



New Zealand Dementia Summit

Final report

Synopsis

The projected increase in the numbers of people with dementia, and a traditional health system that is focused on acute care rather than the care of people with long term conditions, has led to much debate about what we need to do to provide better care and support for people with dementia and their families in NZ. The recurring questions are: What do people need? How does the health system need to change to respond to these needs? How do we get there? Those critical questions prompted collaboration between the NZ Dementia Cooperative, Alzheimers NZ and Carers NZ to hold the *NZ Dementia Summit* to have a national discussion about the way forward for dementia care in NZ.

Convened in Wellington in November, 2015, the *NZ Dementia Summit* had 224 participants including health professionals, service providers, government officials, educators, researchers and people affected by dementia, including family carers, who all shared their experience, knowledge and expertise. Delivering quality services is a health care priority, especially when it comes to the care of vulnerable people, such as those with dementia.

This report has been drawn up from the participants' discussions and recommendations which were recorded by scribes at each of the 26 tables at the Summit. These are the views of the Summit participants and are not statements by the NZ Dementia Cooperative, Alzheimers NZ or Carers NZ. The report is structured to reflect the way the Summit operated and to mirror the discussions at the tables as the participants covered the issues. As such, there is duplication in some areas, as this is necessary to cover the themes. To mitigate the resulting duplication and length, it is designed to be read in sections.

Summit objectives

1. To outline what is currently working well.
2. To identify what improvements are needed.
3. To identify the steps that could be taken to make the wanted improvements to ensure people's needs are met and appropriate care is provided.

Method

The Summit was held over two days. Both days began with keynote speakers from the world of dementia care in New Zealand. These sessions were followed by round table discussions between the participants. Each table, which seated eight to ten participants, addressed all three questions. The first question was designed to gather each participant's perception of aspects of dementia care that are working well. The second question explored each participant's vision for the future of dementia care and improvements that are needed. The final question was designed to identify the actions needed to bring about the desired improvements. All the feedback was recorded and transcribed.

Ten themes important to dementia care were identified from the transcribed discussions: Prevention; Timely diagnosis; Perceptions; Living well; Managing symptoms; Empowerment; Integration; Workforce; Models of care; and End of life care.

This report presents the Summit participants' responses to the three questions, using the identified themes as a framework.

What is currently working well.

Perceptions

Participants referred to a groundswell of support for people with dementia, with increasing public awareness. Some commented that there are more conversations about dementia in the community and across media (e.g. news and magazines). Others felt there is more education and information available, in part attributed to Alzheimers organisations working to raise awareness. Still others remarked on an increased awareness by professionals, especially of the multiple factors affecting expressed behaviour.

Understanding of the importance of design was thought to be increasing, with the some areas of the country moving to develop dementia friendly communities, and some residential care facilities developing more supportive environments. . Participants also felt that language use is becoming more open and respectful and less stigmatising. Furthermore, some carers and families are developing a clearer understanding of the triggers that influence the behaviour of people living with dementia.

Prevention

Participants applauded campaigns that encourage *"increased awareness of lifestyle choices"* at a younger age and that increase recognition of the need for *"social involvement"*. The availability of genetic testing and improved counselling was also seen as positive.

Empowerment

Some people noted that the voices of people with dementia are increasingly being sought and listened to, with people with dementia being included in research in an attempt to understand their concerns, needs and priorities. Participants suggested that person-centred care and strength-based models are beginning to filter through, with “*Care and dignity*” programmes and cultural awareness also thought to be growing.

Some participants also noted that there was increasing knowledge about medico-legal issues including EPOA and Advance Care Planning (ACP).

Living well

Some participants were of the opinion that there is a growing change in attitude away from ‘dying with dementia’ towards ‘living with dementia’, with increased recognition of the “*importance of participation and socialization.*” This shift in thinking is deemed desirable because “*People function better in [their] own community.*” Participants strongly supported this as a goal and stated that, with appropriate services, it could be a viable option.

Some NASC teams were also identified as becoming more responsive to people with dementia, promoting flexibility and engaging in goal setting.

Timely diagnosis

Many participants commented on the development of cognitive impairment pathways in Primary Care. They stated that, as a result of these, an increased number of people are being referred to Alzheimers organisations. They also welcomed the fact that some GPs are becoming proactive about diagnosis.

Managing symptoms

Public and professional awareness of the multiple factors that influence the expressed behaviour of people with dementia is improving. There is some cognitive stimulation therapy and training available. Groups with age-specific activities are increasing.

Likewise, there is increased awareness of the risks of polypharmacy and inappropriate use of pharmaceutical and physical restraint. Some participants felt that awareness of ‘*unmet need*’ as the reason for difficult behaviours has improved, and there is more training available to assist with managing unpredictable behaviour.

Workforce

Participants identified that there are a number of opportunities available to improve both care staff and family/whānau members’ understanding of dementia, for instance, ‘Open

minds, open doors', 'Walking in another's shoes', and the training offered by local Alzheimers organisations.

According to participants, this has resulted in increased knowledge and awareness and is evidence of *"Collaboration happening to develop good training"*. Participants also stated that there is increased demand for training *"to understand behaviours that challenge in ARC."*

Integration

Participants stated that the development of clinical pathways has helped integration. Others see a growing willingness to collaborate, both in the regional and national sharing of knowledge and expertise.

At the clinical service level, some participants reported improved collaboration, resulting in better coordination of complex care, with the way in which some multidisciplinary teams function in secondary care applauded. Efforts include integrating services across levels and breaking down siloes across disease types, with some examples of inter-sectorial collaboration starting to happen, for example, Home Based Support Services and Hospice collaborating on the delivery of care.

Models of care

The positive influence of the NZ Framework for Dementia Care was acknowledged and its contribution to the potential development of a comprehensive and consistent approach valued. However, participants emphasised that implementation has currently only covered the first elements of assessment/diagnosis, and they expressed strong support throughout the Summit for full implementation of the Framework. They also see progress in communication and an increase in the quality of information flows around clients with the more consistent use of the InterRAI assessment tool.

Participants also noted that the importance of social connections is increasingly recognised. In addition, awareness of the need for person centred care and strength based models is growing.

Some were of the opinion that community based support for people with dementia is increasing, through improved home based care services, including rapid response and an increased numbers of day programmes. Participants reported that access to community support groups for carers has also improved in some areas. The general view is that Alzheimers organisations are doing a great job.

Participants also felt that aged residential care for people with dementia is improving in some instances, with better linkages, more appropriate placement and more mental health support within ARC in some facilities. While there is also more choice of facilities now, people want to see an increase in the range of facilities to further increase choice.

End of life care

There are instances of *“Improved collaboration between service providers”* such as District Health Board (DHB) staff and Hospice staff, a *“focus on living well, not dying”*, with increased emphasis on people living at home, and *“giving people choices about where they live and die”* which were seen as positive.

The improvements that are needed.

Perceptions

People dreamed of a world without stigma and fear of dementia. Reduction of stigma would mean that people are less reluctant to seek timely diagnosis. Participants wanted to see an increased awareness by all about the entire journey made by people with dementia. Addressing the issue of increasing the awareness of younger-onset dementia and people with intellectual disability was considered essential. The effect of language that undermines people with dementia is a major issue. One hopeful outcome of improving perceptions of dementia would be dementia having the same recognition as other chronic health conditions and attracting the same community/philanthropic/empathic attention.

Many participants would like to see dementia-friendly communities, such as Tauranga’s Age Friendly Strategy. The perception is that dementia-friendly cities, work places, transport systems, GP surgeries, and day-stay wards will increase social awareness of the entire journey that people with dementia and their families may have to travel.

Prevention

In general, people thought that there should be increased emphasis on preventative strategies. Participants called for dementia to become a health priority. Ideally, they want a national campaign to raise awareness, simultaneously highlighting preventative strategies and risk reduction through healthy lifestyle choices. Some participants thought stress management, education, and better prevention and management of depression should also be highlighted. The idea is to encourage individuals and families to take responsibility for their future health and become proactive.

Participants wanted to see a society that values mental and physical activity with increased social connectedness. To achieve this, participants suggested that communities need to work together to offset, and even prevent, people living in social isolation. Participants were encouraged by the increased recognition of the importance of social involvement, citing programmes run by Alzheimers organisations as good examples.

Empowerment

Participants stated that people with dementia should be in control of their life journey - not the health professional or provider agency – all the way, ideally including at the stage of requiring palliative care. Care plans should be developed in collaboration with the person and their family/whānau in a timely way, thus allowing decisions to be made by the people most affected by the symptoms. Goal-planning across the person's networks may help to facilitate person-centred care by identifying *“people I know, things I do, what I value.”* Additionally, the referral process and access criteria should focus on the needs of the person with dementia and their family, and not become a barrier to services. Consumer involvement in all spheres of service planning and development would be an indication of a willingness to listen to and empower people with dementia.

Participants thought that the person with dementia always has potential to be an active member of their community-- working, volunteering, attending, and socializing. They stated that we need to empower people who live with dementia to age positively. Many participants wanted increased involvement and empowerment of people with dementia in the wider community, e.g. listening to their opinion on local councils. They envisaged confident spokespeople who are living with dementia and available to comment where relevant: *“nothing about us without us”*. Likewise, listening to the opinions of family carers was considered vital.

Living well

Many of the participants were of the opinion that attitudes are beginning to change from 'dying with dementia' to 'living with dementia', with increased recognition of the *“importance of participation and socialization.”* It was acknowledged that many people with dementia live at home and hope to stay there until life ends. Participants supported this goal and stated that, with appropriate support, this could be a viable option, because *“people function better in their own community.”*

There was strong support for increased and more appropriate community based services. Participants said that home based flexible packages of care that focus on maintaining independence, rather than just on task based personal care and household management, need to be provided. Respite services such as a diverse range of funded community day programmes were seen as critical. Once people choose to move into residential care, participants want to see people maintained in place, rather than moved when their level on care increases. They noted that aged residential care facilities are improving the ways in which end of life care is managed, to avoid moving people to hospital care.

Timely diagnosis

Participants discussed the impact of stigma on people obtaining a diagnosis, with stigma around dementia affecting clinicians' as well as families' attitudes. There was agreement that if there were *“less stigma and fear”* attached to dementia and a national approach to

educating people about dementia symptoms, along with destigmatisation, timely diagnosis rates should improve.

Participants acknowledged the important role primary care plays in timely diagnosis. There was strong support for extending the use of cognitive impairment pathways to inform and support GPs. Participants suggested such a move would require GPs to be able to spend more time with patients and therefore more resources would need to be committed. GPs will need more education and support to increase their confidence around dementia diagnosis and management. Similarly, some participants thought it important for GPs to become more knowledgeable about the different conditions that can cause dementia. The cost to consumers of getting a diagnosis and the costs of ongoing condition management were also of concern to people.

To ensure an accurate diagnosis, there were many comments about the need for the assessment process to be undertaken in the person's home, because that is a familiar environment, rather than in a clinic. People also felt that a multi disciplinary approach is more appropriate for someone undergoing a diagnosis for dementia.

Managing symptoms

Participants thought that the management of symptoms starts with improving public awareness of symptoms and their management, leading to more timely diagnosis and early intervention. People thought that genuine engagement and education for the person with dementia and their family/whanau in the early stages can help people manage better and live well in their community. The focus needs to be on what people's abilities are rather than their disabilities, and a good knowledge of triggers and unusual behaviours is important.

People need social support as well as medical intervention on the dementia journey. Participants want to see a change of attitude to care, with thinking moving beyond medical management of symptoms. They want to see the current reduction in the use of anti-psychotics accelerate, with medication and restraints not used for behavioural management and control,

Participants stated that providers need to avoid taking away opportunities, focusing on positives and abilities rather than negatives and disabilities. People want to see comprehensive support packages of care with improved access to multi-disciplinary teams. The general view was that taking a holistic approach is important, and alternative therapies such as music therapy, talking mats, pets, etc., can be very beneficial for people with dementia. People also want to see a greater use of technology to keep people safe in the community.

Participants thought that funding should focus on person centred care as a comprehensive package that supports independence and maintains people in their familiar environment. This includes more comprehensive home based support that includes services such as

medication oversight and allied health. They think all healthcare settings, such as GP clinics, emergency departments and acute hospitals, should be dementia-friendly and responsive to the needs of people with dementia so they do not have their symptoms exacerbated by confusion and anxiety.

Many people commented that it should be the level of care that changes, not a person's placement as dementia progresses, as familiarity with people and places reduces symptoms. There was strong support for better, more intensive and more flexible home support options and more appropriate residential care options. A village model was seen as beneficial, but participants thought existing facilities could make their environment more dementia friendly by initiating changes that are well evidenced and not costly.

Workforce

Summit participants recognised the passion, commitment and skill of the workforce, both formal and informal, that is providing care for people with dementia. The view was that family carers and volunteers form part of the dementia workforce, working alongside formal roles to provide 24 hour wrap-around support.

People living with dementia have complex health and social care needs, and participants had strong views on the multidisciplinary approach to the workforce that is required to meet people's needs well. The use of nurse practitioners and specialist nurses across primary, community and residential care, and improved access to allied health are seen as key elements of a dementia workforce. The role of a navigator is also seen as very important given the complexity of dementia inevitably involves a wide range of health and social service providers and professionals. There was also a strong view that it needs to be recognised that people with dementia need more time than people with other conditions, and that everyone working in dementia should have *"more time to care"* to meet their needs.

Participants were concerned about the consistency and stability of the workforce, particularly the support workforce. They want to see improved support workforce supply, along with improved working conditions and workers being more valued. The lack of training and education in dementia available to the workforce of all types was a concern. Participants were very clear that there is a need to increase skills across the workforce, both formal and informal. They want to see more education available for family carers through Alzheimers organisations, and specific dementia education included in all training for the workforce delivering health and social care. People want to see dementia as a *"Career direction ... in the workforce"* and for training and employment to reflect this.

Integration

Participants want to see all elements of the NZ Framework for Dementia Care implemented throughout NZ. They have confidence that if fully implemented the key elements of the Framework will improve outcomes and enable people to deliver quality care. They want to see cognitive impairment pathways used to achieve timely diagnosis and care that is centred around the person with dementia and their carer and *"primary led, secondary supported"*. Participants were strongly of the view that the complexity of dementia care requires investment in care coordination and navigation services, and that a

multidisciplinary “*community mental health team*” approach is needed to address people’s needs.

People want to see wrap-around care that is driven by the person with dementia and their family, with the removal of silos and boundaries at the point of care. There was agreement that there needs to be a single care plan that includes both health and social care, involves a coordinator, and is shared across the services involved.

Communication is a key element in ensuring the success of such an approach, and participants want to see integrated IT systems supporting single care plans. They also want to see increased communication between providers, particularly at the point of transition, such as on admission and discharge between hospital and community and residential care, and between home based and residential care services as dementia progresses.

People very much want to see closer working partnerships between providers in health and social care, and there were a number of suggestions that establishing primary care hubs would benefit coordination, with providers able to interact easily. Participants want integration between voluntary and formal services to improve, and greater access to community services such as Alzheimers organisations. There were also suggestions for a one-stop-shop for access to processes such as EPOA, wills, driving assessments, taxi chits and disability support, to reduce fragmentation.

Participants want to see nationwide consistency of the type and quality of services. There was also strong support for the development of mechanisms for sharing knowledge, experience and good practice, such as the NZ Dementia Cooperative (NZDC) web portal and Carers NZ’s and Alzheimers NZ’s information resources and websites. The need for development of closer working relationships across regions and districts, both formally and informally was also emphasized.

Models of care

Strong views were expressed on the need for a nationally consistent service model that is integrated, coherent and coordinated. Participants want a national approach that allows for local fits, with more dementia care delivered in the home and community, more use of cognitive impairment pathways, and more consistency across DHBs to achieve best practice.

People want to see dementia care as enabling, empowering and focused on self determination and the desires of the person with dementia. They see the current model as too narrow and focused on secondary care, when people need support earlier to maintain their independence.

The dementia journey is long and complex, and the view is that it’s important to maintain consistency as much as possible for people. The approach should be to change the level of care, not the placement of the person, as dementia progresses. Participants feel that a community focus means there should be more individualized home based care and respite, with strong support shown for increased support for the family group. People want to see carer and family stress better managed, and services more focused on carer relief, with the

aim of preventing carer burnout. Participants were strongly of the view that while people are living in the community, there is a need for a service coordination role, and a consistent navigator as a central element to support people. They also supported better integration of Alzheimers organisations services into the overall support package and supported by appropriate funding.

People think that diagnosis and management of the condition in people with atypical onset of dementia is not working well at present. There is too much emphasis on age, and they want to see more recognition of needs of younger people and people with intellectual disability, with more appropriate community support available. There was also a strong call for more appropriate residential care places for people with atypical onset of dementia.

In general, people think innovation and funding is required to expand the range of services available to people in the community. These include different approaches to home based support, both clinical and non-clinical, with more of a multi-disciplinary team approach, support workers doing more social caring and community connection, intergenerational programmes and better use of technology.

For people living in aged residential care, there was a general consensus of opinion that large institutional models are too impersonal, too stimulating, and confusing. Participants wanted a move away from this type of facility to supported living in small group models in the community or a village setting, with a homelike environment, smaller units and individualized care. Examples included IDEA Services group homes, the Abbeyfield model and the De Hogeweyk style Rotorua village. They want facilities that accommodate different options, such as couples with different needs living together, and culturally flexible and intergenerational models.

People want to see care facilities that are not isolated but are part of the community, with more interaction with families and others in the community, and more integration between home based care and residential care, such as the provision of an inpatient night hospital model that people living at home with complex needs can use.

End of life care

There is a need to change ideas on dying to focus on enabling the person to live to the best of their ability before dying with dignity. There was a general consensus of opinion that people need choice about where they die and that palliative care should be provided in the environment the person chooses. Participants said this means increasing palliative services in home based care. For those already in residential care, participants called for collaboration between a palliative care team and the facility staff. A number of participants want a greater focus on the needs of people dying with younger onset dementia.

The need to support family/whānau and carers during the dying process was also highlighted, and people stated that it's important that providers accommodate cultural

differences and needs at the end of life. The participants also advocated that Advanced Care Planning should be encouraged so that wishes are known in a timely manner. Participants said that people who are reaching the end of their life should have access to specialist care, especially people living with younger onset dementia. They thought that GPs need education and support so that they are more capable of supporting people who want to remain in their own home. Family / whānau members should be well informed on what to expect.

The steps that could be taken to make the wanted improvements.

Perceptions

The way to achieve the desired stigma reduction was seen to be education for everyone, to encourage societal attitude change so that older people are respected and valued. To achieve this it would be necessary to start young; school education should include recognition of dementia and acceptance of people with this condition.

A national education campaign to raise awareness and highlight new knowledge about dementia, such as the Alzheimers NZ campaign, would help to reduce stigma. Suggestions put forward included media campaigns to promote health and explain symptoms, the use of a range of different media channels, including arts media, such as *Keys in the Margarine*, and children's books, was encouraged. Communication networks and websites could also be used to encourage discussion, disseminate information and demonstrate how to be positive and use words that do not stigmatise ageing or dementia. Examples include the Carers NZ website and webinars.

Participants saw the development of dementia friendly communities as vital for reducing stigma. This includes dementia-friendly cities, public facilities, businesses and services, work places, transport systems, and local spaces. It was suggested that Government departments working together and modelling dementia-friendly workplaces could reduce stigma in central government, while the way to achieve dementia friendly communities would be through engaging with city councillors to improve transport and the design of public spaces and transport. Local Alzheimers groups could collaborate in co-design.

Prevention

Participants suggested that education and promotion of healthy lifestyles should begin with young people at school and continue on throughout life through national campaigns. Education would address the five lifestyle factors that reduce risk of dementia: diet, exercise, healthy habits, socialisation and ongoing intellectual stimulation. Some thought

that GPs have a role to play in providing an annual 'Warrant of fitness', aligned to information about risk reduction to increase people's knowledge while also placing an increased emphasis on individual responsibility for health. However, participants recognised that not all dementias can be prevented by life-style changes so a variety of messages may be required.

For people to maintain social connection, communities need to proactively prevent social isolation early. Participants wanted more community development of social groups with age appropriate activities e.g. scrabble, walking groups, bowls etc., made available with a green prescription. Participants suggested inter-generational activities would help to involve older people in all aspects of life.

Funding for ongoing research into prevention of dementia and/or improved understanding of causes for its onset was seen as important. Multi-national research partnerships are valuable. There was a suggestion that *"solving the gender riddle"*, that is, why dementia is more common in women, should be a research priority.

Empowerment

To improve outcomes for people with dementia, participants thought we need to change the culture of care so that the focus is on the person not the disease, and so that services engage with the person with dementia and their family/whānau to learn about their needs, their hopes and ambitions for the future. People with dementia and their families should be involved in all aspects of care planning with plans developed in collaboration with them. Plans might include partners continuing to live together and being able to make choices about their care. Families should be empowered in decision-making, especially around palliative care. There was recognition that not everyone comes with "happy families"; an advocate should be available for people who feel unsafe with their family.

For people with dementia to be genuinely at the centre of their own care, there will need to be a shift to a person-centred funding model. There were suggestions to *"unbundle the NASC assessment process to enable the person with dementia to drive the process."* Any development of new approaches needs to involve specific groups, such as people with intellectual disability, Asian, Pacific and younger people, older men caring for their wives and those with pre-existing mental health issues, to truly enable the provision of person-centred care. Ongoing quality improvement and service evaluation is important.

Participants thought there needed to be much more understanding about medico-legal issues, including EPOA and Advance Care Planning, services, rights and entitlements. Some thought the EPOA legislation needs a "complete overhaul" and that making an EPOA should be more affordable. There were also calls for a one-stop-shop across health and social services, so that people can easily access what they need, for example, EPOA, taxi chits, and disability support, without having to go from service to service.

Living well

Overall, participants very much wanted to be able to respond to people's needs in more innovative ways to support them to *"do the things they have always done"*. There were calls for *"less rules, bureaucracy, and red tape"* and suggestions that as a system we *"relook at our current risk aversion"* in order to do this.

Many participants expressed the view that people with dementia could remain in their own home if a range of services were provided, but that the dementia journey is complex, so the role of a navigator is critical.

While NASCs are starting to promote goal setting, participants thought that people should have their abilities assessed as well as their needs, to determine an appropriate care plan. There was a call for NASC staff to have better information about the services available in their area.

Participants suggested that day support and respite services become centres of excellence where people can maintain their abilities by engaging in activities that will enable them to live well and to use retained skills and knowledge, while having fun. It was noted that these facilities would need to address different levels of cognitive impairment.

Participants called for more ability to provide creative respite, such as volunteers having people in their home for the day, joint holidays for the person with dementia and carer together, and short term drop-in centres and activities in the community. Transport to access these services would enable people to stay connected in their community. Participants thought that when people choose to move into residential care, the transition could be eased by introducing a stepped care approach to ensure a smooth transfer.

People think enabling people to live well with dementia means collaboration between service providers will need to improve, to ensure wrap-around services that are flexible. Participants suggested local providers could form Health Hubs as a base where providers (DHB, PHO, Allied Health, NGO) could interact easily.

Changing attitudes and approaches requires education, and participants strongly supported living and dying with dementia being included in the curriculum of all health professional and support service training curriculums.

Timely diagnosis

Participants thought a national strategy was required to improve rates of timely diagnosis. For any developments in the health sector to have a significant impact, they need to be underpinned by a national campaign to improve public knowledge and reduce stigma around dementia, so that people are less reluctant to seek a diagnosis. If others involved

with the person, such as family members or home based support services, could refer people, this would also impact on diagnosis rates.

There was strong support for extending the use of cognitive impairment pathways to inform and support GPs, with the aim of making them mandatory. However, people think there needs to be recognition of the time a diagnosis takes, and the time and resources involved in ongoing condition management in primary care. Participants stated strongly that primary care faces funding barriers around the process of dementia diagnosis, as the episodic nature and time limited primary care model doesn't adapt well to the extended assessment and management process required for dementia diagnosis. It was suggested that GPs need to increase their confidence around dementia, and that more education and support was needed, as well as GPs having direct referral for CT scans and improved access to secondary care support. It was also suggested that the development of Dementia Nurse Specialist roles would improve dementia diagnosis and management in primary care.

The complex health and social care nature of dementia means there needs to be a range of people with multiple skills involved in the long term journey. Participants called for a multidisciplinary team approach to diagnosis and ongoing symptom management, which would involve an increase in the use of allied health in primary care (occupational therapists, diversional therapists, speech language therapists). People also suggested primary care needs to have more nurse practitioners and better access to psychogeriatricians and improved integration with secondary services.

People raised the potential for alternative referrers, with family members and home based support workers who spend extended time with people being able to refer for diagnosis. This would require education and training and the development of clear pathways and processes for HBSS people to pass on their concerns through an established process. There were a number of comments about increasing access to Alzheimers organisation services, prior to a diagnosis, for people who may have dementia. Currently, these services are only available after diagnosis. People thought this may help people get support to obtain a diagnosis. There were also suggestions that Alzheimers organisations key workers should be able to refer people for diagnosis.

The acknowledged need for increased education across the health sector and the community led participants to call for increased government funding for specialised dementia education, and for such education to be mandatory in all health training programmes. It was noted that there was a particular need to educate health professionals about atypical presentation of dementia and the conditions that could lead to this.

The issue was raised of developing a national dataset through the collection of diagnostic data.

Managing symptoms

Summit participants see the management of dementia as a community issue, with the development of dementia friendly communities able to minimise symptom triggers and misunderstandings. People also thought the management of symptoms would improve if there was less stigma attached to dementia, and better public awareness of the nature of the condition and its symptoms. Media promotion and public education campaigns would lead to people recognising the triggers and symptoms, seeking earlier diagnosis, and having more knowledge of what people with dementia can do and how they can live well in the community. This can occur through multi-media campaigns, education in schools and easily accessible websites such as the Alzheimers NZ website.

Participants want to see more accessible diagnosis and assessment available to encourage and support people to seek a timely diagnosis and early symptom management. There were calls for referrals to be opened up, so that a greater range of people who work with older people and those who are likely to have atypical presentation can refer for diagnosis and support. Participants also want to see support services available early, such as people being able to receive support from Alzheimers organisations prior to a formal diagnosis.

People think a change of service culture is required so that there is genuine recognition and respect for the knowledge and insights of people with dementia and what will really enable them to live well. Assessment and diagnosis would ideally focus on the person in their environment, be comprehensive, and include assessment of depression, vision, hearing and balance to identify other possible causes of symptoms. Improving symptom management will involve services becoming more flexible, with comprehensive packages wrapped around the person and their carers, focused on purposeful activity and engagement as priority interventions.

Research shows that the design of facilities has a significant impact on people with dementia. Some participants thought mandatory design requirements would help in future, suggesting that no new buildings should be funded that are contrary to minimum design specifications.

Participants were very clear that specialised knowledge is required across all disciplines who work with people with dementia and their families, and that dementia training should be included for all people who work in health and social care.

Participants had strong views on the need for a multidisciplinary team approach to dementia care, and their views on the make-up and deployment of the workforce were quite specific. The use of nurse practitioners and specialist nurses across primary, community and residential care, and improved access to allied health are central to providing good care and support. People also want to see MDT teams as more mobile, so people can receive care in a place that's familiar, rather than having to go to a clinic. Good coordination and the role of a navigator were consistently raised and seen as necessary in dementia care.

Participants thought that GPs and secondary care specialists need to work more closely together throughout a patient's dementia journey. Phone and web consults are seen as benefitting people with dementia as a way for GPs and specialists to provide care without people having to attend a clinic. Acute care environments are particularly challenging for people with dementia, and can exacerbate symptoms if not managed well. People thought that specialised dementia knowledge needs to improve in acute care, particularly in ED, and hospitals could have specialist dementia nurses for use in admissions.

Participants think the support workers working with people in their homes need specialised dementia training, and that dementia awareness and unit standards should be compulsory for the entire kaiawhina workforce in aged, disability and social services.

Services that are better integrated were seen as critical for people with dementia. Participants advocated a '*One Plan*' approach, where a person has a care plan that includes all the support and care they need, and is shared among the services involved. This means greater collaboration and integration between voluntary & formal services is needed. In an integrated system, participants see coordinator roles as important and think they should be funded, and they discussed the need for case records to be integrated and shared, which involves getting IT systems introduced and synchronised across services.

Consistency is a theme that came up regularly throughout the Summit, and participants had strong views on the need for mechanisms for sharing knowledge & experience across regions and districts, formally & informally. Participants want to see the '*dementia community*' demonstrate and share good practice across health and social services, sharing information and talking to one another. People want to work more closely with others and think web portals, such as the NZDC interactive platform, can provide the sector with the opportunity to work more closely together.

Participants were clear that current funding models across all services didn't deliver good symptom management. Their view is that funding in Primary Care doesn't support the comprehensive assessment process required for diagnosis, or a more appropriate home based assessment, and that this needs to be recognised and adjusted. Participants think that service funding models will need to change to accommodate more support for family carers and more varied and flexible packages of care in the community. Funding for home based care needs to include more than personal care and household management, and focus on maintaining independence and social connection. Funding is also needed for better support, education and information services both for people with dementia and care partners. Technology that helps keep people safe in the community will need to be included in these packages. In residential care, participants thought funding would need to cover improved staffing levels, for staff to be less task focused, greater involvement of allied health, and programmes focused on maintaining independence.

Workforce

We need to develop and manage a dementia workforce that is tailored and flexible enough to deliver person centred care. The call for an integrated approach to care was clearly articulated by Summit participants, with the need for a multidisciplinary team approach emphasised, including the use of nurse practitioners and specialist nurses across primary, community and residential care, and improved access to allied health as key elements. Mobility of the workforce is seen as important, with suggestions that dementia MDTs be located in Primary Care and deployed in the community and residential care. The funding of coordinators and navigators was repeatedly suggested.

Ensuring an adequate supply of properly trained support workers was also seen as critical. Threaded throughout the discussions was the need for improved recruitment and retention of the workers in both residential and home and community care, with consistent employment, adequate remuneration, training, and the valuing of workers' contributions and skills seen as key to achieving this. An example of incorporating child care and school transport into aged residential care was cited as a way of improving recruitment and retention there. Participants suggested innovation was needed to address the supply of support workers, such as including support workers on the skilled migrant list, and changing Work and Income's penalty for support workers working above their 20 hours threshold for benefits.

Participants supported recruiting support workers to a high standard and suggested talking to school leavers about the role, to build a career pathway from high school. Participants said there needs to be adequate staff employed, and time to allow support workers to be less task focused and deliver person centred care.

Family carers and Alzheimers organisations field workers were seen as an essential part of the workforce in supporting people to live well. Therefore participants think a wider range of more flexible supports for family carers, and better access to Alzheimers organisations, is needed. Participants talked about the need to extend government regulation on parental leave payments to family members caring for a person with dementia.

Participants were strongly of the view that specialised knowledge is required across all disciplines who work with people with dementia and their families. Dementia training should be included for all people who work in health and social care, including medical, nursing and allied health training, social workers, and support workers. Participants suggested that this training should involve consumers and family carers. Participants think that dementia awareness and unit standards should be compulsory for the entire kaiawhina workforce in aged, disability and social services, and that education opportunities should be available for families and support network members through Alzheimers organisations, such as the *Walking in Another's Shoes* programme.

Other suggestions for education were for everyone across the dementia sector to have access to palliative care education and knowledge and training in delirium recognition and management. Modelling and coaching is seen as a valuable way to advance dementia knowledge across the sector.

Integration

The call for mandated, nationally consistent and integrated service delivery was clearly articulated and consistent across all the participants. There were strong views that a national plan for dementia care would aid integration. Participants thought that achieving integrated services would be challenging, and would have to be approached on a national basis, needing politicians, the Ministry of Health, the MSD Office for Senior Citizens, DHBs and the sector to get behind it. There were strong views that a national plan should have a timeline with measures and monitoring required for successful implementation.

Participants want to see the NZ Framework for Dementia Care fully implemented. This was stated consistently throughout the Summit. People see the Framework as an appropriate and achievable guide for achieving the changes in the system of care that are needed to enable people to live well with dementia. Calls for introducing Framework elements such as coordinators and navigators as key elements of integrated services were consistent, and people felt these should be mandatory across DHBs, with allowance for local flexibility.

Integrated funding models are seen as essential for providing integrated health and social care. People want to see funding silos broken down, with person centred funding introduced that will seamlessly facilitate the involvement of the multiple services people need across their dementia journey. Technology was seen as core to successful integration, with appropriate developments needed for providers to share and protect information. People called for lobbying to develop information sharing pathways using web based databases accessed by relevant providers through DHB approved access technology.

Participants think that closer working partnerships between providers in health and social care is key to achieving better outcomes, and want providers to commit to this. People consistently described a spectrum that includes health and social care, primary, secondary and community based, formal and informal care all playing important roles. They are all seen as equal parts of the matrix of care needed to support people with dementia and their families. People suggested primary care hubs were an ideal way for providers to connect and collaborate. There were suggestions that a '*road map*' of services would be needed so that the relationship between services is clear to providers and the public.

Participants were in no doubt that client driven, flexible and integrated care would be challenging to develop and operate, but they were very clear that this is what's needed, and want policy makers, funders and providers to take action to achieve it. The amount of policy and service development that's required to address the issues means we need to work together nationally, to share knowledge, experience and good practice. Participants saw web portals, such as the NZDC interactive portal, as an innovation that means people can work together virtually, easily, cheaply and flexibly to find the solutions to achieving integration of services and improving outcomes.

Models of care

There were strong calls for a national plan, with the changes required needing national leadership. Participants' support for a service model focused on maintaining independence

and the desires of the person with dementia means developing a person-centred funding model, more focused on services in the community, with flexible person centred packages of care that are flexible as needs change. There is also recognition that dementia is not just a health issue; an appropriate model of care needs a whole community approach, requiring the removal of funding silos and a true integration of funders across both health and social services.

People thought the required changes in the model of care and the way it's funded are so significant that contracts need to be deconstructed and reassembled to reflect a new model of care that matches individual and family needs, allowing for flexibility and creativity. The need for better integration of services, and a team approach focused on collaboration, was well recognised, with a call for changes to the current competitive RFP approach so that providers are given incentives to work together.

People recommended that these new approaches be piloted, with outcome measures developed so services and initiatives can be audited and evaluated to ensure service provision is effective.

End of life care.

Participants thought attitudes to dementia needed to change, so that it is not regarded as a *'long slow death'*, with people being supported to live to the best of their ability until their death.

Participants thought there should be more emphasis on Advanced Care Planning, so that it is accessible, and plans are specific and focussed. People want to see the person in control of the journey and service planning driven by the individual's plans. Empowerment of families in decision-making was important to participants, and they want to see the needs of family carers attended to through the dying process. They think that consumers need education and support so that the person and their family are well informed about the dying stages of dementia. Participants also want to see EPOAs more available and affordable.

People thought better collaboration is needed between GPs, specialists and palliative care services to enable people to die with dignity. They thought GPs in particular need education and specialist support to care for people dying with dementia. People thought the concept of living and dying with dementia should be included in the curriculum of all health professionals.

Critical action

Historically, dementia services have been fragmented in New Zealand, and seen as unable to meet people's needs adequately. NZ Dementia Summit participants were clear that changes are urgently needed in the health and social care system, to better meets people's needs now, and to ensure the system is robust enough to weather the projected increase in

the number of people with dementia. They acknowledge that some of these changes are significant paradigm shifts, e.g.: the change of focus from secondary care to primary care, more flexibility in service responses, integration of services and increased community support. Participants know these changes will be challenging, and while people weren't necessarily specific about who should do what when, there was a clear view that national leadership is needed. Participants reported that people throughout the sector are already working hard to improve care, but they are aware that to make the changes needed, everyone in the dementia sector needs to work together, to collaborate and share knowledge and expertise. There was a strong commitment from the Summit to do this.

The Summit participants made recommendations for critical action. They are:

NZ Dementia Summit Critical Actions

1. **Create a National Dementia Plan, with adequate funding attached.**
2. **Shift the paradigm from Secondary Care to Primary Care.**
3. **Raise awareness and encourage timely diagnosis.**
4. **Value people with dementia through person centred flexible services.**
5. **Value family carers/ Improve options for respite.**
6. **Improve integration, coordination and navigation.**
7. **Develop an appropriate dementia workforce.**
8. **Establish dementia-friendly environments.**

Critical Action	What it will look like	Measures
Create a National Dementia Plan in 2017, with adequate funding attached.	Form a national committee or Dementia Council that works with government and provides leadership to create a national dementia plan. This will involve all relevant stakeholders. A Plan is developed by the Dementia Council	A Dementia Council is established. The Dementia Council establishes a timeline & measures for the National Plan. The Health of Older People Strategy has actions for people with dementia.

Critical Action	What it will look like	Measures
	<p data-bbox="775 240 1144 272">& published to the timeline.</p> <p data-bbox="775 320 1294 352">The National Plan has funding attached.</p> <p data-bbox="775 400 1379 464">The Dementia Council to monitor and oversee the implementation of the plan.</p>	<p data-bbox="1402 240 1935 344">Improved integration and consistency of services across New Zealand are demonstrated over time.</p>
<p data-bbox="147 480 707 544">Shift the paradigm from Secondary Care to Primary Care.</p>	<p data-bbox="775 480 1335 584">Make Cognitive Impairment Pathways mandatory nationally. Care to be “<i>primary led, secondary supported</i>”.</p> <p data-bbox="775 639 1346 743">More resources available in Primary Care to enable GPs to undertake timely and appropriate assessments.</p> <p data-bbox="775 799 1357 1054">More resources for long term condition management for people with dementia to enable a multidisciplinary team approach by primary care practitioners. Funding required for increased roles, e.g. nurse practitioners/ dementia nurse specialists, allied health, service coordinators, navigators.</p> <p data-bbox="775 1110 1379 1286">Resources in Home & Community Care need to be focused on meeting the needs of people with dementia to live well, e.g. maintaining skills and activities and maintaining social connection.</p> <p data-bbox="775 1342 1294 1366">Resources for Alzheimers organisations,</p>	<p data-bbox="1402 480 1890 544">Cognitive Impairment Pathways used nationally.</p> <p data-bbox="1402 639 1816 663">Increase in assessments by GPs.</p> <p data-bbox="1402 799 1984 975">Multidisciplinary teams operating in Primary Care, more Long Term Care management by nurse specialists. Service packages are well coordinated & families have access to a known navigator as part of their package.</p> <p data-bbox="1402 1110 2002 1206">Home & Community Care contracts redefined to include support to maintain skills & activities and social connection.</p> <p data-bbox="1402 1342 1991 1366">Increases in NGO support services and ability</p>

Critical Action	What it will look like	Measures
	<p>Carers NZ & other NGOs who deliver social connection services to people impacted by dementia are adequate to meet the needs of the population in their area.</p> <p>More education and support for families is needed – support and resources for Carers NZ & resources for Alzheimers organisations to respond to Cognitive Impairment Pathway referrals.</p>	<p>to respond to referrals from CIPs, & increased national consistency in services offered.</p> <p>Increased ability of Carers NZ and Alzheimers organisations to support carers.</p>
<p>Raise awareness and encourage early diagnosis</p>	<p>Extend/continue the national campaign to raise awareness of dementia in the general public</p> <p>Extend/continue the work by DHBs to support and provide information and education about diagnosis of dementia for GPs.</p> <p>Having a simple, informal checklist visible in public places .e.g. waiting rooms, restaurants, takeaways, supermarkets, schools etc, funded by the MOH and led by Alzheimers NZ.</p> <p>Link dementia-related risk reduction messages, channels and audiences into the generic national health promotion campaign – including that it is never too late to start.</p>	<p>An increase in rates of early diagnosis.</p> <p>CIPs used throughout NZ.</p> <p>Hits on the Alzheimers NZ website and the NZDC Portal.</p> <p>The number of new referrals to Alzheimers organisations.</p> <p>Consumer feedback about the process.</p> <p>Health & social care practitioner feedback about the process.</p>

Critical Action	What it will look like	Measures
<p>Value people with dementia through person centered flexible services.</p>	<p>Change the culture of care so that the focus is on the person not the disease. The focus is on identity of the person e.g. people I know, things I do, what I value</p> <p>Services engage with the person with dementia and their family/whānau to learn about their needs, their hopes and ambitions for the future.</p> <p>All aspects of care planning are developed in collaboration with the person with dementia & their family.</p> <p>Comprehensive packages of care are provided that support the maintenance of skills & activities & social connectedness, & maintain people in their familiar environment.</p> <p>An individualised funding model is in place that enables a package of care to be provided to meet each person's needs.</p>	<p>Develop NZ appropriate outcome measures to evaluate the impact of services or new initiatives on quality of life, change in wellbeing & the effectiveness of the care.</p> <p>Use client and carer feedback to measure reduction in social isolation and increased activities.</p> <p>People are maintained in place, rather than moved when their level on care increases, including once people are living in residential care.</p> <p>Contracts are deconstructed and reassembled to match a comprehensive package of care approach that meets individual and family needs.</p>
<p>Value family carers/ Improve options for respite</p>	<p>Respite is allocated based on the needs of the carer.</p> <p>Establish respite that is flexible and user</p>	<p>Introduction of a carer's needs assessment as a standard approach.</p> <p>Change in residential care respite contracts to</p>

Critical Action	What it will look like	Measures
	<p>friendly.</p> <p>Increase the supply of respite nationally</p> <p>Change access to respite in residential care to make it easier to provide & access.</p> <p>Provide overnight respite in residential care for people living at home.</p> <p>Provide a more diverse range of respite options.</p> <p>Provide funded community day programs that support people to maintain their abilities by engaging in activities where they can use retained skills and knowledge, while having fun.</p> <p>Fund transport so that respite is accessible.</p>	<p>reduce compliance around respite & enable more flexible use of ARC. Increased use of ARC for respite.</p> <p>Contracts for diverse respite options established and programs evaluated. After 3 years, do a stock take of programs available to determine diversity and geographical spread.</p>
<p>Improve integration, coordination and navigation</p>	<p>NZ Framework for Dementia Care fully implemented throughout NZ.</p> <p>Integrated funding models are introduced to cover health and social care.</p> <p>Coordinator and Navigator roles are established and funded throughout the country.</p>	<p>DHBs report on Framework implementation.</p> <p>Removal of silos and boundaries at the point of care.</p> <p>All people with dementia have access to a navigator</p>

Critical Action	What it will look like	Measures
	<p>The standard approach to care involves:</p> <ul style="list-style-type: none"> • A single care plan that includes both health and social care • A multidisciplinary and cross sector/cross agency team <p>Integrated IT systems support single care plans.</p> <p>Integration between NGO and Primary and Secondary Care services is standard.</p> <p>Primary care hubs are established.</p> <p>Mechanisms exist for sharing knowledge, experience and good practice, such as the NZ Dementia Cooperative web portal and the Carers NZ webinars.</p>	<p>Consumer feedback on seamless access to services.</p> <p>Provider feedback on increased communication between services.</p> <p>Issues around transitions, (admission and discharge) are reduced.</p> <p>Consumers' use of home and community services such as Alzheimers organisations increases.</p> <p>Primary & community based services co-locate.</p> <p>Knowledge sharing opportunities funded, & used by the dementia sector.</p> <p>Improved integration and consistency of services across New Zealand are demonstrated over time.</p>
Develop an appropriate dementia workforce	<p>Recognize family carers and volunteers as part of the dementia workforce, working alongside formal roles.</p> <p>A multi-disciplinary team approach is standard care. MDT is located in Primary Care for increased mobility & involves nurse</p>	<p>Consumer feedback on inclusion in care planning.</p> <p>Service evaluations show a multi-disciplinary team approach is standard care.</p>

Critical Action	What it will look like	Measures
	<p>practitioners, specialist nurses & allied health, and NGOs, across primary, community and residential care.</p> <p>Service coordination and navigators are standard care.</p> <p>Develop and implement a strategy to increase the workforce so there are skilled staff available when the numbers increase.</p> <p>Stabilize the support workforce through improved workforce management and working conditions.</p> <p>Increase skills across the workforce both formal & informal:</p> <ul style="list-style-type: none"> • Specific dementia education included in all training for the workforce delivering health and social care. (Including medical, nursing and allied health training, social workers, and support workers.) • Dementia unit standards are compulsory for the entire kaiawhina workforce in aged, disability and social services • Provide more education for family carers through Alzheimers organisations. 	<p>Track workforce turnover.</p> <p>Reduced workforce turnover.</p> <p>Review of training programmes.</p> <p>Increase in dementia unit standards completed.</p> <p>Measure rates of Alzheimers organization service delivery & attendance.</p>
Establish dementia-friendly environments	Develop dementia friendly environments in	We will know when objective has been

Critical Action	What it will look like	Measures
	<p>all healthcare settings, such as GP clinics, emergency departments and acute hospitals, & in public & private community areas.</p> <p>Establish a <i>Dementia Friends</i> programme including pledges taken to make a difference (Alzheimers NZ lead)</p> <p>Extend the dementia-friendly recognition programme that is underway (Alzheimers NZ lead) to encourage business and service industry to make tangible changes to become more dementia-friendly</p> <p>Local Alzheimers Member organisations (MOs) to work with their local councils to support and promote local dementia-friendly initiatives</p> <p>Alzheimers NZ to work with Office for Seniors to promote dementia-friendly criteria as part of age-friendly cities</p> <p>Existing community awareness campaigns are extended.</p> <p>Achievements in this area are celebrated and people given Oscar-type awards.</p>	<p>achieved when people with dementia and their care partners no longer experience stigma and when they are valued and able to live well.</p>

Critical Action	What it will look like	Measures