Supporting People to Live Well with Dementia

It is estimated there are currently 78,000 people with a diagnosis of dementia across New Zealand. This number is expected to rise to 154,000 by 2050. Diagnosis, management, and support around dementia has been a key priority for the Government over the last three years. As a result, funding has been allocated to implement the key elements within the New Zealand Framework for Dementia Care.

New Zealand Framework for Dementia Care / MINISTRY OF HEALTH, 2013

Problem
Many people with dementia are undiagnosed or receive a diagnosis late in their disease. This impacts on the support they receive and their ability to make an informed plan to live well with dementia.

Reasons for late diagnosis include:
- confidence of primary care to recognise the importance of and provide timely diagnosis for people living with dementia
- adherence to the available Cognitive Impairment Pathways
- level of awareness and associated stigma
- provision of ongoing support for people with dementia and their families in the community
- current medical model is more focused on the disease than living well with dementia
- variability of access to dementia support services.

Project aims
The South Island Primary Care-Dementia Education Project was initiated to:
- support health care professionals to provide a more timely diagnosis for people with dementia
- increase knowledge and confidence around dementia within primary care settings.

Methodology
An action research model was used to survey primary care providers about their experiences diagnosing dementia.

A collaborative approach was used to deliver face-to-face education sessions, featuring specialist services, non-government organisations and primary care training teams.

Training was delivered using an appreciative inquiry approach, with easy flow of dialogue both ways, and combined input from specialist services, non-government organisations and primary care training teams.

Measures of improvement
- 86% of participants rated the education sessions as above average. They said:
  - “I loved the videos, extremely moving and powerful. Great facilitators and sense.”
  - “Great to hear of supports available to people and their family with dementia. I will refer more people on to Alzheimer’s organisations.”
  - “I learned about the cognitive impairment pathways. I backed these up with the person with memory/ cognitive impairment generally doing tests to know early for planning, self-awareness and making the most of rest of their life.”
  - “Great information around the importance of a timely diagnosis and great to know of subsidised medications for dementia.”
  - “Learning about electronic referrals and referral to Alzheimer’s organisation was helpful and the patient books. I will keep open discussions with GP and family...build the puzzle.”
- A questionnaire will be provided to all staff who complete the online training for primary care health professionals, to assess the level of confidence in diagnosing dementia and implementing a management plan before and after training. South Island results will be collated six monthly.
- South Island referrals to Alzheimer’s organisations will be collated six monthly.

Outcomes
In the South Island, referrals to Alzheimer’s organisation increased 195% from January 2015 to June 2016 (excluding one district health board due to insufficient data).

I WILL HAVE GONE FROM THIS...
- “My mum was admitted to hospital three times. The third time, her discharge summary said she had Dementia-probable Alzheimer’s type” – no one had told me and no one told me what this meant. What’s meant to us we was we wasn’t able to take her medication by herself, she wasn’t able to cook or prepare meals, so she started losing weight. We wish it was been explained in more depth so we understood and also wish it was picked up on one of the first two admissions, because the third could have been avoided.” – June, 43
- “Four people came to see me today from the hospital. I didn’t know who they were but they kept saying ‘we’re going to see you soon’ and they all brought different things and told me different information.” – June, 79
TO THIS...
- “Since my diagnosis there has been lots of support and help from the local Alzheimer’s organisation, either my GP started the process I didn’t know what having Alzheimer’s was. The Alzheimer’s organisation has made me feel secure. It’s great to be with others on the same journey and my wife feels the same. When there is tension at home we can ring up and talk to someone.” – Paul, 70
- “I knew diagnosis of dementia prior to admission. Previously living alone in own home. During admission I heard of problems with sensory functioning including – word finding difficulties, poor memory recall, poor orientation to person, place and time, poor problem solving techniques and task initiation, information organisation and psychosocial agitation. These signs are all consistent with progression of the dementia.” – Resident nurse on patient discharge paperwork.

South Island interventions
- Surveyed primary care providers about their experiences diagnosing dementia and used this to develop educational resources.
- Collaborated nationally to develop a national online training resource.
- Filmed interviews with people living with dementia and their carers discussing their diagnosis and dementia experience, in partnership with Alzheimer’s Canterbury.
- Provided consultation and feedback on national resources developed by Alzheimer New Zealand.
- Filmed health care professionals around the assessment and support for people with dementia and their families.
- Conducted a review of all South Island cognitive impairment pathways to identify points of consistency and differences.
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- Provided electronic referrals to local Alzheimer’s organisations using existing systems.
- Established and facilitated a resource group to provide an interface between primary care, specialist services and community care health professionals across the South Island and guidance on the development of educational material.
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Take-home messages
- Timely diagnosis early in the disease process is beneficial for the person with dementia and their family.
- Primary care is being provided with education, resources and knowledge to support this.
- People can live well with dementia if provided with the support they need.
- A whole of system approach is essential to improve outcomes for people living with dementia.