred approaches to care:
- involve seeing people as equal partners in developing support to make sure it is appropriate for their needs
- mean people have a choice about the types of services they receive and how they are delivered
- recognise and appreciate the variety of characteristics that make individuals unique including race, ethnicity, gender, sexual orientation, socioeconomic status, age, physical abilities, religious or political beliefs and other ideologies
- support the important relationships between service providers, consumers and their carers
- value and seek to know the people they care for, to understand their experience and support them to retain as much independence and dignity as possible
- occur when staff know how to facilitate support and not just deliver care
- are only possible when teams are nurtured and supported and staff are valued
- require ongoing listening, learning and action.

There are numerous models, guiding theories and different types of centredness described in published and unpublished (grey) national and international literature (see Appendices 1 and 2).

Some models have been developed to meet the needs of specific care environments, including the residential care setting and hospital environment. Others have been developed to describe person-centred care provided by different professional groups, for example, nursing and allied health.

The Resource supports the standpoint that the many different types of centredness all contain, at a conceptual level, the same underlying themes. Some services may have developed a model of care or service that incorporates the principles of person-centred care. This resource has been developed to complement existing models of care and to assist organisations to assess how person-centred their approach to care is.
The level of support that a person living at home with dementia receives will vary considerably. In some cases people might have no other formal or informal support apart from your service. Others will be receiving support from multiple sources, of which your service is but one.

Seeing consumers and their support networks in their entirety will help you to work with them in a person-centred way.

The model below left identifies the importance of the relationship network between the person living with dementia and the people that are key to the support they may need. At the heart of this network are carers, staff who provide support in the home and the organisation that supports those staff. The model also highlights external factors that can influence how people are supported.

The Community Support Networks diagram below represents a snapshot of potential support networks, all of which should be considered potential partners in care.
HOW TO USE THE RESOURCE

The Resource is made up of both the Valuing People website and this book. All information contained in this book is available at valuingpeople.org.au.

The book is organised into six sections that describe the steps necessary for community care providers to identify achievements in person-centred care and areas in need of improvement.

Section 1 Provides the background, overview and broad structure of the Resource

Section 2 Provides an overview of change management approaches and tools to assist in the necessary steps required to implement successful change

Section 3 Describes the structure of the Framework in detail, including the Guiding VALUEs, Elements and Actions required to ensure good practice

Section 4 Explains how to manage the assessment process, determine where quality improvements can be made and how to implement them

Section 5 Contains the five Organisational Self-Assessment Tools (OSATs):

- Consumer
- Carer
- Staff – Direct Care Worker
- Staff – Non-Direct Care Worker
- Leader

Section 6 Contains supplementary information including:

- Appendices
- Supplementary documents for printing

The Resource is not a ‘how to’ guide for person-centred care but can:

- support your organisation with practical knowledge and tools to facilitate person-centred approaches
- enable you to take action and implement change within your organisation, for both consumers and staff.
## KEY TERMINOLOGY

<table>
<thead>
<tr>
<th>Term</th>
<th>Rationale (or Description)</th>
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<tbody>
<tr>
<td>Board</td>
<td>Representatives or officials responsible for governance or supervision of an organisation.</td>
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<tr>
<td>Carer</td>
<td>A person, such as a family member, friend or neighbour, who provides assistance and support to another person, who may not otherwise be able to live independently at home.</td>
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<tr>
<td>Care Plan</td>
<td>A document reflecting the individualised support to be provided, based on assessed need(s) and a service user’s choice.</td>
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<td>Change Champion</td>
<td>A person who leads change within the organisation, by championing the change and managing and planning its implementation.</td>
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<tr>
<td>Contracted Services</td>
<td>Brokered services provided through a written agreement with another organisation, agency, or individual. The agreement specifies the services or personnel to be provided on behalf of the applicant organisation and the fees to provide these services or personnel.</td>
</tr>
<tr>
<td>Community Care Providers</td>
<td>Organisations that provide care and support for people who want to remain independent and live at home for as long as possible. This includes Home and Community Care Services and providers of community packaged care and respite care services.</td>
</tr>
<tr>
<td>Consumer</td>
<td>The person receiving care and services through Home and Community Care Services and providers of community packaged care and respite care services.</td>
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<tr>
<td>Dementia</td>
<td>The impairment of brain function, involving memory, thinking and concentration. Dementia usually becomes progressively worse, eventually making it difficult for the person to manage independently without help.</td>
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<tr>
<td>Direct Care Worker</td>
<td>Staff that provide support and assistance to people in their homes. They can also be called Personal Care Assistant, Personal Support Worker, Home Care Aide and more.</td>
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<tr>
<td>Diversity</td>
<td>The concept of diversity encompasses a commitment to recognising and appreciating the variety of characteristics that make individuals unique, including race, ethnicity, gender, sexual orientation, socioeconomic status, age, physical abilities, religious beliefs and political beliefs or other ideologies.</td>
</tr>
<tr>
<td>Leader</td>
<td>A person who influences others towards the achievement of the organisation's governance, management, clinical and support functions and processes. This includes senior managers and members of the executive.</td>
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<tr>
<td>Non-Direct Care Worker</td>
<td>Staff that support the Direct Care Workers. This can include Case Managers, Care Coordinators, Assessment Officers or Team Leaders.</td>
</tr>
<tr>
<td>Staff Member</td>
<td>As appropriate to their roles and responsibilities, all people who provide support and services for the organisation, including those receiving pay, volunteers and students.</td>
</tr>
<tr>
<td>Service Provider</td>
<td>An organisation funded or approved to provide services under government legislative frameworks, including Home and Community Care Services, providers of community packaged care and respite care services.</td>
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