Supporting Family & Whānau of People Living with Dementia

Education Guidelines

A guide for education providers to develop effective, person-centred education programmes for family and whānau supporters of people living with dementia.

Produced by:
National Dementia Framework Collaborative

January 2019

Next review date: January 2021
Introduction

The needs and perspectives of people with dementia should be at the heart of all dementia education. A person-centred approach towards content and delivery is enabling, respectful and inclusive of the person with dementia and the people supporting them.

Family and whānau supporter education aims to improve:

- understanding of dementia, across all stages, from pre-diagnosis to death
- wellbeing and confidence in supporting/caring for people living with dementia
- connections and networks with support services/organisations and with people experiencing similar situations.

This document provides recommendations for core education topics for family and whānau supporting people living with dementia relevant to the stages of early and mid-stage dementia. There are also add-on topics relevant to pre-diagnosis and late stage dementia.

The information is not intended to be prescriptive. Providers will need to adapt the content and delivery of their education depending on the needs and characteristics of the participants and the people they are supporting. Content developed by providers will draw on experience from other courses they have run and/or resources and content from other education providers. Some examples of good practice resources are included in the Recommended Topics tables (see pages 9-8).

This document is divided into the following sections:

- The New Zealand context
- Family and whānau supporter considerations
- Support for education providers
- Recommended format
- Recommended core topics
- Recommended add-on topics.

For more information or support regarding education programmes for family and whānau of people living with dementia, contact Alzheimers New Zealand (www.alzheimers.org.nz) or Dementia New Zealand (www.dementia.nz).

Produced by the National Dementia Framework Collaborative with extensive input and feedback from across the sector, including family and whānau of people living with dementia.

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Other agencies
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Paul Sullivan, Dementia New Zealand
Jean Gilmour, Alzheimers New Zealand
Emma Fromings, Dementia Wellington
Rebecca Purcell-Hewitt, Ministry of Health
Phil Wood, Ministry of Health
Responsiveness to Māori

Māori as a group share cultural beliefs and practices but “also have a diverse range of realities and health education needs. It would be difficult to find one health education resource that meets the needs of all Māori” (Ministry of Health, 2012, p.9). Rauemi Atawhai: A guide to developing health education resources in New Zealand, provides information and advice to help develop effective education resources for Māori.

A Whānau Ora approach to education includes tailoring how the information is delivered and organised to meet the needs of the whānau. Principles enabling the time and flexibility to be opportunistic and responsive include:

- involving the extended whānau in discussions
- delivering the education in the whānau home, or local marae
- working in partnership with a local Māori health provider to include dementia education in a local Māori health day or event
- ensuring that people who deliver the education are culturally competent and/or have appropriate cultural support such as a Māori health worker, kaumātua or kuia.

For more Whānau Ora information see Whānau Ora on the Te Puni Kōkiri website.

Links to resources for people working with Māori with dementia and for Māori whānau supporting someone with dementia are available on the Family and Whānau Carer Education Providers forum on the New Zealand Dementia Cooperative web portal (see Support for education providers on page 3 for more information).

New Zealand Framework for Dementia Care

Education and training for people with dementia and family and whānau supporters is an overarching factor in all elements of the New Zealand Framework for Dementia Care. The framework provides best practice examples and education resources.


The framework states that “educational and training opportunities for people with dementia and their families and whānau should:

- be developed following the principles set out in Rauemi Atawhai: A guide to developing health education resources in New Zealand (Ministry of Health 2012)
- be provided throughout the person’s life with dementia
- focus on living well and emphasise the positive aspects of living with dementia
- acknowledge the value of being physically and socially active
- use plain language
- address different learning styles and abilities, including English as a second language
- acknowledge cultural differences and values” (Ministry of Health, 2013, p.9).
Supporters of Pasific peoples with dementia

Appendix 3 of Rauemi Atawhai: A guide to developing health education resources in New Zealand (Ministry of Health, 2012) describes the Fonofale Model, a framework for engagement and developing resources reflecting a Pacific world view. The principles described from the Whānau Ora approach can also be adapted.

Supporters of culturally and linguistically diverse migrants and refugees with dementia

CALD Guidelines for Dementia Patients in Aged Residential Care,³ by Kathy Peri and Gary Cheung, is a useful preparatory resource for educators.

Supporters of people with intellectual disability and dementia

A pathway for people with intellectual disability who develop dementia is being developed. It would be beneficial for supporters to be aware of the pathway to enable them to work with intellectual disability providers, general practice teams and specialists, to ensure the person they’re supporting receives the care they need. Once completed, the pathway will be published on the New Zealand Dementia Cooperative web portal. Other resources are provided in the Recommended core topics table (see Caring for family and whānau, page 7).

Supporters of people with younger onset dementia

People who develop dementia at a younger age (generally under 65) are often still working and may be supporting a household, including children at home. They are likely to be physically and socially active. Young Dementia UK is a consumer focused site with lots of resources and would be useful for educators. Other resources are provided in the Recommended core topics table (see Understand Dementia, page 5).


Younger supporters (under 25) of people with dementia

Many younger supporters may not think of themselves as supporters or carers – it’s just what they’ve always done. Family and whānau supporter education might consider recognition of the impact these responsibilities may have on their life; for example, managing friends and school, and ensuring their mental and physical health needs are being met. Other resources are provided in the Recommended core topics table (see Caring for family and whānau, page 7).

Support for education providers

A forum called Family and Whānau Carer Education Providers has been established on the New Zealand Dementia Cooperative web portal. In this forum you can ask questions, share what is working well, and access resources from other education providers. The forum can be accessed at www.nzdementia.org/forums. You will need to register and log in.

You may also like to check out some of the other forums for specific groups; for example, people with intellectual disability and dementia, and younger onset dementia. These can also be accessed here: www.nzdementia.org/groups.

DEEP, the UK Network for Dementia Voices, provides a range of guides that may also help you to provide effective education programmes that are informed by the voices of people with dementia, and are easily understood and accessible.
Recommended format

- Equal weight is given to delivering information and creating a supportive environment for participants to share and feel connected to the group. This recognises the importance and value of the shared experience.

- In general, it is recommended that the topics outlined in the following tables are provided face-to-face, in a format appropriate for the participants. Delivery will take several hours and over a minimum of 3-4 sessions.

- The education outlined in these guidelines should be included as part of wider and ongoing education and support, which might also include individual sessions. There may be some people who prefer or can only access alternative formats, such as webinars, video clips and online chat groups.

- Topics can be delivered in a variety of ways, such as video clips, activities, and small and large group discussions. Inviting people to share their concerns and symptoms upfront can be a good starting point to understand what information participants may need, what is relevant and, importantly, set the scene for sharing experiences.

- Feedback should be sought from participants to ensure the learning experience is useful and to identify improvements for future sessions.
## Recommended core topics

<table>
<thead>
<tr>
<th>Topic</th>
<th>Outcome</th>
<th>Resources</th>
<th>Time</th>
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</thead>
<tbody>
<tr>
<td><strong>Understand dementia</strong></td>
<td>Participants are able to:</td>
<td></td>
<td>Minimum 1.5 hours</td>
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<tr>
<td></td>
<td>- identify their supported person's type of dementia, current symptoms and anticipated progression of the disease</td>
<td><a href="https://www.alzheimersociety.org.nz/about-dementia">About dementia. A guide for people with dementia and their families.</a></td>
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<td></td>
<td>- discuss how these symptoms are connected to changes within the brain.</td>
<td><a href="https://dementia.org.nz/about-dementia/12-younger-onset-dementia">About Dementia 12 – Younger onset dementia.</a></td>
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<td>Carer Education Programme. <a href="#footnote1">4</a></td>
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<td></td>
<td>Dementia Auckland. Contact <a href="mailto:info@dementiaauckland.org.nz">info@dementiaauckland.org.nz</a></td>
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<td></td>
<td><a href="https://dementia.org.nz/about-dementia/12-younger-onset-dementia">About Dementia 12 – Younger onset dementia.</a></td>
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<td>Alzheimer's Research UK. [5]</td>
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<td><strong>Communication</strong></td>
<td>Participants are able to:</td>
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<td>Minimum 1.5 hours</td>
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<td></td>
<td>- identify current/future communication changes</td>
<td>Carer Education Programme. [4]</td>
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<td></td>
<td>- discuss strategies to respond to communication needs.</td>
<td>Dementia Auckland. Contact <a href="mailto:info@dementiaauckland.org.nz">info@dementiaauckland.org.nz</a></td>
<td></td>
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</tbody>
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Note: Dementia Auckland’s *Carer Education Programme* is a comprehensive, evidence-based workbook for people providing education, information and advice to family and whānau supporters of people with dementia. Email [info@dementiaauckland.org.nz](mailto:info@dementiaauckland.org.nz) for instructions to download it.

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[4](#footnote1): Dementia Auckland’s *Carer Education Programme* is a comprehensive, evidence-based workbook for people providing education, information and advice to family and whānau supporters of people with dementia. Email [info@dementiaauckland.org.nz](mailto:info@dementiaauckland.org.nz) for instructions to download it.
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<tbody>
<tr>
<td><strong>Living well with dementia</strong></td>
<td>People are able to:</td>
<td>- identify strengths of the person with dementia and ways of supporting them to live well and independently</td>
<td>Minimum 1.5 hours</td>
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<td></td>
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<td>- describe delirium and depression, understand strategies for lowering risk, and recognise and respond to symptoms promptly.</td>
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<tr>
<td></td>
<td></td>
<td>Carer Education Programme, Dementia Auckland. Contact <a href="mailto:info@dementiaauckland.org.nz">info@dementiaauckland.org.nz</a>.</td>
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<td>Dementia environment at home (video). Social Care Institute for Excellence (UK).</td>
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<td></td>
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<td>Keeping safe at home. Alzheimers's Society (UK).</td>
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<td>Dementia Design Checklist. IHC New Zealand.</td>
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<td>Living well with dementia: A guide for people diagnosed with dementia. Alzheimers New Zealand.</td>
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<td>Preventing delirium while in hospital. Canterbury District Health Board.</td>
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<td>THINKdelirium – preventing delirium among older people in our care. Canterbury District Health Board.</td>
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<td>Treating Dementia with Cholinesterase Inhibitors. Canterbury District Health Board.</td>
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<td>YOUR brain matters. Dementia Australia.</td>
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<td><strong>Changed behaviour</strong></td>
<td>People are able to:</td>
<td>- recognise changed behaviour as occurring due to brain changes and/or discomfort with health/environment/interactions</td>
<td>Minimum 1.5 hours</td>
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<td></td>
<td></td>
<td>- discuss strategies to preempt/respond to changed behaviour.</td>
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<tr>
<td></td>
<td></td>
<td>Carer Education Programme, Dementia Auckland. Contact <a href="mailto:info@dementiaauckland.org.nz">info@dementiaauckland.org.nz</a>.</td>
<td></td>
</tr>
<tr>
<td><strong>Topic</strong></td>
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</table>
| **Support services and resources** | Participants are able to:  
- identify supports/services available, how they work together, and who, when and how to contact them  
- describe the benefits of using community supports for both the person with dementia and their family and whānau supporters. | A Guide for Carers, Carers New Zealand.  
Alzheimers New Zealand.  
Dementia New Zealand, Phone: 0800 004 001.  
Health & Disability Commissioner.  
Needs assessment and Service Coordination services (NASC), Ministry of Health.  
New Zealand Framework for Dementia Care, Ministry of Health.  
Seniorline, Ministry of Health. | Minimum 1.5 hours |
| **Early planning: care and financial** | Participants are able to:  
- explain the steps required to set up an EPOA/will/ACP, or review what is already in place  
- discuss EPOA responsibility and capacity conversations, and appropriate timing for activating an EPOA. | Advance care planning, Health Quality & Safety Commission.  
Caring for someone with a health condition, injury or disability, Work and Income, Ministry of Social Development.  
Health Passport, Health & Disability Commissioner.  
New Zealand Framework for Dementia Care, Ministry of Health.  
Personal Assist, Public Trust. | Minimum 1.5 hours |
| **Caring for family and whānau** | Participants are able to:  
- discuss the complex feelings that may be experienced  
- discuss the support and resources within personal networks  
- discuss strategies/supports for wellbeing and health | Are you a young carer? Carers New Zealand.  
Carer Education Programme.  
Dementia Auckland. Contact info@dementiaauckland.org.nz.  
Dementia explained – young kids, juniors and teens, Alzheimer's Research UK.  
New Zealand Framework for Dementia Care, Ministry of Health.  
Supporting a person with dementia – a guide for family/whānau and friends, Alzheimers New Zealand.  
Young Carers NZ (Facebook page). | Minimum 1.5 hours |
## Recommended add-on topics

<table>
<thead>
<tr>
<th>Topic</th>
<th>Outcome</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing for respite/long term care</td>
<td>Participants are able to:</td>
<td>Carer Education Programme. Contact <a href="mailto:info@dementiaauckland.org.nz">info@dementiaauckland.org.nz</a>.</td>
</tr>
<tr>
<td></td>
<td>• recognise when and how to use respite/long term care</td>
<td>Long-term residential care for older people – what you need to know, Ministry of Health.</td>
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<td></td>
<td>• discuss the transition process.</td>
<td>Needs assessment and Service coordination services (NASC), Ministry of Health.</td>
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<td>Seniorline, Ministry of Health.</td>
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<td>Transitioning into residential care – a guide for people caring for someone with dementia, Alzheimers New Zealand.</td>
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<tr>
<td>Supports of people in a care facility</td>
<td>Participants are able to:</td>
<td>Complaints procedure, Seniorline, Ministry of Health.</td>
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<td></td>
<td>• describe the progression of dementia through the later stages</td>
<td>Code of Health and Disability Services Consumers’ Rights, Health &amp; Disability Commissioner.</td>
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<td>• discuss their life changes when the person they support has moved into care</td>
<td>The partnership between you and the residential facility, Dementia Australia.</td>
</tr>
<tr>
<td></td>
<td>• discuss opportunities to create a shared care approach with the care facility</td>
<td>Transitioning into residential care – a guide for people caring for someone with dementia, Alzheimers New Zealand.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The later stages of dementia and end of life care – a guide for people with dementia and their family/whanāu, Alzheimers New Zealand.</td>
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