Disability Support Advisory Committee

Meeting

Wednesday 13 March 2013

1:00pm

Training Room
CCS Disability Action
14 Erson Avenue
Royal Oak
Auckland

*Hei Oranga Tika Mo Te Iti Me Te Rahi*
*Healthy Communities, Quality Healthcare*
INTRODUCTIONS
ATTENDANCE AND APOLOGIES
CONFLICTS OF INTEREST
Conflicts of Interest Quick Reference Guide

Under the NZ Public Health and Disability Act Board members must disclose all interests, and the full nature of the interest, as soon as practicable after the relevant facts come to his or her knowledge.

An "interest" can include, but is not limited to:

- Being a party to, or deriving a financial benefit from, a transaction.
- Having a financial interest in another party to a transaction.
- Being a director, member, official, partner or trustee of another party to a transaction or a person who will or may derive a financial benefit from it.
- Being the parent, child, spouse or partner of another person or party who will or may derive a financial benefit from the transaction.
- Being otherwise directly or indirectly interested in the transaction.

If the interest is so remote or insignificant that it cannot reasonably be regarded as likely to influence the Board member in carrying out duties under the Act then he or she may not be “interested in the transaction”. The Board should generally make this decision, not the individual concerned.

Gifts and offers of hospitality or sponsorship could be perceived as influencing your activities as a Board member and are unlikely to be appropriate in any circumstances.

- When a disclosure is made the Board member concerned must not take part in any deliberation or decision of the Board relating to the transaction, or be included in any quorum or decision, or sign any documents related to the transaction.
- The disclosure must be recorded in the minutes of the next meeting and entered into the interests register.
- The member can take part in deliberations (but not any decision) of the Board in relation to the transaction if the majority of other members of the Board permit the member to do so.
- If this occurs, the minutes of the meeting must record the permission given and the majority’s reasons for doing so, along with what the member said during any deliberation of the Board relating to the transaction concerned.

IMPORTANT

- If in doubt – declare.
- Ensure the full nature of the interest is disclosed, not just the existence of the interest.

<table>
<thead>
<tr>
<th>Name of Member</th>
<th>Organisation</th>
<th>Role</th>
<th>Financial Interest</th>
<th>Nature of Interest</th>
<th>Date of Latest Disclosure</th>
</tr>
</thead>
<tbody>
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<td>Sandra CONEY (Chair)</td>
<td>Councillor Auckland Council</td>
<td>Chair Parks Committee</td>
<td>Fees</td>
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<tr>
<td>Jo AGNEW (Deputy Chair)</td>
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<td>Salary</td>
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<td>7 September 2011</td>
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<tr>
<td>Max ABBOTT</td>
<td>Auckland University of Technology Raeburn House Health Workforce New Zealand AUT Millennium Ownership Trust Social Services Online Trust The Rotary National Science and Technology Trust</td>
<td>Pro Vice-Chancellor (North Shore) and Dean – Faculty of Health and Environmental Sciences Patron Board Member Board Member Chair Board Member</td>
<td>28 September 2011</td>
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<tr>
<td>Pat BOOTH</td>
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<tr>
<td>Susan BUCKLAND</td>
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<td>Northern Region Ethics Committee</td>
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<td>Lester LEVY</td>
<td>University of Auckland Business School</td>
<td>Professor (Adjunct) of Leadership</td>
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<td>1 November 2012</td>
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<td></td>
<td>New Zealand Leadership Institute</td>
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<td>Waitemata District Health Board</td>
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<td>Auckland Transport</td>
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<td>Robyn NORTHEY</td>
<td>Self employed Contractor</td>
<td>Project management, service review, planning etc.</td>
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<td>20 June 2012</td>
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<td>Hope Foundation</td>
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<td>Michelle CAVANAGH</td>
<td>Te Taurahere O Ngati Porou Ki Tamaki</td>
<td>Involvement</td>
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<td>7 March 2012</td>
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<td></td>
<td>WDHB – HWFNZ Hauora Maori Coordinator</td>
<td>Part time employee</td>
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<td>Northland DHB</td>
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<td>Kai Ora Hauora Northern Regional Coordinator</td>
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<td>NAME OF MEMBER</td>
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<td>Maria HULL-BROWN</td>
<td>Employee Mental Health Foundation</td>
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<td>Board member HOPE Foundation for Research on Ageing</td>
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<td>Council Member Age Concern Auckland</td>
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<td>Dairne KIRTON</td>
<td>CCS Disability Action National Board</td>
<td>Northern Regional Representative</td>
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<tr>
<td>Jan MOSS</td>
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<td>MOH Disability Workforce Reference Group</td>
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<td>Susan SHERRARD</td>
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<td>Russell VICKERY</td>
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<td>Disability Consultant</td>
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<td>Auckland University Nursing School</td>
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CONFIRMATION OF MINUTES
- WEDNESDAY 14 NOVEMBER 2012
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<tr>
<th>2</th>
<th>ATTENDANCE AND APOLOGIES</th>
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<tbody>
<tr>
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<td>The Chair declared the meeting open at 1:02pm.</td>
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<tr>
<td>Committee Members</td>
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<tr>
<td>Sandra Coney (WDHB) (Chair)</td>
<td>Jo Agnew (ADHB)</td>
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<td>Pat Booth (WDHB)</td>
<td>Susan Buckland (ADHB)</td>
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<td>Dr Lester Levy (ADHB &amp; WDHB)</td>
<td>Robyn Northey (ADHB)</td>
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<td>Marie Hull-Brown</td>
<td>Dairne Kirton</td>
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<td>Jan Moss</td>
<td>Russell Vickery</td>
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<td>Management in Attendance</td>
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<td>ADHB</td>
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<td>Denis Jury – Chief Planning &amp; Funding Officer (WDHB)</td>
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<td>WDHB</td>
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<td>Tim Woods – Group Manager Funder NGOs</td>
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<td>Samantha Dalwood – Disability Strategy Coordinator</td>
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<td>Sue Skipper – Operations Manager Older Adults and Home Health</td>
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<td>Secretary</td>
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<td>Ian Bell – Board Administrator (ADHB)</td>
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<td>Apologies</td>
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<tr>
<td>Apologies had been received from Max Abbot (WDHB), Michelle Cavanagh, Susan Sherrard, Dr Dale Bramley (WDHB) and Ailsa Claire (ADHB)</td>
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</table>

3 CONFLICTS OF INTEREST

There were no declarations of conflicts of interest for any item on the agenda.
Pat Booth advised that he had connections with Fairfax Media; however this had no impact with his position on the Committee. Russell Vickery advised of an amendment to the register to delete Chairing the Wilson Home Trust 75th Jubilee Committee as this event had been held.
### CONFIRMATION OF MINUTES 22 AUGUST 2012

**Moved Marie Hull-Brown; seconded Robyn Northey**

*That the minutes of the ADHB and WDHB Disability Support Advisory Committee meeting held on 22 August 2012, with the correction to the HBSS Workforce under 9.6 to refer to the diversity of carers, be confirmed as a true and correct record.*

**Carried**

It was noted that Japan and England have had aging populations which is now being experienced in New Zealand.

The recommendations concerning the support for the Caring Counts report had been to both Boards who requested information on the funding implications. Denis Jury and Tim Woods are to provide some estimate of what the costs would be to implement the recommendations. It was noted that a previous Minister of Health had tried to direct funding to care workers but had been unable to enforce that directive.

### ACTION POINTS 22 AUGUST 2012

**Waitemata Assigned Parking**

There was plenty of disability parking at North Shore Hospital in the new parking building on the ground floor; however the ramp to gain access up to the hospital was not ideal. There was more disability parking on the top floor. A review of parking at Waitakere was being undertaken to see if the disability parking could be located closer. Tim Wood is to update the Committee on parking arrangements to the next meeting.

Sandra Coney advised that the question of footpath access had been raised at the last WDHB Board meeting and that it was hard to find your way around North Shore Hospital. This was being reviewed by the CEO looking at all on ground access.

Denis Jury advised that the matter of access barriers to carparks had been raised with Auckland Transport and CCS Disability Action however there were few developments for an appropriate technological solution. Facilities had been requested to consider if it was possible to have parking outside the barrier.

**Auckland Council Disability Group**

Contact with this group is to be followed up by the Secretary as well as the Chair. Colleen Brown was the Chair of Counties Manukau DSAC and Deputy Chair of the Auckland Council Disability Group. A question was raised whether that group, while advising the Auckland Council, also advised Auckland Transport. Lester Levy advised that he would follow this up and that the new trains were very accessible. Comment was made that meeting the minimum access requirements may not resolve access issues and these needed to be addressed at the planning stage and be practically tested during implementation.

**Walk Through Patient Journey**

There was investigation into the way funding for accessibility issues are addressed by the DHBs.

**Remuneration and Reimbursement of Consumer Representatives**

The approach to remuneration and reimbursement of consumer representatives was being aligned between the two DHBs and the possible issue of FBT was being addressed. This action was carried forward.
Dr Rosemary Marks, Development Paediatrician and Jacqui Finnigan, Clinical Nurse Specialist were in attendance.

Rosemary Marks advised that there was regular contact with other DHBs with common issues being access to services, particularly for young people, and that there was a lot of clerical work for clinical staff that takes up time that should be spent on clinical services. It was difficult within the MoH to try and resolve funding boundaries for people with very high needs, with an example of a person in Starship Hospital unable to be discharged due to gaps between categories of funding to meet their high needs. This is a 14 week old with Down’s Syndrome that needs tube feeding but this was being categorised as personal health, not related to disability.

Since devolution of funding there had been more applications declined by Disability Support Services. DHB carer support also needed forms filled out without really understanding the requirement of the patient having support of their carer. When a need is predicted it was essential to resolve issues before discharge and referral to a paediatric specialist, that will follow the child, may assist.

DHBs were experiencing a reduction in funding so alternative solutions with fewer resources needed to be proposed. The fundamental boundary issue was that it allowed people to say “no”. It was suggested that one way to use resources more wisely was to have a coordinator and address requirements on the basis of need, not categorising patients, but drawing money from the appropriate funding stream or streams. It was also suggested that where situations are stable that reassessments should only be done every five years rather than three years. There was an inconsistent approach by NASC across the country and the MoH needed to be cooperative in seeking resolutions. It was suggested that metro Auckland could suggest a pilot to provide evidence in reducing funding barriers. Taikura were aware of the issues but were bound by the guidelines. It was noted that there was some cooperation in the Waikato which had reduced the problems. Part of the problem with NASC were that their assessors were not practicing physicians. The interim funding pool had been established after devolution of funding to address cost shifting by the MoH to DHBs.

In considering a recommendation to the Board there was a need for management to bring forward options and while the problem is defined it was better to approach the MoH with solutions and options for a way forward. A pilot for 0-1 years was suggested as a way forward. The paper should come to the Committee who could then make a recommendation to the Board. It was important that time was taken to ensure the right approach.

**Moved Sandra Coney; seconded Susan Buckland**

*That Officers bring back a paper for options for funding children with disability and health needs to improve services with a possible pilot for 0-1 years in both DHBs.*

**Carried**

### 9.1 Funding Boundaries

Obtaining equipment was an issue knowing what was available and how to access equipment with gate keeping between agencies. This was not necessarily advised in hospitals. Equipment requirements should be included in the needs assessment. One of the problems was that people are assumed to have knowledge and that they don’t escalate their problems. There was a readmission project at Waitemata to predict who may be readmitted and address their needs to avoid the re-admission. This had shown that there was a need for more social workers. It was noted that one of the driving values at Waitemata was “compassion”. It was noted that DHBs have a relationship with ACC.

**Moved Sandra Coney; seconded Jo Agnew**

*That the Committee recommends that ACC be written to concerning funding boundary issues that impact on clients and patients.*

**Carried**
It was also suggested that ACC be invited to discuss these issues with the Committee.

6 Advance Care Planning

Leigh Manson was in attendance and presented to the Committee. Advance Care Planning (ACP) was a process of discussion and shared planning for future health care through conversations that involved the patient, whanau and healthcare professionals. This gave patients the opportunity to develop and express their preferences for end of life care. It gave people the opportunity to think and talk about what the future may hold for them and what matters to them, what that meant in context of medical treatment and care and their preferences in advance. It was noted that more people planned for after death events, i.e. their funeral rather than the time leading up to death.

The ACP Development Model has elements of engagement, education, continuous quality improvement and system infrastructure underpinned by a conducive policy environment and availability of human and financial resources. There was a national Advance Care Planning cooperative. Key focus areas were engagement; with the community through media and websites and the “conversation that count” project, education; to have a competency framework with the health workforce for training and enhancing staff skills as well as with people/consumers providing tools and information resources to guide and record an ACP. The systems area was to increase recording of conversations and plans, with a major increase in the regional DHBs of plans recorded.

ACP needs to be driven by the individual noting that, moving to the future, more people will be managing their own healthcare. There was some concern about unqualified people discussing ACP.

8.1 Quarterly Report on the Implementation of the NZ Disability Strategy

Disability awareness e-learning was noted with a suggestion that disability awareness training needed to be mandatory for all staff. Samantha Dalwood advised that she would promote training across the DHBs and have it included as part of the orientation for new staff with a view to it becoming mandatory in the longer term. It was noted that a barrier free advisor has assessed the plans for refurbishment of Level 6 at Starship Hospital.

Moved Jo Agnew; seconded Sandra Coney

That the report be received.

Carried

8.2 Health of Older People Quarterly Report

A retrospective chart audit had noted that 46% of over 65 year olds showed some form of dementia which was higher than expected. It was noted that there was the ability to put in a manager if Aged Residential Care facilities did not meet audit standards but this was not possible in the Home Based Support Services, although work was being done on remedies.

Moved Sandra Coney; seconded Pat Booth

That the Health of Older People quarterly report be received.

Carried

7 Chairpersons’ Report

Sandra Coney, Jo Agnew and Marie Hull-Brown had attended the Caring Counts Stakeholder Summit with Sandra and Jo being the only elected DHB members with most others being staff. Dwayne Crombie had offered to take the work forward and an invite had been received to attend a follow-up on 27 November 2012. Another issue evolving was care workers being paid for travel time. The report on the Caring Counts Stakeholder Summit was noted.
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<tr>
<th>General Business</th>
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<tr>
<td><strong>Garden</strong></td>
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<tr>
<td>Sandra Coney advised that she had been approached by a group to support disabled people with an organic garden on the Shore with Tim Wood looking at what, if any, support could be offered.</td>
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<tr>
<td>The meeting closed at 4:00pm</td>
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<td>The next scheduled meeting is:</td>
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<td>1:00pm, Wednesday, 13 March 2013</td>
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<td>Training Room, CCS Disability Action</td>
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<td>14 Erson Avenue</td>
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<td>Royal Oak</td>
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<td>Chair:</td>
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ACTION POINTS

- WEDNESDAY 14 NOVEMBER 2012
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<th>Item</th>
<th>Detail</th>
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<tr>
<td>1</td>
<td>Carried forward Waitemata to review the assigned parking positions to see that they are in the right locations and size.</td>
<td>Tim Wood</td>
<td>Comment in Disability Paper re front of hospital parking.</td>
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<td>2</td>
<td>Carried forward The Secretary was to follow up with Colleen Brown on organising a meeting with the Auckland Council Disability Group.</td>
<td>Ian Bell</td>
<td>Chair advised she would contact Colleen</td>
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<td>3</td>
<td>Carried forward Facilities Management of both DHBs be asked to address the Committee on access issues including prioritisation of work</td>
<td>Debbie Holdsworth</td>
<td>Verbal update</td>
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<td>4</td>
<td>Carried forward The Committee requested that someone present on InterRAI being implemented</td>
<td>Sue Waters, Tim Wood</td>
<td>Verbal</td>
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<td>5</td>
<td>Carried forward The Committee asked for information on remuneration and reimbursement and the Terms of Reference of the Regional HOP Consumer Representatives Group.</td>
<td>Katrina Lenzie-Smith, Tony O'Connor</td>
<td>Verbal</td>
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<td>6</td>
<td></td>
<td>Denis Jury, Tim Wood</td>
<td>Scoping of this work has started</td>
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<tr>
<td>7</td>
<td>Some estimate of what the costs would be to implement the Caring Counts report recommendations</td>
<td>Denis Jury, Tim Wood</td>
<td>Verbal update</td>
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<td>8</td>
<td>Management to bring forward options to reduce funding barriers and while the problem is defined it was better to approach the MoH with solutions and options for a way forward. A pilot for 0-1 years was suggested as a way forward.</td>
<td>Denis Jury</td>
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CHAIRMAN’S REPORT
IMPROVEMENT ACTIVITIES

7.1 Quarterly Report on the Implementation of the NZ Disability Strategy

7.2 Quarterly Report on Activities
7.1 Quarterly Report on the Implementation of the NZ Disability Strategy
Date 13 March 2013

To Auckland and Waitemata DHB - DiSAC Committee

From Debbie Holdsworth, Chief Planning & Funding Officer, WDHB
Denis Jury, Chief Planning & Funding Officer, ADHB

Author Samantha Dalwood, Disability Strategy Coordinator, WDHB

Functional Group Auckland and Waitemata DHB Funding and Planning Managers

Subject DISAC Update Report on the implementation of the NZ Disability Strategy in Auckland & Waitemata DHBs

Purpose

The purpose of this report is to provide an update to DiSAC on the progress and activities occurring across both DHB’s to implement the NZ Disability Strategy. Material is provided across both Boards where appropriate, and for specific boards as outlined.

Recommendation:

That the report be received by DiSAC.

NZ Disability Strategy Implementation Plan 2010-2013

The joint WDHB/ADHB Implementation Plan status report is attached in Appendix I.

Disability Awareness e-learning

Following some discussions with Learning & Development, the Disability Awareness e-learning training will not be made mandatory to all staff. This is due to the high number of mandatory clinical training that staff already undertake. The Disability Strategy Coordinator is working with Learning & Development to raise awareness of the course, particularly at staff orientation.

The Disability Awareness e-learning training has not gone live yet at ADHB – the summative quiz (an ADHB requirement that enables tracking of who has done the training) is now in test mode before being rolled out.

Health Passport

With almost half of all DHBs now using, or moving towards using, the Health Passport, the Health & Disability Commission has widened its approach to the establishment of the Health Passport as a tool that is part of ‘business as usual’ in all DHBs. To date, the dissemination of the Health Passport into the community has been the responsibility of each DHB. From 1 July 2013 HDC will be working directly with relevant community organisations to facilitate distribution to consumers on a nationwide basis. HDC have not provided details on how this will be done, but it should mean that more Health Passports are coming into hospitals and being presented to staff. It also means that DHBs can concentrate on raising awareness about the Health Passport with their staff, rather than trying to raise awareness both across the DHB and the community.

2013-2016 Disability Strategy Implementation Plan

The two DHBs are working closely to plan the 2013-2016 Disability Strategy Implementation Plan with a joint planning meeting on 2nd April. This meeting will celebrate what has been achieved over the last
three years and focus on what needs to be done over the next three. Staff, members of the disability sector and community from both DHBs will be at the meeting and we will produce a joint plan.

Members of the DiSAC will be invited to the meeting which will be from 10.00am – 12.30pm on 2nd April. The fully accessible venue will be confirmed in the next few weeks.

Needs Assessment Service Coordinator supports for in-patient discharge for people with impairments

The November meeting discussed a complaint about the NASC service made by a disabled person. The issue was around NASC not being flexible enough to meet with the person before they went into hospital to discuss their unique and complex needs on discharge. Liz Munt, NASC Inpatient Team Leader, sent an update on the work that the NASC are doing to make changes to their processes. WDHB NASC has met with ADHB staff regarding patients requiring assessments in the hospital and a formula regarding the discussion of services with WDHB patients.

WDHB NASC is still looking at trialling some pre-assessments with the elective surgery patients and this should start later this year.

Advanced Care Planning (ACP)

Further to the presentation by Leigh Manson at the November DiSAC meeting, the Disability Strategy Coordinator is now a member of the National Advance Care Planning Cooperative. Her role is to make sure that the national ACP work is fully inclusive.

Car Parking

Car parking for disabled people remains unsatisfactory at the North Shore Hospital site. All disabled parks require patients to get to the hospital entrance via a ramp or the sloping road in front of the building. There are no safe spaces close to the entrance for disabled parks to be placed that do not require navigation of a slope. There are no immediate options to have car parking for people with disabilities at the front of the hospital.

Options to have some spaces behind the hospital are to be explored. However, this requires patients to enter the hospital through the MRI unit. If this option is identified as being feasible then improved signage will be required to ensure people can navigate their way appropriately.

Appendix I: Joint WDHB/ADHB Disability Strategy Implementation Plan progress report.
## Disability Awareness

**Educating staff and challenging stereotypes & assumptions**

### Current Status at 1 March 2013

<table>
<thead>
<tr>
<th><strong>What</strong> we will do... actions</th>
<th><strong>Who</strong> will work on this... Partners / Collaborators</th>
<th><strong>When</strong> will actions take place... in what order</th>
<th><strong>What</strong> is the current status?</th>
</tr>
</thead>
</table>
| Provide a range of disability awareness training, targeting specific services. | Head of Departments GMs and key leaders DiSAC Committee Learning & Development | Ongoing | • **COMPLETED** Collaborative work with Northland DHB to develop a Disability Awareness e-learning module. The training went live on 19 Sept 2011.  
  • August 2012 – ADHB to start using the training as part of staff orientation.  
  • November 2012 – The fifth training scenario - working with people with high/complex needs- has been completed and added to the Disability Awareness e-learning training. |
| Write article for Healthlines on Disability Coordinator role. | Communications | Q1 2010/2011 | **COMPLETED** April 2012 - Article on NZSL Week taster sessions and new booklet in Healthlines. |
| Target team meetings to introduce Disability Coordinator role. | Head of Departments GMs and key leaders | Ongoing | Taking the Health Passport to Team Meetings. |
| Develop clearer policies and procedures for working with patients with disabilities. | Quality Community Organisations | Q1-Q4 2010-2012 | November 2012 – draft report will be brought to DiSAC once completed. |
| Develop 'Disability Champions' across WDHB and ADHB. | GMs Operations Managers Charge Nurse Managers | Q1-Q4 2010-2012 | August 2012 – ADHB have committed to training six Barrier Free 'Disability Champions' in the 2012/13 Annual Plan. |
### Physical Access  
**Overcoming a disability society**  
**Current Status at 1 March 2013**

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Increase knowledge of Mobility/accessible parking by security staff.</td>
<td>Traffic Services</td>
<td>Ongoing</td>
<td></td>
</tr>
<tr>
<td>Create maps of accessible car parking. Include maps in appointment letters and have them available on website.</td>
<td>Traffic Services Communications Dept Outpatient Departments</td>
<td>Ongoing</td>
<td>COMPLETED Nov 2011 – new site maps have been completed. New information to be included with Outpatient appointment letters.</td>
</tr>
<tr>
<td>Walk through ‘patient journey’ to look at accessibility issues.</td>
<td>Community Groups - IHC, Age Concern, Foundation for the Blind. Facilities Department</td>
<td>From Q1 – Q4 2010-2012</td>
<td>ADHB accessibility report has raised issues that go across both DHBs. November 2012 – External signage and way finding audit has been completed. Recommendations being presented next month. November 2012 – Introduction of coloured dots on the floor of ED/ADU to improve way finding.</td>
</tr>
<tr>
<td>Complete barrier free audits of all leased buildings.</td>
<td>Barrier Free Advisor Facilities Department</td>
<td>From Q1 – Q4 2010-2012</td>
<td>Oct 2011 – Disability Strategy Coordinator has completed the 2-day Barrier Free training.</td>
</tr>
<tr>
<td>Task</td>
<td>Responsible Teams</td>
<td>Timeframe</td>
<td>Notes</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
<td>-----------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Develop accessibility audit policy and process for all new facilities.</td>
<td>GM Facilities Team</td>
<td>By Q4 2010-2012</td>
<td><strong>March 2013</strong> – The WDHB Standardisation Guidelines for all new buildings include Barrier Free recommendations.</td>
</tr>
<tr>
<td>Ensure public waiting areas, wards and treatment areas meet the needs of a range of impairments, including autistic spectrum disorders.</td>
<td>Facilities Team Outpatients Team</td>
<td>Ongoing</td>
<td><strong>Nov 2011</strong> – it is now standard that the Disability Strategy Coordinator and the Consumer Engagement Coordinator are included in facilities planning.</td>
</tr>
<tr>
<td>The Disability Reference Group will work to raise and improve access issues.</td>
<td>Disability Reference Group</td>
<td>Ongoing</td>
<td><strong>March 2012</strong> – Community Engagement Coordinators from both DHBs are working together to develop a community engagement joint strategy. The Disability Strategy Coordinator is linked into this work.</td>
</tr>
</tbody>
</table>
**Communication and Access to Information**  
*Empowering people through knowledge and understanding*

**Current progress at 1 March 2013**

<table>
<thead>
<tr>
<th><strong>What</strong> we will do... actions</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Participate in development of Health Passport and work with HDC to plan roll out.</td>
<td>Health &amp; Disability Commission (HDC) Quality Team, HOD Nursing</td>
<td>Draft passport out for consultation July 2010 Implementation during 2010/2011 Ongoing</td>
<td><strong>March 2013</strong> – ADHB – A draft implementation Plan has been developed and will begin to be rolled out into the community. Ongoing work at WDHB.</td>
</tr>
<tr>
<td>Ensure WDHB/ADHB website is accessible – both internet and intranet.</td>
<td>Communications Team</td>
<td>Ongoing</td>
<td>May 2012 – feedback has been very positive with most people able to access the information that they need from the WDHB website. Some useful comments were made and these have been given to the Web Content Manager, who is keen to make any changes needed.</td>
</tr>
<tr>
<td>Ensure patient information is in plain language with clear layout and good visuals.</td>
<td>Communications Team, Waitakere Health links &amp; Health Link North Literacy Reference Group</td>
<td>Ongoing</td>
<td><strong>March 2013</strong> – Disability Strategy Coordinator is a member of the National Advanced Care Planning Cooperative to ensure accessible information.</td>
</tr>
<tr>
<td>Increase formats of key documents, e.g. District Strategic Plan.</td>
<td>Communications Team</td>
<td>Ongoing</td>
<td><strong>March 2013</strong> – developing guidelines for Communications Team on how to make communications more accessible and inclusive to all.</td>
</tr>
</tbody>
</table>
**Community and Consumer Engagement**

**Building relationships and being responsive to needs**

**Current Progress at 1 March 2013**

<table>
<thead>
<tr>
<th>What we will do... actions</th>
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<th>When will actions take place... in what order</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Set up Disability Reference Group.</td>
<td>- Waitakere &amp; Rodney Health links &amp; North Shore Community Health Voice. - Community Engagement Team. - General Managers. - Quality Team. - Community Groups working with traditionally ‘silent’ groups, eg. People with intellectual disabilities, people with Alzheimer’s disease.</td>
<td>Ongoing</td>
<td>August 2012 – Ongoing work to make sure that people with disabilities are being included in all areas of planning and development across both DHBs. For example, Bowel Screening project. WDHB worked with Deaf Aotearoa to produce information in NZSL and the Association of Blind Citizens to make sure the process was as accessible as possible.</td>
</tr>
<tr>
<td>Ensure people with disabilities are identified as stakeholders in planning projects.</td>
<td>General Managers DISAC and Board members (to request reports)</td>
<td>Ongoing</td>
<td>See above.</td>
</tr>
<tr>
<td>Improve the complaints process and make it more transparent.</td>
<td>Quality Team</td>
<td></td>
<td>COMPLETED There is a dedicated person in the Quality Team to respond to complaints. The whole complaints process is being reviewed and the aim is to make a clearer, more transparent process accessible to all.</td>
</tr>
<tr>
<td>Develop group of self-advocates with intellectual disabilities.</td>
<td>IHC – Self Advocacy Team &amp; Health Advisor. Spectrum Care People First.</td>
<td>Ongoing</td>
<td>August 2012 – working with the Dieticians to look at how the nutritional needs to people with intellectual/learning disabilities are being met in hospital, particularly people with communication difficulties.</td>
</tr>
</tbody>
</table>
### Employment Opportunities

Providing employment opportunities for people with impairments and carers

**Current Progress at 1 March 2013**

<table>
<thead>
<tr>
<th>What we will do... actions</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Review all recruitment and employment policies and make recommendations as required.</td>
<td>HR Group Manager Recruitment Manager Workforce Planning</td>
<td>Q1-Q4 2010-2011</td>
<td>COMPLETED Reviewed and rewritten the 2006 “HR Guide for Recruitment and Retention of People with Impairments” with HR. Involved in review of HR policies.</td>
</tr>
<tr>
<td>Review support given to Hiring Managers during the recruitment process.</td>
<td>HR Group Manager Recruitment Manager Occupational Health General Managers</td>
<td>Q1-Q4 2010-2011</td>
<td>COMPLETED Working with HR to review the ‘Impairments at Work’ Policy.</td>
</tr>
<tr>
<td>Encourage the use of ‘Mainstream’ and other supported employment agencies.</td>
<td>HR Group Manager Recruitment Manager Workforce Planning Hiring Managers</td>
<td>Ongoing</td>
<td>August 2012 – ADHB have employed two staff members through the Mainstream programme.</td>
</tr>
<tr>
<td>Review the process for the recruitment of staff with disabilities.</td>
<td>Occupational Health HR Group Manager Recruitment Manager Hiring Managers</td>
<td>Q1-Q4 2010-2011</td>
<td>COMPLETED Have reviewed the process. Met with Occupational Health to discuss their role. There is work to be done to support Hiring Managers, but centralised budgets are very positive.</td>
</tr>
<tr>
<td>Collect data on the number of staff with disabilities (at the time of employment and/or when a disability is acquired).</td>
<td>HR Group Manager Workforce Planning GM, Decision Support Systems</td>
<td>Ongoing</td>
<td>May 2012 – Working with the Workforce Development Manager to look at how data can be recorded and updated to reflect the number of staff who identify as having a disability are employed by WDHB.</td>
</tr>
</tbody>
</table>
Waitemata District Health Board & Auckland District Heath Board

Would like to invite you to be involved in the development and planning of our joint

Implementation of the New Zealand Disability Strategy 2013-2016

This is an exciting opportunity to come together to develop a plan for the next three years. WDHB and ADHB are working together with a vision of Inclusion for All.

Date: Tuesday 2 April 2013
Time: 10.00am-12.30pm
At: Netball North Harbour
44 Northcote Road
Takapuna
Auckland

Tea and coffee will be available from 9.45am

Please RSVP to Samantha Dalwood, Disability Strategy Coordinator
Email: samantha.dalwood@waitematadhb.govt.nz
Phone: (09) 442 3289
Text: 021 221 7810

If you are able to attend, additional details will be sent to you.

The venue is accessible and there is plenty of parking. If you require any special assistance, please let Samantha know.
7.2 Quarterly Report on Activities
**Date**
27 February 2013

**To**
Auckland and Waitemata DHB - DiSAC Committee

**From**
Tim Wood, Funding & Planning Manager,
Denis Jury, Chief Planning and Funding Officer

**Author**
Katrina Lenzie-Smith, Health of Older People, Programme Manager, Waitemata DHB
Kate Sladden, Health of Older People, Programme Manager, Auckland DHB

**Functional Group**
Auckland and Waitemata DHB Funding and Planning Managers

**Subject**
DISAC Quarterly Report on activities in Auckland & Waitemata DHBs

**Purpose**
The purpose of this report is to provide an update to DISAC on the progress and activities occurring across both DHBs.

**Recommendation:**
That this report is received by DISAC.

**Background**
Improved Health of Older People (HoP) services are a priority for the Minister of Health. Auckland and Waitemata DHB activity to improve these services are documented in the 2012/13 Northern Region Health Plan, (NRHP) and our respective District Annual Plans. Key elements of these plans include:
- planning for growth in demand for dementia and acute services
- strengthening coordination and delivery of whole of system care by enhancing cooperation with the primary, community and ARRC sectors
- providing informed choice for older people in their care to minimise dependence

**The Northern Region Health Plan (NRHP)**
Key performance measures are intended to demonstrate that services better meet the needs of older people while managing growth, and include:
- All DHBs will implement a dementia pathway
- Reduction in falls causing major harm in those age-related residential care (ARRC) facilities.
- Reduction in pressure injuries in ARRC facilities.
- Reduction in patients >75 years readmitted within 28 days
- 100% of ARRC providers will be participating in the roll-out of interRAI
- 50% of clients receiving long term Home Based Support Services have an interRAI clinical assessment within the previous 12 months.

ACP conversation and discussions reported
ACP training is ongoing and conversations continue to be recorded across the region.
Home and Community Sector Services (HCSS)

Auckland DHB

Auckland DHB has an enhanced HBSS based on the restorative model of care. A case mix model is used to cluster client need and associated payment for client need on this basis. There has been a focus on improving the flow of information between Auckland City Hospital wards and the four community HBSS providers to enable the providers to be more immediately involved in the transition of patients from hospital to home care. The AD HB Access Centre acts as a conduit for information and is proactively advising providers of admissions and feedback about discharge plans as soon as possible. Flexible funding is being used to facilitate discharges that do not fit the usual process.

The HBSS Service Development Group is working with University of Auckland to develop performance measures for the restorative model. The first of two workshops has been held as part of this process.

Waitemata DHB

Seven of Waitemata DHB’s HBSS providers have either already achieved certification of the Home and Community Support Sector Standard 2012, or are on track to achieve certification by the required date of 1 September 2013. One small provider is still to inform the DHB of their plan to achieve certification.

Waitemata DHB has initiated a review of Waitemata DHB’s home based support services for older adults. The review gathers together published literature, information on other DHB’s models, and the advice of Waitemata and other New Zealand experts. The review will be presented to the DHBs HBSS Review Steering Group on March 4th. The Steering group will be considering the advice and the next steps. The review and the advice of the Steering Group will be available for presentation at the June 2013 Disability Support Advisory Committee meeting.

Specialist Services for Health of Older People at Auckland DHB

A project brief for development of a dementia care pathway has been written and a project manager will be employed to facilitate this work. The project Governance Group will have its first meeting in March 2013. See separate paper.

Specialised Services for Older Adults at Waitemata DHB

Progress with the integration under the five work streams continues with the following providing an update since the last report.

a) Delirium - Progress continues within the four work streams which are:
   a. Assessing Risk and Making a diagnosis
   b. Minimising Confusion (Cognitive interventions)
   c. Modifiable Risk Factors (Physiological interventions)
   d. Medication management

b) Facilities
   • Work has been completed to upgrade the high care area in the Kingsley Mortimer Unit into a 2-bed mental health intensive care unit. Works were completed on 19 December and a blessing and opening held 21 December 2012.
   • Approval has been given by the Executive Leadership Team for capital funds for remedial work in KMU, planning is underway for this work.

c) Dementia
   Development is underway of a system and processes that will be piloted with up to 60 patients by 6 General Practice teams in each of ProCare and Waitemata PHOs from 1 October 2013 to 30 June 2014 (see separate paper). The developments to date include:

   • The SSOA Clinical Reference Group comprising of clinical leaders from ProCare, Waitemata PHO, Alzheimers Auckland; ARRC, and Waitemata DHB. As the SSOA Clinical Reference Group addresses other topics the membership will be amended to include the key clinical leaders.
Development of the Dementia Clinical Pathway systems and processes in readiness for the pilot are premised on earlier recognition and enhanced assessment skills of Dementia by primary care, earlier linking of patients and their whanau with community based Dementia education / support / management services; and for those patients requiring it earlier referral to the appropriate secondary and/or tertiary care services.

d) Workforce
A Clinical Educator has now been appointed who will develop a plan to start rolling out key education programmes across the DHB. The education programmes include:

- Complete interventions training
- Dual diagnosis/Co-existing problems (i.e. those clients with mental health and we ll as drug or alcohol problems)
- Embedding the Let’s Get Real Framework for Mental Health
- Sensory modulation training

e) Single Point of Entry
This applies to referrals to Older Adults Home Health Services (OAHH) and Mental Health Services Older Adults (MHSOA) through a single point to enable integrated service delivery across the range of DHB services the person requires. This does not include crisis referrals to MHSOA which are still to be made directly to the Crisis Line.

- The single point of entry screens the referrals and directs them to the appropriate team. For complex referrals a combined OAHH & MHSOA triage discussion is held to determine which service will lead the assessment requested in the referral.
- Work is underway to streamline this referral and strengthen the combined triage processes.

ARRC at Waitemata DHB

Over the last quarter, the 58 ARRC facilities have had the opportunity to meet in two forums (the quality forum for managers and owners) and the RACIP work group. The purpose of these meetings is to network, inform and develop clinical guidelines. These meetings also interface with the NZHPP and Waitemata District Annual Plan.

One example is the falls and pressure injuries targets with the First Do No Harm (FDNH) team. Local ARRC facilities have agreed in principle through the forums to send data on falls and pressure injuries in return for information on how they compare in anonymised data across the region. FDNH are offering training days on models of improvement. The GNS are available to support facilities to implement planned change to reduce falls and pressure injuries. Data collection will be through the RACIP programme. Development of an improved mechanism for collating data is being explored.

Current projects of RACIP Work Group include:
1. Pamphlet for families of people with advanced dementia living in ARRC (Attached) has been finalised, with a mini launch on 23 April. It will shortly be available at www.wdhb-agedcare.co.nz.
2. Booklet for families of people with advanced dementia living in ARRC. The aim of this booklet is to inform families about end stage dementia, Advanced Care Planning, appropriate and inappropriate interventions. The development of this is currently on track with consumer and clinical consultation to be undertaken prior to the booklet is finalised.

ARRC at Auckland DHB

Two forums have been held over the last quarter for ARRC:
- A training day for registered and enrolled nurses; 48 nurses attended. Topics covered included wound management, female catheterisation, trouble shooting and simulated scenarios.
- A training day for ARRC facility managers; 63 people attended. Topics covered included dementia care, infection control, cluster group update on falls and pressure injuries and the Regional Health of Older People Plan.

The cluster model for ARRC is proving to be an effective mechanism for engaging with facilities.
facilities are grouped in to 13 geographic clusters that meet monthly with one facility acting as the host. The current focus is collaborative management of falls and pressure injuries.

**Warm up Waitemata DHB**
This programme offers free insulation to low income families across the district. To date (1st July 2012 to 23rd January 2013), of all the referrals received they have included households who identified as European (57%), Maori (17%), Asian (16.5%) and Pacific (9.5%).

Referrals are distributed across Waitemata DHB as follows:
- 66% from West Auckland
- 14% from the Rodney District
- 20% from the North Shore

65% of referrals own their own homes, and 35% occupy a rental property. Of the households who have applied to the project they include 288 children under the age of 14 years and 148 adults over the age of 65 years.

**Long-term Supports for Chronic Health Conditions (LTS CHC)**
Devolution of LTS CHC from the MoH to DHB was completed in Q1 2011. The Northern Region has put in place arrangements to manage a regionally work plan and report on LTS CHC.

Key achievements in from October to December 2012 include:
- The 2012/13 LTS CHC work plan has been drafted and is being actioned by the LTS CHC Service Development Working Group.
- Ongoing work to establish regionally consistent assessments and allocation of services includes:
  - Regional policy has been developed and agreed upon regarding the transfer of LTS CHC clients to the HoP funding stream.
  - Drafted and accepted ToR for Peer Review meetings.
  - Bimonthly LTS CHC Regional Review Panel review and monitor of clients with packages of care over $80k per year
  - Process followed for 2 complex high end clients by contracting for specialist case management resource and a specialist support needs assessment.
- Ongoing enhancement of provider contracts includes:
  - Specific terms and conditions are now added to contracts for all individual NHI complex residential rehabilitation contracts.
  - Counties Manukau DHB has contracted for Individually Funded (IF) services.
- Service development work continues to progress with a focus on better understanding the client base, their requirements and potential contracting and funding implications for 2012/13 and out years.
- The Region continues to work with the MoH to address the contracts the MoH devolved with outdated Heads of Agreement, and Terms and Conditions. In the mean time, the region is providing short term resolution of issues on a need by basis arising from contracts.
- Currently the National Reviewer reviews LTS CHC and DSS clients on a case by case basis that have disputed funding stream eligibility. Some clients are resolved, other client cases are left with the DHB as the funder. The DHBs have requested that a national resolution panel is developed with multi-discipline and agency representation. This national resolution panel would peer review and allocate an appropriate funding stream through robust decision making for clients with complex needs and unclear funding stream eligibility.
- The MoH was approached by the region to develop a national risk pool for clients over $500K pa, in response to a new client in the Northern Region whose costs are likely to be well over $1m pa. This client has since been accepted by ACC and is now being transferred to ACC for
on-going management.

- The Northern Region’s deficit has been finalized on a cash basis at $1.68m for 2011/12. The risk share model has calculated apportionment based on each DHB’s population based funding formula (PBFF) share.
- Ongoing regional analysis is being conducted to better understand the predicted overspend of the Northern Region’s population based funded allocation. The Northern Region and Midland has agreed to peer review clients to compare case management and service utilisation.
- Client profiling and analysis of Northern expenditure relative to the Midland region.
- Following the agreed regional process for newly identified high end complex clients to maximize the patient’s potential and mitigates on-going financial risk.
- Gaining a better understanding of the client base and provider services currently available to better scope service demand and establish contracting and funding requirements that will meet the needs of the clients.
Definitions

Progressive, degenerative: will get worse and lead to death

End of life care: last phase of physical life (this varies in length from person to person)

Care strategies: options for care

Useful resources

New Zealand

Alzheimers Auckland
Ph: (09) 6224230, www.alzheimers.co.nz

Age Concern
Ph: (09) 8200184, www.ageconcern.org.nz

Advance Care Planning
www.advancecareplanning.org.nz/

Information for Care Givers (is available in other languages)
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=529

Waitamata District Health Board
www.wdhb-agedcare.co.nz

Citizens Advice Bureau: 0800 FOR CAB (0800 367 222) to find an office near you.
www.cab.org.nz/

Community Law Centres: There are community law centres throughout the country.
www.communitylaw.org.nz/

Family Court: Information on personal orders, welfare guardians, property rights, property orders and enduring powers of attorney

Australia

Hunter New England Local Health Network Australia

Palliative Care Australia
www.palliativecare.org.au

Australian Government: Guidelines for a palliative approach to residential aged care

International

Fact sheets in other languages
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=569

Classification number: 010-06-03-004 (Review Date: November 2015)
Dementia and decision-making

Dementia is a progressive, degenerative disease. Providing comfort and dignity for people with dementia is a priority. This is especially important during the late stage and during end of life care.

As the disease progresses, the person gradually becomes unable to make decisions. There comes a time when decisions are made without input from the person. Family/whānau do not need to make these decisions alone. The healthcare team at your facility will support you. Everybody’s input is valued. We are happy to arrange a time for a family/whānau meeting with the healthcare team to discuss options for care.

Respecting the expressed wishes of the person with dementia includes cultural, religious and spiritual beliefs. This should guide all care, including end-of-life care.

When making decisions on behalf of a person with dementia it is important to follow their preferences, if these are known. Even if the person has not already let others know their preferences, knowing their values and beliefs can help everyone to make a decision that reflects what they want.

Some people have an Advance Directive or “Living Will”, or an Advance Care Plan that will help family/whānau members to carry out their wishes. If plans have not been made, or there are differences among family/whānau, you may want to consider asking a lawyer or third party, eg, a member of our team, religious or community leader or counsellor to help.

The clinical team will discuss options for care with you and your relative’s Enduring Power of Attorney or Welfare Guardian (see “Useful resources” on the back page for more information).

The guiding principles of compassion, comfort and respect will be upheld

Family/whānau will continue to be involved in decision-making about care strategies, with the support of the clinical team.

Continued communication with your facility’s medical practitioner, manager, nurse practitioner and registered nurse will be important at this time.

These decisions should take into consideration:

- the progression of dementia
- the person’s overall health
- risks and benefits of care strategies.

Care is given to provide the best possible quality of life, by maintaining functioning and relieving suffering.

Goals of care for end of life

As the brain fails because of dementia, the emphasis shifts from prolonging life to making sure the person is comfortable, safe and having the best compassionate care possible. This goal of care can be thought of as palliative (comfort) care.

A person with dementia receiving palliative (comfort) care will be actively monitored for symptoms such as pain, breathlessness or agitation, and be kept comfortable.

Maintaining a person’s dignity is of utmost importance as death approaches. Palliative (comfort) care is given until natural death occurs.
8.1 National Dementia Cooperative
8.2 Regional Dementia Workgroup
8.3 ADHB Dementia Care Pathway
8.4 WDHB Demential Care Pathway
8.5 Waitemata PHO Dementia Care Pathway
8.1 National Dementia Cooperative
Date | 13 March 2013
---|---
To | Auckland and Waitemata DHB - DiSAC Committee
From | Dr Chris Perkins, Chair National Dementia Cooperative (NDC)
Author | Chris Perkins and Marja Steur (NDC National Coordinator)
Functional Group | Auckland and Waitemata DHB Funding and Planning Managers
Subject | DiSAC Quarterly Report on activities in Auckland & Waitemata DHBs

**Purpose**

To provide DiSAC with an overview of the National Dementia Cooperative

**Recommendations:**

1. The Committee **approve** the continued support by both Waitemata DHB and Auckland DHB in following areas:
   - Support for the 2013 Dementia Knowledge Exchange forum / conference
   - Showcasing dementia research and innovation in Waitemata and Auckland through Awhina Health Campus
   - Inclusion of the NDC in relevant strategic forums in the region
   - Using the NDC as a vehicle for spreading best practice across the range of providers

**Background**

Formed in November 2011, the National Dementia Cooperative (NDC) is an innovative interdisciplinary group of people committed to improving the standards of care and support for people with dementia and their families/whānau /caregivers.

The cooperative has the following vision objective and goals.

**Vision**

People with dementia and their family/whanau have the support they need to achieve an optimum level of health and functioning.

**Objective**

To co-operate and collaborate with like-minded people who are passionate about advancing knowledge of approaches to dementia care in New Zealand.

**Goals**

1. To promote life after a diagnosis of dementia;
2. To encourage early diagnosis and early intervention;
3. To increase awareness and understanding of dementia by government and the wider community
through collaborative action;
4. To contribute to, and thereby influence, national policy development regarding dementia specific services, workforce, and education;
5. To encourage specialised training for all service providers working with people with dementia and their carers;
6. To coordinate nationwide action and effort by knowledge sharing thus avoiding duplication of effort;
7. To promote New Zealand-based research into dementia based on identified areas of need e.g. prevention, cure, and care;
8. To influence practice by providing impetus for, and input into, dementia care initiatives;
9. To support implementation of a national framework for dementia care pathways, and facilitate dialogue, and advocate for consistency, between public and private organisations regarding local pathways;
10. To develop and promote a standard of excellence in dementia care aligned to international trends.

A 12-member elected steering group including health professionals from various organisations and geographical regions leads the cooperative.

The NDC is sponsored by BUPA, the Selwyn Foundation, Presbyterian Support and Good Partners (Invercargill). Waitemata DHB / Awhina Health Campus assisted with the recruitment of a coordinator and, along with Canterbury DHB have hosted the coordinator. Waitemata DHB also makes a contribution to administration costs.

Clinical leaders from Waitemata and Auckland DHBs are integral to the Cooperative.

### Achievements to date:

A part time coordinator, Marja Steur, was employed in February 2012.

Monthly steering group meetings are held, hosted and catered by Bupa, with teleconference facilities provided by Waitemata DHB. The Steering group established six national action groups during 2012. These focus on:

1. dementia care pathways
2. advocacy
3. informal carers
4. information sharing
5. research
6. workforce development.


Regional meetings in Rotorua, Wellington and Christchurch, with videoconference links to other centers, have been well attended. Catering for these events was funded by Geneva Health Care, Ryman, and Healthcare NZ; venues and videoconferencing were funded by Lakes, Capital and Coast, and Canterbury DHBs.

A contacts and membership list has been established; over 500 people are enrolled on the contact list. A monthly email gives members an update on NDC activity.

### Outcomes

An NDC profile has been established. This is evident in the growth in awareness, membership numbers and diversity nationwide. The NDC is now seen as an entity and being approached to present at conferences and participate in reviews and strategic forums.

Knowledge of dementia-specific trends in NZ has increased:
- With support from Te Pou, a dementia knowledge-exchange strategy has been developed.
- Awhina Health Campus is exploring hosting a national dementia knowledge-exchange database
commencing with Waitemata, Auckland and Canterbury DHBs.

Collaborating with the Ministry of Health, members of the NDC have input into the development and implementation of a national framework for Dementia Care Pathways.

The Information Sharing Action Group, recognizing the benefits of face-to-face contact, established a regional network in Wellington for the purpose of sharing local information and providing a link with national groups.

A glossary of language was compiled to increase awareness about language use when speaking about dementia.

Challenges
Face-to-face meetings are preferable; however with the wide spread distribution of interested people and groups teleconferencing is a necessity.

Individual members’ ability to commit time to work on Action Group goals.

Liaising with other organisations e.g. Alzheimer’s NZ and Carers NZ (includes providing support and technical, scientific and professional advice/resources).

Sustainability (initial sponsorship and funding was for the period to February 2014).

Priorities for 2013
Increased linkage and connection with community groups and conferences; (develop strong alliances with other organisations such as Alzheimer’s NZ, Carers NZ, DHBs and primary health care).

Consider establishing regional dementia community networks after piloting the Wellington group.

Continue to contribute to the National Framework for Dementia Care Pathways; support consultation and road-shows, using networks for feedback regarding implementation.

Ensure people with dementia and their carers are heard by drawing together what has already been done to identify their needs.

Support a Knowledge Exchange Forum, a two-day conference in late 2013 (November?)

Each Action Group will work on some or all of these priorities
8.2 Regional Dementia Workgroup
To Auckland and Waitemata DHB - DiSAC Committee

From Tim Wood, Funding & Planning Manager,
Denis Jury, Chief Planning and Funding Officer

Author Richard Worrall
Clinical Director MHSOP, ADHB

Functional Group Auckland and Waitemata DHB Funding and Planning Managers

Subject DISAC Quarterly Report on activities in Auckland & Waitemata DHBs

Date 13 March 2013

Purpose
The purpose of this report is to provide an update to DISAC on the progress and activities occurring in the Northern Region Dementia Workgroup.

Recommendation:

1. Endorse the Northern Region Dementia Services Guide.
2. Note the development of the Living Well with Dementia Plan tool.
3. Note the development of the national Dementia Framework and the input of the northern.
4. Endorse the future work plan.

Background
The Northern Region Dementia Workgroup was tasked with supporting dementia service development in the northern region as part of the Health of Older People Clinical Network. This identified that dementia service planning needs an integrated, whole of system, whole of journey approach.

Progress to Date

Northern Region Dementia Services Guide:
The absence of any national strategy or framework to guide service development lead the Northern Region Group to develop such a document, which attempted to describe a minimum standard for service provision. The Northern Region Dementia Services Guide (Appendix 1) was developed by members of the Dementia Workgroup, with reference to selected international literature, in particular similar service guide documents. The final draft is out for consultation.

One of the challenges of developing such a guide has been to leave definitions general enough to allow local variation in mode of service delivery whilst defining a consistent minimum standard.

We are in the final stages of developing a tool to support a consistent, comprehensive partnership approach to care provision: the Living Well with Dementia Plan. The idea of a living well with dementia plan has been adopted by the National Dementia Framework.

The Living Well with Dementia Plan includes “This is Me” a document completed primarily by the person with dementia and their family which supports a personalised and person centered approach to...
care planning.

The draft Living Well with Dementia Plan includes a checklist of post-diagnosis supports such as:

- providing information on dementia
- carer assessment and support
- referral to Alzheimer’s Association
- information about support services
- dementia medication and prescription information
- Enduring Powers of Attorney
- Advance Care Planning
- Wills
- Regular physical and medication reviews.

The idea behind this checklist is to ensure that these elements which are likely to make a difference to outcome for people with dementia and their families are addressed early on and that subsequent involvement with services is informed by this planning.

**National activity:**

During the process of developing the Dementia Services Guide, the National Dementia Framework project began. Members of the northern region group have contributed through either DHB representation or through National Dementia Cooperative involvement. This cross-involvement will result in a National Framework that is compatible with our more specific Services Guide.

Dialogue has also begun with one of the national leads for the shared care planning project, and it is planned that an electronically available form of this plan can be included to support consistency and a person and family–lead approach to care throughout the journey.

Work with Alzheimer’s Auckland to improve information resources has recently been undertaken, and there is a recognised need for improved and constantly maintained information resources.

**The Future Work Plan is likely to include:**

- Identifying current service gaps and opportunities for standardisation, for example:
  - decision support tools and shared care planning
- Agree on priority areas of service provision and decide by consensus those in which regional consistency may be possible: for example
  - Information
  - Service provision models to support accurate and timely diagnosis
  - Post Diagnosis Information and care
  - Ongoing support and monitoring
  - General Hospital screening, diagnosis and support.
  - Complications Services
    - Aged residential care supports
    - End of life care.
- The group will continue to be a mechanism by which local service development initiatives can be reviewed and supported during the implementation both locally and regionally.
Northern Regional Dementia Work Group

Dementia Services Guide

December 2012
Table of contents

EXECUTIVE SUMMARY .......................................................................................................................... 3
BACKGROUND TO THIS DOCUMENT .................................................................................................. 4
REGIONAL DEMOGRAPHICS ............................................................................................................... 5
REGIONAL DEMENTIA SERVICES GUIDE .......................................................................................... 6
PRINCIPLES UNDERPINNING THE SERVICES GUIDE ......................................................................... 6
ON PERSON CENTRED CARE: ........................................................................................................ 7

PATIENT JOURNEY ELEMENTS ........................................................................................................... 8
PREVENTION / HEALTH PROMOTION / AWARENESS ......................................................................... 8
SCREENING ........................................................................................................................................... 10
SUSPICION / Initial INVESTIGATIONS .................................................................................................. 11
ASSESSMENT / DIAGNOSIS .................................................................................................................. 14
POST-DIAGNOSTIC INTERVENTIONS – MILD COGNITIVE IMPAIRMENT .......................................... 19
POST-DIAGNOSTIC INTERVENTIONS – DEMENTIA .......................................................................... 21
ONGOING COMMUNITY CARE – PERSON WITH DEMENTIA .............................................................. 24
ONGOING COMMUNITY CARE – FAMILY AND CARERS .................................................................... 26
PHYSICAL HEALTH CRISIS/ GENERAL HOSPITAL PRESENTATION ................................................ 29
COMPLICATIONS OF DEMENTIA/ NON-COGNITIVE SYMPTOMS OF DEMENTIA ......................... 32
TRANSITION INTO AGED RESIDENTIAL CARE .................................................................................. 35
ONGOING CARE IN AGED RESIDENTIAL CARE ................................................................................ 37
END OF LIFE CARE .............................................................................................................................. 39

SUPPORTIVE OR WHOLE POPULATION ELEMENTS ......................................................................... 42
COMMUNITY AWARENESS .................................................................................................................. 42
WORKFORCE DEVELOPMENT AND TRAINING .................................................................................. 44
RESEARCH / ELECTRONIC RESOURCES ........................................................................................... 46
IT AND DOCUMENTATION .................................................................................................................. 47
GOVERNANCE: LOCAL – REGIONAL – NATIONAL .............................................................................. 48
FINANCIAL: FUNDING AND COST ANALYSIS ................................................................................... 51
FACILITIES DESIGN .............................................................................................................................. 53
LIST OF ACRONYMS: ........................................................................................................................... 55
REFERENCES: ........................................................................................................................................ 56
APPENDIX 1 ........................................................................................................................................... 57
APPENDIX 2 ........................................................................................................................................... 69
Executive Summary

The purpose of this document is to assist healthcare providers in the Northern Region in planning and developing a whole of system approach to supporting people with dementia, and their family/whanau and caregivers throughout the course of the illness. Fundamental to service design is empowerment of the person with dementia and their family/whanau. Because dementia follows a progressive course with changing care needs, involving multiple providers, innovative approaches to integration of care and sharing knowledge of the person’s unique history and care needs are essential. A knowledgeable and skilled workforce will be a foundation to implementation of dementia assessment and care provision.

This document is aspirational, and aims to guide future service development. No Northern Region District Health Board provides all of the elements as described herein. This document focuses on what needs to be delivered rather than prescribing how implementation will occur. It is accepted that service models will be developed according to local population needs, resources, geography, and current skill mix. Governance structures at local, regional, and national level are required to facilitate implementation and prioritise elements for implementation as growth in funding allows.

The format of this document is designed to describe the entire component Elements and set Standards for a fully-resourced Dementia Pathway. Some of the Elements describe the care and standards to be provided at each point in the journey of someone with Dementia. Supportive Elements are less concerned with individual care and more directed at making sure that the Pathway can operate effectively and efficiently, and that quality of care is ensured. Attempts are made to highlight innovative or exemplar service provision already occurring. Vignettes aim to illustrate in a simplified way the experience of people with dementia and their families. Key performance indicators (KPI’s) are provided to support continuous quality improvement but are not considered an exhaustive list.

Models of dementia care are evolving rapidly and although effort has been made to represent current standards of care, it is hoped that this guide may be revised over time.
Background to this document

As populations around the world age, the need to plan for supporting people affected by age-related conditions and in particular dementia is being recognised as a health priority.

Countries around the world have developed strategies in response to this issue, notably the United Kingdom (UK) Dementia Strategy (2009) and the Healthcare for London Dementia Services Guide (2009) and the National Framework for Action on Dementia (2006) improved awareness, early diagnosis and intervention, and high quality care and support throughout the course of this progressive illness are the common themes underlying these documents (Alzheimer’s Disease International summary)

In recognition of growing need dementia care planning has been made a priority by the Minister of Health. The Minister of Health’s “Letter of Expectations for District Health Boards and their subsidiary entities for the 2012/13 year” identified Health of Older People as a priority area for health services, focussing on improving the health and well-being of older people, especially those with dementia.

The Ministry has set out an expectation that District Health Boards (DHB) would develop and implement dementia care pathways by June 2013. Funding has been earmarked for Dementia Pathway development and DHB’s are expected to report on use of this funding.

The Northern Region Health Older People Network includes a dementia work stream. This work stream has evaluated planning documents from international and national dementia initiatives and has now developed this service guide for dementia service delivery in the Northern Region.

In parallel to the development of this document the Ministry of Health has been working with the DHBs and the National Dementia Cooperative to develop a Dementia Services Framework, and it is intended that this Services Guide will complement and enhance the guidance provided by the National Framework.
Regional Demographics

The number of people affected by dementia in New Zealand is projected to increase from 40,726 (1.0% of the total population) in 2008 to 74,821 (1.5%) in 2026, and 146,699 (2.7%) by 2050. New cases in 2050 will comprise 0.8% of the population and number 44,376 nationally, suggesting in excess of 15,000 new cases of dementia in the northern region per year (Dementia Economic Impact Report, Alzheimer’s New Zealand 2008).

The Northern region has a projected 5 year growth rate of people over 65 of 21% 2011-2016 and 37% for the period 2016-2021. Current figures for cases of dementia in the region area are not available, however Counties Manukau District Health Board (CMDHB) currently estimates a current prevalence of around 3000, and an annual incidence of around 1000 cases based on the Alzheimer’s New Zealand Economic Impact report figures. Although ethnicity and age distribution demographics vary across the region extrapolated across the northern region prevalence and incidence are roughly (although demographics may vary across DHB’s)
Regional Dementia Services Guide

Vision:
A society in which people with dementia and their families and whanau remain accepted members of the community. This acceptance encourages people with dementia and their families and whanau to engage early with an integrated health and support system which recognises them as valued partners and supports them to achieve optimal wellbeing and quality of life throughout their journey with dementia.

Principles underpinning the Services Guide

Services will be supported to:
1. Support awareness of dementia and acceptance of, and respect for people with dementia.
2. Acknowledge the central role of the person affected by dementia, their carers and family / whanau.
3. Aim to empower and support people with dementia, family whanau and everyone involved in dementia care, through effective communication and education.
4. Address needs across the entire journey of the person with dementia.
5. Focus on early recognition, health improvement and maintenance, optimising well being and independence.
6. Encourage recognition of individual variation in symptoms, disease progression and needs.
7. Support standardisation and consistency whilst recognising the need for local variation.
8. Ensure ease of access, responsiveness, efficiency and affordability.
9. Provide high quality evidence based care through developing and retaining a skilled workforce.
10. Be sensitive to social, cultural, economic context and location.
11. Ensure continuity of care throughout the journey of dementia through integration and flexible service provision.
**On Person Centred Care:**

The principles of person-centred care and generally accepted as underpinning good practice in the field of dementia care (Nice Guidance).

The principles assert:

“...the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them”

“the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia”

“the importance of the perspective of the person with dementia (and) the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being”

( Brooker, D, 2004)

A fourth principle emphasizes the imperative in dementia care to consider the needs of carers, whether family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia. This is increasingly described as ‘relationship-centered care’ (NICE – SCIE Guideline No 42)
# PATIENT JOURNEY ELEMENTS

## Prevention / Health Promotion / Awareness

### Introduction

Dementia is a disease which is associated with stigma and fear. In both the general public and in health professionals a reluctance to acknowledge cognitive changes and lack of understanding of the disease may result in early cognitive symptoms being dismissed as normal aging.

Cognitive decline has been found to be associated with a range of modifiable risk factors, and lifestyle changes and management of cardiovascular risk factors (such as smoking, lipids, hypertension, diabetes) and depression hold the greatest promise in reducing dementia prevalence. Destigmatisation, health promotion and prevention messages may help reduce rates of dementia and may promote earlier assessment.

### Standards

- Promote the benefit of prevention and or early diagnosis in delaying the development or progression of dementia related symptoms, accessing support and planning for the future. Promote the idea that “living well with dementia” is a realistic goal
- Promote strategies and lifestyle changes which encourage the early identification of risk factors and signs of dementia
- Promote strategies and lifestyle changes that may reduce or delay the onset of dementia
- Promote cognitive, emotional, mental, and physical well being
- Ensure responses to major alcohol reduction campaigns include such messages as the potential to develop alcohol related brain damage

### Potential Providers

- Alzheimer’s New Zealand
- Ministry of Health
- All Healthcare Providers

### KPIs

- Evidence of public national awareness campaign re
Dementia Pathway Elements and Standards 17th December 2012

<table>
<thead>
<tr>
<th>prevention that:</th>
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<tbody>
<tr>
<td>o Encourages maintenance and development of social links</td>
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<td>o Encourages continuing education</td>
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<tr>
<td>o Encourages cognitive stimulation</td>
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<tr>
<td>o Encourages physical exercise</td>
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<tr>
<td>Evidence of strategies and promotional campaigns aimed at early identification and risk minimisation</td>
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</table>

Local Initiatives | Alzheimer’s New Zealand (ANZCT) “We Can Help” campaign |

Christine decides to drop in to her elderly parents for breakfast. On arrival she smells smoke coming from the house. She finds her mother has put the Edmonds cook book in the toaster. She had seen the same thing on television the month before in the “We can help campaign”. After discussion with her distressed father, Christine and her parents meet with an Alzheimer’s Auckland Charitable Trust (AACT) representative the following week.
## Screening

<table>
<thead>
<tr>
<th>Introduction</th>
<th>Universal screening of older people is not a required or evidence-based stage of the pathway. At this stage case finding (assessment when concerns or suspicions of cognitive impairment are raised) is the recommended approach. However there are opportunities for screening to occur in certain circumstances by agreement between providers. Cognitive screening could become part of driving licence renewal at ages 75 and above in Primary Care. Secondary Care inpatients or those in Emergency Department (ED) could have universal screening for confusion / dementia above an agreed age, by agreement.</th>
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<tbody>
<tr>
<td>Standards</td>
<td>Yet to be agreed</td>
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</tbody>
</table>
| Potential Providers | Primary Care (Mandatory Driving Licence Renewal)  
Secondary Care (Patients over agreed age such as 75 or those with agreed presentations could be screened for Delirium or Dementia) |
| KPIs | Completion of agreed screening on identified population |
| Local Initiatives | Auckland DHB Hospital Dementia Pathway |

Elsie is 85 and suffers from Chronic Obstructive Pulmonary Disease (COPD) and hypertension. She is admitted to hospital after a fall at home and suffering a fractured humerus. Routine screening of people over 75 admitted to hospital is carried out using the GP COG. Elsie scored 6 on this test, and the nurse then asks further questions of Elsie’s daughter as part of the informant interview. This reveals that Elsie has had memory problems developing over 2 years but has been more confused than usual in hospital.

- GP COG – The General Practitioners Assessment of Cognition  
### Suspicion / Initial Investigations

**Introduction**
A person with dementia or their family may present with concerns about memory problems or behavioural change to their General Practitioner (GP). Or their GP may have noticed a change in the person which might raise the suspicion of some cognitive impairment. Even if their GP does not feel confident to diagnose dementia, he or she should undertake some initial screening tests or investigations, and seek to exclude other possible causes. This section, therefore defines a sensible approach to a person with possible cognitive impairment, leading to the GP being able to refer to a specialist service if still concerned.

The same standards should be met in other services such as Secondary care when concerns about a person are raised, and a decision is being made about referral to an appropriate service.

This standard is lower than that required to confirm a diagnosis of dementia, and is targeted at making sure referrals for specialist assessment are appropriate.

**Standards**

<table>
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<th>Standards</th>
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<tr>
<td>• Evaluate and validate a suite of standardised screening and diagnostic assessment systems and tools (this may be done nationally / internationally)</td>
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<tr>
<td>• Promote the benefit of early diagnosis in delaying the progression of dementia through education of healthcare providers including primary care</td>
</tr>
<tr>
<td>• Assess existing dementia services in order to identify barriers to equity of access and consider recommendations for resolving these issues</td>
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<tr>
<td>• Physical examination, (including neurological examination to exclude stroke or Parkinson’s disease)</td>
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<tr>
<td>• Interview or contact with family member for collateral history</td>
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<tr>
<td>• Use of appropriate screening tools such as The General Practitioners Assessment of Cognition (GPCog) <a href="http://www.gpcog.com.au/">http://www.gpcog.com.au/</a> or Mini Mental Status Exam (MMSE) <a href="http://nzpops.co.nz/docs/AdaptedMMSE.pdf">http://nzpops.co.nz/docs/AdaptedMMSE.pdf</a></td>
</tr>
<tr>
<td>• Inquiry about functional deficits and driving safety</td>
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<tr>
<td>• Inquiry about other possible causes such as:</td>
</tr>
<tr>
<td>Potential Providers</td>
</tr>
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</table>
| Primary Care services - including those in Aged Related Residential Care facilities (ARRC) Secondary Care services | ▪ Primary care clinicians are confident in an initial approach to people presenting with memory difficulties, and know when and where to refer  
▪ People with cognitive impairment and their carers report improved access to dementia care services regardless of where they live, their health status, their age, their cultural background, or financial and social circumstances |

<table>
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<tr>
<th>Local Initiatives</th>
</tr>
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| ▪ Request for blood tests and urine specimen to exclude thyroid, vitamin deficiencies or infection  
▪ Referral to specialist service if concern about mild cognitive impairment or dementia is confirmed |
Ernie is 75 and has recently retired from his Accountancy practice. At a routine check-up Ernie’s wife prompts him to mention to the general practitioner that his memory is not as good as it used to be, that he is having difficulty relaying phone messages to his wife, having difficulty remembering names when introducing people he knows quite well when at Probus Club, and is misplacing his wallet and glasses often. His wife has had no concerns about Ernie’s driving.

The GP carries out a MoCA, physical examination and orders routine blood tests. He asks Ernie’s wife to complete the IQCODE. The results suggest Ernie is developing memory problems greater than normal aging and Ernie is referred to the local memory service for further assessment.

- MoCA – Montreal Cognitive Assessments
- IQCODE - Informant Questionnaire on Cognitive Decline in the Elderly
## Assessment / Diagnosis

### Introduction

People with Dementia require an assessment completed by an appropriately trained health practitioner, leading to a clear diagnosis. Diagnosis is the basis on which future care can be planned. This should include an assessment of dementia type, carer burden, needs assessment and presence of complications. This assessment may be entirely completed in Primary Care (with or without the input from a Dementia service) or any part of the Secondary Health Sector depending on the case and expertise available. The areas of Secondary Care with this expertise will commonly be General Hospital Inpatient Services, Health of Older People (HOP) and Mental Health Services for Older People (MHSOP). However the assessment may be completed by a specialist Dementia Service, following initial workup in Primary Care or some other setting. This is likely to be necessary for difficult cases or to ensure that the type of dementia is identified. The preferred setting in any one DHB will depend on local expertise and resourcing, but all people should have access to a specialist assessment if required. Assessment must lead to comprehensive care planning shared across healthcare providers.

### Standards

**Standards for the Assessment (for all providers)**

A comprehensive assessment must be completed. This may be completed over more than one session. This will include:

- Explanation of the assessment process and likely outcomes should be provided and consent obtained.
- A full history from person with memory problems. Structured formats are recommended. Include description of time course and symptom progression
- Collateral history from family or caregivers, including carer burden
- Assessment of functioning including:
  - basic and
  - instrumental Activities of Daily Living (ADLs)
  - risk and vulnerability.
- Review of risk factors including modifiable cardiovascular risk factors and complications of dementia such as Behavioural and Psychological Symptoms of Dementia (BPSD)
- Medical history and medications including allergies should be obtained, as should history of alcohol or other substance abuse
- Cognitive assessment using measures validated for diagnosis should be used, as well as measures of mood and functional ability
- Assessment of social situation, care package, and powers of attorney. Enquiry about elder abuse and neglect. Some appreciation of legal competency should be gained. Cultural and spiritual identification should be ascertained. Where indicated assessment of decision making capacity is available
- Review of risks to the person and family / carers
- Physical examination including neurological and cardiovascular systems. Routine Blood tests should include Full Blood Count, Electrolytes, Renal function, Calcium, Liver Function tests, Vitamin B12 and Folate, fasting glucose and lipid profile. Consider Syphilis serology, Human immunodeficiency virus (HIV) on clinical grounds
- Computed tomography (CT) / Magnetic Resonance Imaging (MRI) or Single Photon Emission Computed Tomography (SPECT) scan requested and performed within an acceptable time frame
- Diagnosis should be made, including specification of type of dementia (as far as this is possible)
- Promote best practice guidelines in referral for specialist diagnosis
- Referrals or second opinions should be sought for those with specific presentations such as neurological symptoms, early onset of dementia, atypical presentations or rapidly progressive cognitive decline
- Diagnosis must be shared with person and their family
- Diagnosis will be entered into computerised patient records, with alerts as appropriate. This should include a local register.
- These standards will be incorporated into guidelines, protocols or computerised pathway guides
- Assessors will have skills to deal with all referrals including those people who are younger, have underlying learning disability or psychiatric or neurological disorder, or those from (Culturally and Linguistically Diverse Groups) CALD groups
- Develop single referral and assessment pathways to maximise sharing of assessment information between GPs, Secondary services and ARRC.
If the service is being provided by a Specialised Dementia service or Memory clinic, then:

- Access to a single point of expert dementia care and advice
- The service should have a defined title and role with promotion
- There should be identified referral criteria and mechanism for referral
- There will be an efficient triage processes and prioritising of cases
- There should be defined response times for both triage and first appointment
- Clear instructions will be provided re appointments
- Written feedback will be provided to both the person and their family, and referrers
- The case will be reviewed with the Multi-disciplinary team
- Documentation will be comprehensive
- There will be staffing and resourcing to meet demand
- Help to find, organise and coordinate services from a range of local providers

Where the Assessment is provided by a combination of services:

For example, by GP and Primary care practice nurse, supported by visiting Dementia Service Clinician:

- There will be a clear responsibility for tasks to be completed by each of the participants, including diagnosis and clinical decision making
- Clinical documentation will be accessible to all parties
- Response and process times will be defined

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<thead>
<tr>
<th>Potential Providers</th>
<th>Primary Care</th>
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<tr>
<td></td>
<td>Secondary Care Providers</td>
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<td>Specialised Dementia Care Provider</td>
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<th>KPIs</th>
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<tr>
<td>Identified governance structure and articulated diagnostic pathway.</td>
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<td>Number of diagnoses and subtypes</td>
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<tr>
<td>Rating of severity</td>
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<tr>
<td>Number of GP referrals</td>
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<tr>
<td>Number of GP’s using the service</td>
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<tr>
<td>Proportion of estimated population dementia prevalence</td>
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<td>Place of diagnosis</td>
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<tr>
<td>Response times</td>
<td></td>
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<tr>
<td>Number needing to see specialised dementia service</td>
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</tbody>
</table>
Number of referrals without dementia  
Risks factors identified  
Presence of Complication rates  
Time from assessment to feedback letter to GP / referrer

| Local Initiatives | Taranaki Primary Care Pathway  
| | Canterbury Dementia Pathway Guide  
| | Memory Clinics – multiple DHBs  
| | Counties Manukau Dementia Care Pathway (coming!)  

**Primary Health Care**

Bob has moderate dementia with a progressive decline consistent with Alzheimer’s disease. He attends his GPs after concerns are expressed by his family. His GP carries out a MoCA and asks family to complete the IQCODE along with his history of decline diagnoses Alzheimer’s Disease. The Practice Nurse organises blood tests and completes some screening tests such as cognitive testing and ADL’s. A Clinical Nurse Specialist (CNS) from the local Dementia Service reviews Bob at the surgery. A CT scan is ordered through the DHB. The diagnosis is discussed at the surgery and the CNS meets with the person and their family to discuss this.

Result: Assessment Diagnosis and engagement with Specialist service

**Memory Clinic Diagnosis**

Martha is referred to the local Dementia Service by her GP. He requests a specialist opinion because of her young age (67) and because she has been experiencing hallucinations and falls. She is reviewed in memory clinic by a CNS, Geriatrician and Psychologist over two appointments. Her family is interviewed separately. A feedback visit to her home is organised to discuss the diagnosis and plan ongoing treatment. Letters confirming her diagnosis are sent to Martha and her GP.

Result: Assessment and Diagnosis via Memory Clinic with referral back to Primary Health Care
General Hospital Diagnosis

Fred is admitted to the General Hospital following a stroke. He receives rehabilitation on the Geriatric ward, during which time it is recognised that he is confused. A full assessment is completed including CT Scan, while he remains an inpatient. After discussion with the Liaison Geriatrician a diagnosis of Vascular Dementia is made.

Result: Assessment and Diagnosis
## Introduction

Mild Cognitive Impairment (MCI) is a brain disorder in which thinking abilities are mildly impaired. Individuals with mild cognitive impairment are able to function in everyday activities but have difficulty with memory – this can include difficulty remembering the names of people they met recently, following a conversation, misplacing things. The individual may be aware of these difficulties and compensate by writing notes and using calendars. The diagnosis of MCI relies on the fact that the individual is able to perform all their usual activities successfully, without more assistance from others than they previously needed. In this regard, MCI is different from dementia.

Some people with MCI develop a progressive decline in their thinking abilities over time and go on to develop a dementia. However many do not show any progression and some may even improve with time.

When someone is diagnosed with MCI, they need to be offered a specific package of care, in anticipation of the possibility of future deterioration. This may be followed by discharge from the service (with re-referral if deterioration does occur) or regular reviews (such as annual check-ups).

## Standards

- Education about MCI, including the possibility of future deterioration and dementia. Both the person and their family need to be involved
- Counselling about future signs and symptoms of dementia.
- Creation of MCI Future Care Plan
- Education about healthy living and management of risk factors, including alcohol intake
- Prompting for assessment in Primary Care for management of vascular disease risk
- Contact with Primary Care to outline diagnosis
- Appointment of Enduring Powers of Attorney (EPOA)
- Review of driving risk
- Advanced Care Plan (ACP) where appropriate
- Review of medications
- Review need for referral to Needs Assessment and
<table>
<thead>
<tr>
<th>Service Coordination (NASC)</th>
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<tbody>
<tr>
<td><strong>Potential Providers</strong></td>
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<tr>
<td><strong>KPIs</strong></td>
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| Local Initiatives           | Memory clinics |

Ernie has been assessed by his local Memory assessment service and diagnosed with mild cognitive impairment, amnestic type. He and his wife are informed of the diagnosis, and given information about the condition, including the possibility that his memory problems will progress. After cognitive testing and driving questionnaires it is decided that Ernie is probably safe to continue driving, but it is explained that his fitness to drive will require regular review and he and his wife are made aware of red flags for concern about driving.

Review of his medication reveals that a sleeping tablet started during a recent hospital admission is no longer needed and sleep hygiene strategies are discussed.

Ernie already has EPOA set up. He is given information about advance care planning and it is agreed that this will be completed with his GP. Carer assessment reveals no major concerns for his wife at this time.
### Post-Diagnostic Interventions – Dementia

**Introduction**

Receiving a diagnosis of dementia is a stressful time for the person and their caregivers. At the same time having a name for what is going on, information and a plan for the future can provide some sense of relief in what has been a time of uncertainty.

This is a time for all those involved in care to share in planning for the future.

Given that there are a number of facets to post diagnosis care a structured way of recording and communicating what has been offered is advised.

<table>
<thead>
<tr>
<th>Standards</th>
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<tbody>
<tr>
<td>- Add to dementia register</td>
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<tr>
<td>- Post-diagnostic support and counselling to the person with dementia and their carers.</td>
</tr>
<tr>
<td>- Provide information about diagnosis prognosis treatment and available supports</td>
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<tr>
<td>- Communicate with other healthcare professionals and share living well with dementia plan.</td>
</tr>
<tr>
<td>- Clarify roles in ongoing care with primary care</td>
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<tr>
<td>- Refer to support services: Alzheimer’s New Zealand, NASC services</td>
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<tr>
<td>- Carers assessment:</td>
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<tr>
<td>- Carers of Frail Older People - COPE Index (CI)</td>
</tr>
<tr>
<td>- Book Annual reviews of physical state and prescribed medications</td>
</tr>
<tr>
<td>- Review repeat prescriptions</td>
</tr>
<tr>
<td>- Prescribe dementia medications if appropriate</td>
</tr>
<tr>
<td>- Initiate living well with dementia plan:</td>
</tr>
<tr>
<td>- This is me document</td>
</tr>
<tr>
<td>- Capturing the diagnosis</td>
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<tr>
<td>- Advice re legal matters EPOA, wills</td>
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<tr>
<td>- Advance directives and advance care planning</td>
</tr>
<tr>
<td>- Review of immediate safety/ self care issues</td>
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<tr>
<td>- Work, income and dependents, driving, ADLs, vulnerability.</td>
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<tr>
<td>- Identification of GPs with special interests and the instigation of dedicated GP/Practice Nurse sessions</td>
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<tr>
<td>- Promote access points, referral and assessment pathways and options for information to be available in other languages</td>
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</tbody>
</table>
- Identify and promote the best ways to assist people with dementia, their families and carers to navigate the community care system
- Continue supporting people with dementia to maintain and develop skills that enable them to remain connected to their communities for as long as possible
- Identify and promote the best ways to assist people with dementia that are culturally appropriate
- Identify and promote a range of responses to people with dementia that include not only medical and functional diagnosis, treatment care and support but innovative opportunities for people with dementia to remain connected to their communities

| Potential Providers | Primary Care  
| Primary Care  
| Memory Clinics  
| Older People’s Health Services  
| General Hospital Services  
| Alzheimer’s Societies  
| Mental Health Services for Older People (where person is a current patient) |

| KPIs | • Number of people given verbal and written information about dementia  
• Number of people on dementia register/number of people estimated to have dementia in target population  
• Number of people with dementia diagnosis who have living well dementia plan  
• Number of people with ACP’s  
• Number of people referred to Alzheimer’s New Zealand  
• Number of people offered/receiving cholinesterase inhibitors  
• Number of people with EPOA  
• Number of carer assessments completed  
• Evidence of user friendly promotional material |

| Local Initiatives | Memory Clinics  
| Alzheimer’s NZ support services |
The point of diagnosis

Alice was a 52 year old nurse working in a general hospital. In recent years she had noticed increasing difficulty keeping up with younger staff members, she assumed it was just difference in training. However in the last few months she has become increasingly forgetful, had difficulty recalling what tasks she had to do during the day, and recently made 2 significant medication errors. At home she was less able to organise meals and found it impossible to assist her daughter with her school work. After much discussion her GP finally agreed that her behaviour was a concern and referred her to a Neurologist who diagnosed Alzheimer’s Disease.

It was a relief too Alice, who had thought she was losing her mind. The Neurologist started her on Cognitive Enhancers and after discussions with her employer, Alice decided to leave nursing and stay at home to enjoy time with her husband and daughter.
**Introduction**

Dementia is a progressive and evolving illness. It is viewed as necessary for the person with dementia to have regular follow-up, plus availability of services should crises occur. On-going support and guidance helps with the monitoring of the illness and its complications, and allows the families and carers access to advice quickly. There will also be on-going encouragement for the person in living well with dementia and coming to terms with the illness. It also allows for the timely interventions such as ceasing driving or activation of EPOA’s when necessary.

On-going community care is frequently provided through a combination of home or clinic appointments with the family, and the availability of groups in the community.

**Standards**

- Emergency support is available, which provides general and specialist advice, and physical and practical help
- Patient information hub: - A service or information kit for each patient, carer and key worker, which includes all information on the patient, all relevant services and the agreed detailed care pathway is given to each patient/family dyad (this is both patient held and electronic records)
- Medicine management and administration: advising patients and carers on basic medicines management and compliance is provided as a standard intervention
- Practical assistance is offered within the home e.g. home help
- Support is provided with everyday social activities – on a 1:1 basis or in group interventions. This should include activities and social engagements that patients and carers can do together
- Care planning includes the patients needs and wishes
- Care planning is agreed with the key worker/primary care team
- Copy of the care plan sent to the 24/7 telephone and admin support system.
- Copy given to patient and shared with support team
- Advanced care and capacity planning is organised
- Clinician engagement over prognosis involving continuous feedback
- Unnecessary General Hospital admissions are avoided due to
**secondary service input**
- Identify and address the needs of older couples where one or both partners have dementia

| Potential Providers | Primary Care  
|---------------------|-----------------|  
|                     | Specialised Dementia Services  
|                     | Alzheimer’s Associations |

<table>
<thead>
<tr>
<th>KPIs</th>
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<tr>
<td>▪ Patient information packs are issued to every patient</td>
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<tr>
<td>▪ Numbers of people with a recorded diagnosis of dementia is reflected in prevalence data</td>
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<tr>
<td>▪ Number of people with dementia who have a living well with dementia care plan</td>
</tr>
</tbody>
</table>
| ▪ Number of alternative care options available e.g.  
- Transfer to acute hospital setting  
- End of life care  
| ▪ Number of late stage dementia patients assessed for planned palliative care |
| ▪ Number of people with dementia who receive a NASC assessment |
| ▪ Number of scheduled visits to the person with dementia |
| ▪ Percentage of these visits cancelled |
| ▪ Numbers of calls out to crisis service |
| ▪ Number of hospital admissions avoided |
| ▪ Evidence that the needs of older couples where one or both have dementia have been identified and met |

| Local Initiatives |
### Ongoing Community Care – Family and Carers

**Introduction**

Many people with dementia are able to maintain their lifestyle within the community with the support of families, carers, friends and the health services. However at present services are fragmented and carers often struggle with obtaining a diagnosis and accessing appropriate services and resources. Better services need to be available to all New Zealanders regardless of their location, culture differences or socio economic status. Services need to value and respect the dignity of people with dementia as well as the significant role of both families and carers. We know that carers of people with dementia are at high risk of depression, poor physical health and social isolation. Early psycho education intervention, support and coordination of care can have positive effects.

**Standards**

- Round the clock clinical and emotional support for patients and carers
- Staff, carer and family training support to encourage trust
- Development of peer support networks – facilitated by secondary service organisations
- A named key worker who can be contacted quickly
- Day programmes are available, accessible and affordable
- Night care is available accessible and affordable
- Out of hours support – providing rest and support for carers
- Provide practical day to day support and hands on work
- Access to specialist staff and advice on call 24 hours
- Promote counselling services and education and awareness programs to carers of people with dementia at all stages of the care pathway
- Explore availability of advocacy services for carers and people with dementia including Health and Disability Advocacy Service etc.
- Develop flexible models of respite care (including culturally appropriate) in collaboration with local communities including care providers
- Support the provision of care and support for people with dementia and their carers where “risk” of abuse is escalating or where there is evidence of abuse occurring
- Identify health literacy needs for people with dementia and carers and develop strategies to promote health literacy
| Potential Providers | Alzheimer’s New Zealander  
Secondary Providers e.g. NASC, MHSOA and OPH  
NGOs providing Home help, personal cares, respite and carer support |
|---------------------|-----------------------------------------------------------------
| **KPIs**            | ▪ Family/Carer information packs are issued to family/carer  
▪ Time from referral to completion of needs assessment  
▪ Numbers of carers that have access to carer support and numbers of carers who use this support and types of use of this package  
▪ Numbers of carers that have access to respite programme and numbers of carers who use this support and length of use, where and frequency  
▪ Numbers of carers that have home help  
▪ Numbers of carers that have personal care support  
▪ Numbers of carers that are referred to Alzheimer’s New Zealand  
▪ Numbers of carers that consequently take up Alzheimer’s New Zealand engagement  
▪ Regular Carer forums held to discuss issues and needs of carers and appropriate support information disseminated to them.  
▪ Evidence of ‘best practice’ respite care  
▪ Carer surveys are completed annually and Families and Carers report satisfaction with service provided  
▪ Evidence that management of high ‘risk ‘ circumstances has improved the safety and wellbeing of people with dementia and their carers |
| Local Initiatives   | CMDHB Dementia Service |
Coordinating Services

Helen, who was widowed, lived in her own home, and had been independently active for many years. Her GP diagnosed Dementia and referred her to OPH for an assessment of the impact of Dementia on her and her ability to remain at home alone in the future.

Initially she received supportive home visits from the MHSOA Community Mental Health Nurse (CMHN), who referred her to NASC. This service organised home help so that she could continue shopping, and could attend 3 monthly GP check ups.

Helens daughter Tracey found it particularly difficult understanding her mother’s illness and worried about her future. Tracey met with the MHSOA team who suggested she engage with AACT. Tracey attended there Carer Education programme, and became actively involved with other carers.

Tracey took her mother to the Public Trust who arranged EPOA for welfare and property management. Helen continued to live at home with the support of Home Help and later Personal Cares.

However eventually as her disease progressed Tracey and her family suggested that Helen come and live with them in a small flat attached to there home. Helen continued to live in this supportive environment for a further two years; Tracey helped with meals, assisted with finances and was supported by AACT and Helens CMHN.

The inclusion of carer support means that when Tracey and her family have needed a break Helen has able to go to the local rest home for a short stay.
# Physical Health Crisis/ General Hospital Presentation

## Introduction
Physical Health problems are common in people with dementia, but the presence of dementia can complicate diagnosis and management.

Failure to identify dementia and ensure the care needs of the person with dementia are met can compromise recovery of the index health problem and result in additional morbidity.

Dementia is frequently complicated by Delirium when people become physically unwell. This adds to risk for the person while in hospital, and may lead to future deterioration in cognitive impairment if not managed effectively.

A move to the unfamiliar environment of the hospital can be unsettling for people with dementia.

## Standards
- Health care providers will screen for cognitive impairment in vulnerable populations such as hospitalised people aged over 75 using validated tools.
- A structured person centred approach to evaluating capabilities and support needs which involves the person with dementia and their family/ caregivers is recommended (for example the “This Is Me” document). Where this type of care planning has previously occurred the plan is available to hospital staff and the physical health crisis is considered a time for review of this plan.
- Guidance and education for general hospital staff in caring for people with cognitive impairment in hospital should be available (e.g. Best Brain Care)
- Guidance and education for general hospital staff in caring for people with Alcohol Related Cognitive Impairment and its medical co-morbidities, interventions and outcomes – including funding issues.
- Family involvement in care is supported.
- Ongoing assessment for the presence of delirium complicating dementia, and managing any identified cause.
- Staff will be aware of and evaluate competency to consent to proposed medical treatments, and use appropriate legislation to support care provided.
- Where dementia is newly diagnosed the standards for
Dementia Pathway Elements and Standards 17th December 2012

<table>
<thead>
<tr>
<th>Potential Providers</th>
<th>Primary Care, General Hospital, Emergency Medical Services, ARRC</th>
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<tbody>
<tr>
<td>KPIs</td>
<td>▪ Number of ED admissions for people who have a diagnosis of dementia</td>
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<tr>
<td></td>
<td>▪ Number of ED admissions that don’t result in admission to the main hospital</td>
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<tr>
<td></td>
<td>▪ Average length of stay</td>
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<td></td>
<td>▪ Percentage of admissions for Dementia related issues</td>
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<tr>
<td></td>
<td>▪ Number of admissions for Delirium</td>
</tr>
<tr>
<td></td>
<td>▪ Percentage of admissions who are referred to MHSOA</td>
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<tr>
<td></td>
<td>▪ Percentage of admissions who are referred to Psych Liaison</td>
</tr>
<tr>
<td></td>
<td>▪ Availability and utilisation of local guidelines for identification of dementia and delirium in general hospital inpatients</td>
</tr>
</tbody>
</table>

Local Initiatives  Hospital Dementia Pathway Auckland DHB

**Reducing hospital admissions:**

Helen was receiving palliative care at her family home, being supported by CMDHB Dementia Service. She had end stage COPD, CHF and a vascular dementia. Her daughter rang the Dementia Service Navigator/Key worker in the evening because Helen had become increasingly confused, was resisting cares, which was unusual for her, and was newly incontinent.

The Navigator, who visited Helen and her family, was able to establish through electronic records, recent sudden change in behaviour and review of her previous medical history that Helen was delirious as a consequence of Urinary Tract Infection (UTI).

She called Helen’s General Practitioner who prescribed antibiotics. The Navigator arranged a short term increase in Helen’s personal care hours.

Result: Helen returned to previous level of functioning, and hospital admission was avoided.
**Post stroke delirium**

Fred is noted to be more confused than usual post stroke, is disoriented wanting to leave the ward and go to work. At first he doesn’t recognise his wife. He is awake at night and disturbing other patient’s sleep.

He is assessed by the medical team who diagnose a post stroke delirium and institute the best brain care management plan, and work with Fred’s family to complete the “this is me” document. This supports a personalised approach with reorientation, assistance with sleep routines including bringing in his favourite pyjamas, ensuring Fred is supported with food and fluid intake. Family are supported to visit often and bring in his favourite music on an MP3 player which helps calm him.
### Complications of Dementia/ Non-Cognitive Symptoms Of Dementia

**Introduction**

Behavioural and Psychological Symptoms of Dementia (BPSD) occur in the majority of people with dementia at some point in their illness. These may include hallucinations or delusions, anxiety or depression, agitation, resistiveness with cares and aggression, wandering, apathy, and socially inappropriate behaviours. Some of these syndromes are more common in different types of dementia, emphasising the need for accurate diagnosis. As well as causing distress for the person with dementia, they are frequently a major cause of carer stress and may precipitate the decision to move the person into ARRC.

Such behaviours also cause significant challenges in the aged residential care setting.

Pharmacological treatments have historically been the first approach but typically have modest efficacy and are associated with risk/harm. There are also a number of non-pharmacological tools to manage these behaviours, and carers and families need training and guidance in employing these.

**Standards**

- Specialist Assessment Teams are available to receive referrals for people with Behavioural and Psychological Symptoms (Usually Mental Health Services for Older People).
- These services will have effective triage and crisis functions and linkages with referrers and other healthcare providers (including ARRC).
- These services will support family and existing healthcare providers to manage the spectrum of complications of dementia.
- These services will carry out a comprehensive assessment which evaluates environmental, psychological (including depression), social and physical health (including pain) contributions to the current presentation.
- Assessment will include a person centred focus which takes into account consideration of the person’s life history, personality, interests and preferences, family, and recent transitions in care, and seeks to understand the message communicated by the behaviour.
- Multi disciplinary and Multi team approach – primary carer and other teams.
- Education and ongoing support for carers (either family or in the ARRC setting) is a mainstay of management and includes engagement, support and education about appropriate techniques
- Evidence based interventions will be available including
  - Carer education, Non-pharmacological approaches as an initial approach (which may include aromatherapy, personalised music, massage, multisensory stimulation, animal assisted therapy) (NICE Guidance) and pharmacological treatments (NICE Guidance)
- Case management will be available as required
- Legal and ethically responsibility - Consent is a cornerstone of care

### Potential Providers
- Informal carers
- Aged residential Care
- Primary Care
- Older People’s Health Services
- General Hospital and Liaison Psychiatry Services
- Mental Health Services for Older People

### KPIs
- Number of transfers of care into specialised units Dementia Units (DU) / Psychogeriatric Unit (PG), Regional Mental Health Unit (RMHU)
- Injuries to staff
- Falls monitoring includes evaluation of antipsychotic and benzodiazepine prescription.
- Evidence that MHSOP services routinely support non-pharmacological management of BPSD (Audit)
- Number of hospital admissions avoided
- Identify target symptoms or behaviours
- Rates of prescription of antipsychotics
- Target for reduction in prescriptions
- Target for mean duration of prescription of antipsychotics
- Evidence of time limited trials of antipsychotics
- Reduction of polypharmacy
Although Fred’s sleep cycle improves and other features of delirium resolve his memory does not improve back to normal. He is assessed by the occupational therapist who finds that he has perceptual difficulties and problems with sequencing elements of a simple task (making a cup of tea) he is diagnosed with a vascular dementia and the team follow the steps of diagnosis and support as above. Fred develops the belief that his wife has been unfaithful with a neighbour whilst he has been in hospital, and cannot be reassured by this. He is angry when she visits and threatens to “sort the neighbour out” when he gets out of hospital. He is assessed by the liaison psychiatry team and an antipsychotic is prescribed. Visits with family are encouraged, and a schedule is kept to remind Fred of when his wife has visited. Family spend time reminiscing about favourite holidays in the past and staff have photos to support this reminiscence. Fred’s concerns abate over a week. Fred has graduated leave with his wife and son prior to discharge.
## Transition into Aged Residential Care

### Introduction

Many people with dementia end up moving into an ARRC facility. There are three major predictors of entry to residential care, dementia severity, the development of BPSD and the carer’s health and burden of care. However, the move into ARRC is often a time of special difficulty for both the person with dementia and their families. The person is often reluctant to leave their home, and for many carers this is a time associated with feelings of guilt and having failed their loved one. There are also financial implications which impact on this time.

This transition is the time when an ongoing relationship involving aged residential care staff, the person and their family/whanau begins and is an opportunity for development or review of person centred care plans in which care needs are understood and there is agreement about an individualised support plan.

Residential care provides around the clock care and supervision to a large number of people with dementia when they or their families are no longer able to provide care. However some carers and residents identify issues of concern, including lack of stimulation, training, and inconsistent service provision.

The person and their family need guidance and support through this time from specialised services, and may need assistance with making the decision about suitable placement.

### Standards

- Admission tracking and facilitated discharge to aged residential care from general hospital is available
- ARRC providers will screen for cognitive problems and complications of dementia on admission
- A person-centred support plan which takes into account the persons personal history, likes and dislikes, preferences, abilities and support needs is developed with the person with dementia and their caregiver/family.
- In response to BPSD in residents clear pathways are designed to address:-
  - Management of physical care needs
  - Institution of behavioural and environmental management strategies
  - Psychological engagement
- Care for the carer
- Cautious use of psychotropic medication
  - Carers are supported in the transition of the person for whom they are caring throughout the care continuum including residential care

| Potential Providers | Specialised Dementia Service  
|                     | Alzheimer’s Association  
|                     | Aged Residential Care Sector  
|                     | NASC  
|                     | TBI Sector  

<table>
<thead>
<tr>
<th>KPIs</th>
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| Numbers of general hospital admissions avoided  
| Numbers of psychotropic medications prescribed  
| Numbers of falls  
| Numbers of pressure areas  
| Identify and target symptoms or behaviours  
| Target for reduction in prescriptions  
| Target for time spent on anti psychotics  
| Reduce polypharmacy  
| Time limited use of medication  

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<tr>
<th>Local Initiatives</th>
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| BUPA Map of Life and My Day My Way Care Planning  

Fred’s cognitive impairment progresses. He has three times walked off from home thinking that it is time to go to work and on one occasion was nearly hit by a car. His wife June feels too anxious to sleep at night and she and her children decide that it is time for Fred to go into secure dementia care.

Fred’s Living well with dementia plan includes a “This is me” section which includes information about Fred, his life so far, likes and dislikes, things that tend to upset him and things which help calm him. Staff learn that Fred was an accountant and still likes to do paperwork at a desk at home, that he enjoys music and gardening. This information helps staff to provide support what is a difficult time for Fred who is often worried about where June is and tries to leave on three occasions. The mid afternoon seems to be the time Fred worries most about June and so staff arrange for her to visit at that time.

June is encouraged to take time for herself and receives support from the Local Alzheimer’s' support worker and another woman she met on the Carer’s course who has had similar experiences.

Family also bring in some of Fred’s favourite music on an MP3 player, photos and books for his room and a small desk where he can read the newspaper and do some paperwork in the mornings, or on days when he is more restless raking leaves in the garden.
**Ongoing Care in Aged Residential Care**

**Introduction**
Cognitive impairment is common in Aged Residential Care residents, with rates typically around 70% (Opal Study). Complications of dementia are often the reason for admission to aged residential care. Aged residential care facilities must have a high level of expertise in supporting people with dementia and its complications, and must include family/whanau in ongoing support of the person with dementia.

There are a number of models of care provision which can guide personalised, family oriented and socially inclusive and enabling care. (Person Centred Care, Eden Alternative, Spark of Life)

<table>
<thead>
<tr>
<th>Standards</th>
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<tbody>
<tr>
<td>• Aged residential care providers will screen for cognitive problems and complications of dementia on an annual basis</td>
</tr>
<tr>
<td>• Care is guided by a person-centred support plan which takes into account the person's personal history, likes and dislikes, preferences, abilities and support needs is developed with the person with dementia and their caregiver/family.</td>
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<tr>
<td>• In response to BPSD in residents clear pathways are designed to consider:-</td>
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<tr>
<td>• Identify and initiate appropriate strategies to address the unmet needs of younger people with dementia living in residential care (e.g., peer relationships, occupation, physical exercise, sexuality).</td>
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<tr>
<td>• Support the provision of care and support for people with dementia and their carers where “risk” of abuse is escalating or where there is evidence of abuse occurring</td>
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<tr>
<td>• Identify and initiate appropriate strategies to address the unmet needs of people with dementia living in residential care who have extraordinary support needs:-</td>
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</tbody>
</table>
| **Potential Providers** | Aged Residential Care  
DHB Older People’s Health Services, Mental Health Services for Older People  
Education providers |
| **KPIs**       | Numbers of avoidable admissions to general hospital  
Numbers of dementia unit beds and or psychogeriatric beds are reflected in prevalence data  
Numbers of people with a recorded diagnosis of dementia is reflected in prevalence data  
Number of people with dementia who have a living well with dementia care plan which includes agreed individualised support for ADLS, activity and socialisation.  
Numbers of psychotropic medications prescribed  
Target for reduction in prescriptions /polypharmacy  
Target for time spent on anti psychotics  
Time limited use of psychotropic medication  
Numbers of falls  
Numbers of pressure areas  
Hours of activities and diversional therapy provided in residential care setting calculated per resident.  
Number of alternative care options available e.g.  
   o Transfer to acute hospital setting  
   o End of life care  
Number of late stage dementia patients assessed for planned palliative cares  
Number of ARRC services referring to MHSOA, OPH, Crisis teams  
Number of failed discharges of people with dementia from secondary services  
Number of referrals where service discontinued, by family or secondary provider  
Evidence that management of high ‘risk ‘circumstances has improved the safety and wellbeing of people with dementia and their carers  
Carer surveys are completed annually |
| **Local Initiatives** | Walking in another’s Shoes programme (South Island New Zealand) |
| **Scenarios** |                                                                                                                   |
End of Life Care

Introduction
Dementia is ultimately a fatal illness, although many people with dementia die of other connected or coincident medical problems. People with dementia deserve the opportunity to die with dignity, with their families and to have participated in a discussion about their choices in this regard. There needs to be an open and honest discussion between the person and their family, and clinicians about the prospects of further medical interventions improving quality of life for the person, and the point at which these are becoming less effective. These issues need to be discussed throughout the journey with dementia, with the goal of having some planning by the person and their family in respect of end of life care. This may include Advance Care Planning (ACP) or it may take the form of someone with Enduring Power of Attorney for Personal Care and Welfare knowing the person’s wishes and acting in accordance with these or the principles of “best interest” for that person.

Standards

- Work with acute, community and residential care providers of palliative care to ensure people with dementia, their families and carers are included in decision making about how their services will be provided
- Promote awareness of the need for “forward planning” including Advanced Directives, to people with dementia, carers and families, community care and health services provided
- Promote palliative care for people with dementia that is sensitive to the needs of different cultures or language.
- Palliative care services provide education and training to
  - Aged residential care
  - Primary care
  - disability and mental health providers
  - Home support services
- Palliative care services are educated in dementia and intellectual disability so they can better support the person with dementia and their family/whanau.

Earlier in Journey:

- There will be discussion with person and their family about the need for EOLC planning. There will be encouragement of this as an evolving conversation throughout the journey
- Development of ACP as part of clinical and personal care plan
- EPOA or Welfare Guardian will be in place
- Carers such as Aged Residential Care will be informed about ACP documents or EOLC planning
- There will be knowledge of each patients specific wishes e.g. decisions around resuscitation

**Nearing the End:**

- There will be discussions with person and their family about the point at which active interventions will no longer be sought. This will be guided by expert medical advice from Primary Care or medical staff
- Counselling will be provided around this decision
- A clear decision will be recorded and copy of ACP provided
- Following this, should the person become unwell, there will be a clear clinical decision about clinical management in accordance with principles of palliative care
- Validated palliative care pathways will be used
- Pain control and comfort will be goals of care
- Palliative care team will be asked to advise, or another clinician with these skills
- Family and friends will be provided with space and opportunity to spend time with person
- Families may be advised re funeral services if needed
- Families will be visited following the death of the person
- Families may be directed toward bereavement counselling or support as required (this may be part of the secondary service)
- Families and carers have opportunity to rate satisfaction with service provided
- Health and Support professionals are supported after the death
- Care coordination service informed

| Potential Providers | Primary Care  
Dementia Care Service  
Aged Residential Care  
Palliative Care Providers |
|----------------------|---------------------------------------------------------------|
| KPIs                 | Place of death  
Percentage of people dying in preferred place of death (for patient and carer)  
Percentage of people with ACP  
Percentage of people with EPOA / Welfare Guardian  
Supporting documentation with record of discussions about EOLC wishes and decision making with family |
<table>
<thead>
<tr>
<th>Local Initiatives</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Encourage and support role of the General Practitioner</td>
<td></td>
</tr>
<tr>
<td>▪ Involvement of Palliative Care clinician or equivalent</td>
<td></td>
</tr>
<tr>
<td>▪ Service providers up-skilled and supported to provide quality end of life care</td>
<td></td>
</tr>
<tr>
<td>▪ Carer/Family satisfaction questionnaire</td>
<td></td>
</tr>
<tr>
<td>▪ Information on ‘forward planning’ including advanced directives available through health networks and in the community</td>
<td></td>
</tr>
<tr>
<td>▪ Families are asked for structured feedback 6 months after the bereavement.</td>
<td></td>
</tr>
</tbody>
</table>
## SUPPORTIVE OR WHOLE POPULATION ELEMENTS

### Community Awareness

<table>
<thead>
<tr>
<th>Introduction</th>
<th>One of the biggest obstacles to improving care and awareness of dementia in the community is the fear and stigma associated with the illness.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standards</td>
<td>- Up to date information about dementia, treatment/care options is available to people with dementia, their families and caregivers and to all health professionals</td>
</tr>
<tr>
<td></td>
<td>- Identify and support people with dementia as early as possible through dementia awareness programmes</td>
</tr>
<tr>
<td></td>
<td>- Expand awareness, detection and referral for depression of people with dementia</td>
</tr>
<tr>
<td></td>
<td>- Expand awareness, detection and management of dementia in the disability sector</td>
</tr>
<tr>
<td></td>
<td>- Identify needs of younger people with dementia</td>
</tr>
<tr>
<td></td>
<td>- Identify appropriate strategies to address the unmet needs of younger people with dementia</td>
</tr>
<tr>
<td></td>
<td>- Promote awareness of the need for ‘forward planning’ to people with dementia, carers and families, residential care and other health providers</td>
</tr>
<tr>
<td></td>
<td>- Implement culturally appropriate dementia awareness and risk reduction awareness programmes</td>
</tr>
<tr>
<td></td>
<td>- Participate in national process to determine agreed key messages on dementia</td>
</tr>
<tr>
<td></td>
<td>- Support Age Concern Elder Abuse Service in relation to the needs of people with dementia</td>
</tr>
<tr>
<td></td>
<td>- National Awareness campaign</td>
</tr>
<tr>
<td></td>
<td>- including websites that will hold local and national resources</td>
</tr>
<tr>
<td></td>
<td>- maintain cognitive and mental health wellbeing through promotion of social cognitive, physical and learning activities</td>
</tr>
<tr>
<td></td>
<td>- encouraging health lifestyle e.g. Heart Foundation</td>
</tr>
<tr>
<td></td>
<td>Advocacy Services for carers and people with dementia identified and promoted within the community</td>
</tr>
</tbody>
</table>
### Potential Providers

| Provider  | Alzheimer’s New Zealand  
| All health professionals |

### KPIs

- Needs of people with dementia and their carers included in depression initiatives
- Information on ‘forward planning’ including advanced directives available through health service networks and in community
- Key community awareness messages established
- Evidence of culturally appropriate dementia awareness and risk reduction awareness programs.
- Evidence of strategies and promotional campaigns aimed at early identification and risk minimalisation
- Evidence that initiatives outlined by Aged Concern Elder Abuse prevention package have been implemented
- Collect specialist data – including numbers, time to assessment, and outcomes, regarding diagnosis and treatment of people with dual disabilities e.g.
  - Alcohol dependence and dementia
  - Intellectual disability and dementia
  - Traumatic Brain Injury and dementia
  - Early onset
  - Ethnicity specific

### Local Initiatives
## Workforce Development and Training

**Introduction**

The health workforce must become dementia competent. This will require training for all staff appropriate to their role. The service delivery model in each DHB will influence the level of training required. For example where the aim is the majority of diagnosis and management in primary care the primary care workforce is likely to need specific training.

**Standards**

- Continuity of understanding and consistency of approach, including training, experience and skills, information, and understanding of each patient and their ongoing support
- A highly trained dementia care workforce guided by a rigorous research base
- Education and support to improved sector recognition, engagement and how to access support services
- Assess level of competencies against prescribed training i.e. standards, accredited training and recommend strategies to maximise spread of competency across the community, DHB and NGO sectors
- Instigate a workforce development strategy
- Identify existing dementia training and development programmes
- Develop and implement a sector-wide training and development strategy for working with people with dementia which includes:
  - Baseline competencies
  - On line information and service guides
  - Access to supervision or mentoring
  - Information sharing forums on best practice
  - Performance criteria for ongoing staff development planning
- Seek cooperation from ITO’s including Universities to influence the design and delivery of training for relevant health, community care and aged care professionals with a specific focus on curricula related to dementia awareness and care
- Support the development of a suite of nationally recognised dementia specific qualifications ranging from NCEA to Masters degree level
- Identify incentives and barriers to recruitment and retention of workers in dementia care
- Develop incentives for recruitment and retention of workers in dementia care
- Collaborate to provide joint training and development opportunities that foster linkages across residential care (NGO) and DHB settings
- Provide the residential care sector with regular dementia awareness and skill development training

### Potential Providers
- Alzheimer’s New Zealand
- Secondary Providers e.g. NASC, MHSOA and OPH
- ITO’s e.g. Career Force, Universities

### KPIs
- Baseline workforce competencies in the care of people with dementia identified
- Directory of training providers in-place and on-line for DHB and NGO agencies
- Implementation of a Training and Development Strategy
- Specialist competencies and training pathway identified.
- Evidence of inclusion of dementia awareness and care in relevant curricula.
- A suite of national dementia specific qualifications exists to meet the differing requirements of the workforce
- Evidence that the retention of staff in community, DHB and NGO staff are choosing to work in dementia care
- Evidence of joint professional development initiatives between DHB and NGO sectors
- Dementia awareness and skill level enhanced within ARRC sector as evidenced by:-
  - Types of complaints
  - Audits

### Local Initiatives
## Research / electronic resources

<table>
<thead>
<tr>
<th><strong>Introduction</strong></th>
<th>Knowledge about dementia is rapidly expanding, and research covers a wide ranging number of fields. Increasing the accessibility of new knowledge and translation of this knowledge into clinical practice can be facilitated by the use of electronic resources.</th>
</tr>
</thead>
</table>
| **Standards**    | • Increase the awareness of service provider networks that interact with people with dementia and their carers  
• Establish links between specialist dementia resource/information service with other dementia services e.g. advanced care planning  
• Promote and disseminate agreed key areas of research to key stakeholders and workforce  
• Identify and implement the most appropriate ways to enhance existing practice  
• Enhance existing practice based on research findings. |
| **Potential Providers** | All dementia service providers  
Te Pou, Ministry of Health, |
| **KPIs** | ▪ Current dementia information disseminated actively  
▪ Awareness resources developed  
▪ Established knowledge exchange and transfer systems  
▪ Data analysis, trends, outcome reports  
▪ Linkages established between specialist dementia services and other key information services  
▪ Evidence of promotion and dissemination of agreed key areas for future research  
▪ Identify the extent to which practice guidelines and service models are based on research findings |
| **Local Initiatives** | National Dementia Cooperative research action group. |
## IT and Documentation

### Introduction
Information technology provides great opportunities for active involvement of people with dementia and their families in care planning, and the integration of care across multiple service providers and settings.

Information technology will also allow us to more accurately capture where and how people access services and what is provided when they do.

### Standards
- Centralised scheduling of care
- Electronic clinical records of all interventions for patients and carers
- Accurate clinical outcome, admission prevention and key performance indicator date for providers and planners

### Potential Providers
All healthcare providers

### KPIs
- Evidence of dementia data collection as per national standards
- Evidence of progress towards shared access to care plans

### Local Initiatives
## Governance: Local – Regional – National

### Introduction

Local Governance of Dementia Care requires that there is leadership and oversight of the provision of dementia services to the local DHB population, across the various providers.

Local governance is supported by a Regional process of governance to ensure the sharing of initiatives and comparison of performance. It is also an opportunity to review ways of delivering dementia care in each locality to ensure that services are both effective and efficient. Regional governance may also support equity of access to more specialised services and training.

There should also be a National governance process to ensure standards are updated, that dementia remains a priority for healthcare, and to review the roll-out of dementia care services across the country.

### Standards

<table>
<thead>
<tr>
<th>Local</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify service gaps and plan to ensure services can meet future need</td>
</tr>
<tr>
<td>• Prioritise the creation of new initiatives</td>
</tr>
<tr>
<td>• Plan delivery of services in a manner appropriate to the local population and geography</td>
</tr>
<tr>
<td>• Key initiatives implemented with appropriate policy and funding support</td>
</tr>
<tr>
<td>• Clarify roles and responsibilities</td>
</tr>
<tr>
<td>• Develop dementia specific service models that are responsive to the needs of diverse groups and culturally appropriate</td>
</tr>
<tr>
<td>• Allocate service provision to appropriate local providers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Monitor local and regional trends and collect statistical information to inform service planning</td>
</tr>
<tr>
<td>• Shared training and service development initiatives.</td>
</tr>
<tr>
<td>• Coordinated contracting for Aged residential care and support services to meet regional needs, particularly for extraordinary needs groups (single sex facilities, facilities focused on a particular cultural group, young onset dementia and intellectual disability plus dementia).</td>
</tr>
<tr>
<td>National</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>• Establish dementia as a national health priority</td>
</tr>
<tr>
<td>• Develop Dementia Care Pathways by June 2013 in all DHB’s</td>
</tr>
<tr>
<td>• DHB’s will work in collaboration to develop Dementia Care Pathway</td>
</tr>
<tr>
<td>• Contribute to the National review of regulations regarding Driving</td>
</tr>
<tr>
<td>• Identify barriers to access of care and support for people with special needs</td>
</tr>
<tr>
<td>• Linkages to the National Dementia Cooperative Action Groups</td>
</tr>
<tr>
<td>• Support the work of Advocacy groups to increase awareness about legislative changes that may affect Power of Attorney; the benefits of forward planning and advanced directives</td>
</tr>
<tr>
<td>• Promote and disseminate dementia research findings to community care and health agencies to inform future planning, service management and delivery</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potential Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>DHB’s, Ministry of Health</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>KPIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local</td>
</tr>
<tr>
<td>• Each DHB has developed an DHB dementia care pathway by June 2013 – which responds to identified DHB priorities</td>
</tr>
<tr>
<td>• Identify statistics on projected service demand and gaps</td>
</tr>
<tr>
<td>Regional</td>
</tr>
<tr>
<td>• Develop regional dementia maps showing referral pathways</td>
</tr>
<tr>
<td>• Evidence of dementia specific service models that are responsive to the needs of diverse groups and culturally appropriate.</td>
</tr>
<tr>
<td>• Document and address service gaps and develop initiatives that improve responses to people with dementia and their carers.</td>
</tr>
<tr>
<td>National</td>
</tr>
<tr>
<td>• Evidence of input and joint sign off on policies, plans and reports for local, regional and national initiatives</td>
</tr>
<tr>
<td>• Local, Regional and National linkages maintained</td>
</tr>
<tr>
<td>• Improved awareness of Power of Attorney and Advance Directives procedures amongst people with dementia, their families and carers.</td>
</tr>
<tr>
<td>Local Initiatives</td>
</tr>
</tbody>
</table>

Dementia Pathway Elements and Standards 17th December 2012
Financial: Funding and Cost analysis

Introduction

Caring for people with dementia is costly and will become even more critical as the NZ population ages – in 2008 the total financial cost was estimated at $713 million.

Historically, models of mental health funding have not taken into account dementia. Despite this, around half of patients presenting to older age psychiatry services are affected by problems relating to dementia.

The reliability of dementia diagnosis and data capture is one barrier to evaluation of the cost of dementia care especially in acute and primary care settings.

Standards

When looking at economic investment in dementia services effectiveness and cost effectiveness, should be reviewed, however may be limited to the little research undertaken to date with few cost effectiveness studies available.

The potential for interventions in one service area to create savings in another should be considered. Examples from the available literature are listed below.

- Collaborative care models in primary mental health may be of particular benefit for older adults
- Early provision of support at home can decrease institutionalisation by 22%
- Even in complex cases, and where the control group is served by a highly skilled mental health team, case management can reduce admission to ARRC by 6%
- Older peoples mental health services can help with behavioural disturbance, hallucinations and depression in dementia, reducing the need for ARRC
- Carer support and counselling at diagnosis can reduce care home placement by up to 28%
- Early diagnosis and intervention improves the quality of life of people with dementia
- Cost effectiveness modelling of early diagnosis service is available (Banerjee, 2009)
- Early intervention has positive effects on the quality of life of family cares

**Potential Providers**
- DHB Mental Health for Older People Services
- DHB Older People Services
- Funding and Planning in each of the District Health Boards

**KPIs**
- Identify the cohort of relevant patients and associated volumes
  - Under 65’s, Over 65’s, with intellectual disability, alcohol related cognitive impairment and traumatic brain injuries
- Identify the hospital admissions that relate to this cohort of patients
- Identify the aged residential care admissions related to this cohort of patients
- Identify the total cost savings for each patient on the DHB pathway
- Calculate the gross savings associated with transferring these patients on to a dementia care pathway

**Local Initiatives**
**Facilities Design**

| **Introduction** | The built environment has potential to enable or disable people with dementia, to encourage orientation and a sense of familiarity and meaningful activity, and to promote social models of care. All health care facilities should attempt to make adaptations to the needs of people with dementia, but this is of particular importance in units caring for older people, and all aged residential care facilities. Special consideration should be given to specialist secure dementia care units which cater for mobile residents with additional support needs arising from complications of their dementia. |
| **Standards** | • Audit standards include review of adaptation of facilities towards dementia friendly designs.  
• All new builds or retrofits make attempts to dementia design principles and use existing audit tools (Stirling/Hammondcare audit tool; Environmental Audit tool)  
• Although all facilities should aim to provide the below features, particular attention should be paid in specialist dementia care units where a safe and secure homelike environment, domestic in scale with a garden area which is therapeutic which promotes activity, walking for purpose, and exposure to sunlight. Visual access and multiple types of orienting cues should also be considered. Personalising rooms will also promote orientation. |
| **Potential Providers** | All healthcare facilities and aged residential care providers, architects and construction companies.  
All DHB Funding and Planning  
Aged Care Clinicians |
| **KPIs** | • Agreed national standards for health and residential care facilities likely to be caring for people with dementia.  
• Commitment from Aged residential care providers to dementia friendly designs which are externally reviewed prior to building.  
• Active dialogue and planning between ARRC providers and DHBs to build and contract facilities which meet the range of care needs of people with dementia and cater to specific populations (e.g. young onset dementia, single sex facilities, intellectual disabilities, |
and the range of levels of care rest home, private hospital, secure dementia care, psychogeriatric private hospital
- All new build residential care facilities will be evaluated using a recognised audit tool

<table>
<thead>
<tr>
<th>Local Initiatives</th>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>
**List of Acronyms:**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AACT</td>
<td>Alzheimer’s Auckland Charitable Trust</td>
</tr>
<tr>
<td>ACP</td>
<td>Advanced Care Planning</td>
</tr>
<tr>
<td>ADHB</td>
<td>Auckland District Health Board</td>
</tr>
<tr>
<td>AO</td>
<td>Alzheimers Organisations</td>
</tr>
<tr>
<td>ARRC</td>
<td>Age Related Residential Care</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse Groups</td>
</tr>
<tr>
<td>CMDHB</td>
<td>Counties Manukau District Health Board</td>
</tr>
<tr>
<td>CMHN</td>
<td>Community Mental Health Nurse</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>CT</td>
<td>Computed tomography</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>DU</td>
<td>Dementia Unit (ARRC)</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department</td>
</tr>
<tr>
<td>EPOA</td>
<td>Enduring Power of Attorney</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GPCog</td>
<td>General Practitioners Assessment of Cognition</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>HOP</td>
<td>Health of Older People</td>
</tr>
<tr>
<td>IQCODE</td>
<td>Informant Questionnaire on Cognitive Decline in the Elderly</td>
</tr>
<tr>
<td>MCI</td>
<td>Mild Cognitive Impairment</td>
</tr>
<tr>
<td>MoCA</td>
<td>Montreal Cognitive Assessment</td>
</tr>
<tr>
<td>MHSOP</td>
<td>Mental Health Services for Older Adults</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental Status Exam</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>NASC</td>
<td>Needs Assessment and Service Coordination</td>
</tr>
<tr>
<td>PGU</td>
<td>Psychogeriatric Unit (ARRC)</td>
</tr>
<tr>
<td>RMHU</td>
<td>Regional Mental Health Unit (ARRC)</td>
</tr>
<tr>
<td>SPECT</td>
<td>Single Photon Emission Computed Tomography</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
</tbody>
</table>
References:

This document was developed using some key international documents relating to Dementia Strategies and Guidelines for care, they include the following documents. Appendix 1 (which follows) is a list of recommended reading relating to the various elements of the Guide which may be useful in assisting the development of service provision.

- Minister of Health (2011) Letter of Expectation for District Health Boards and their subsidiary entities for the 2012/13 year
Appendix 1

Patient Journey Elements

Prevention / Health Promotion / Awareness


Screening


Suspicion / Initial Investigations


Assessment / Diagnosis

- Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., Murray, J (2007) Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model *Int J Geriatr Psychiatry*


Ministry of Health (2011) Mental Health and Addiction Services for Older People and Dementia Services: Guideline for district health boards on an integrated approach to mental health and addiction services for older people and dementia services for people of any age Wellington: Ministry of Health


Post Diagnosis Interventions – Mild Cognitive Impairment

Post-Diagnostic Interventions - Dementia


Ongoing Community Care – Person with Dementia


Ongoing Community Care – Family and Carers


Physical Health Crisis / General Hospital Presentation


Complications of BPSD


Transitions into Aged Related Residential Care


- McCleery, J., Fox, R (2012 Antipsychotic prescribing in nursing homes – We need to understand why this practice continues despite the mortality risk BMJ 2012;344:e1093 doi: 10.1136/bmj.e1093 (Published 23 February 2012)

Care in Aged Related Residential Care


End of Life Care


Supportive or whole population elements

Community Awareness


Workforce Development and Training


Funding: Financial and Cost Analysis


Facilities Design


### Appendix 2

#### DEMENTIA WORK STREAM MEMBERS

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Position/Representations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Alan Davis</td>
<td>Northland DHB NDSA</td>
<td>Clinical Director – Department of Medicine – NDHB Clinical Lead – Health of Older People Regional Network - NDSA</td>
</tr>
<tr>
<td>Dr Mark Fisher</td>
<td>CMDHB</td>
<td>Clinical Head – Mental Health Services for Older People (MSHOP)</td>
</tr>
<tr>
<td>Gina Langlands</td>
<td>BUPA</td>
<td>General Manager, Quality and Risk</td>
</tr>
<tr>
<td>Julie Martin</td>
<td>AACT</td>
<td>General Manager</td>
</tr>
<tr>
<td>Dr Terry Mitchell</td>
<td>ADHB</td>
<td>Geriatrician – Memory Clinic ADHB A+ Links Older Peoples Health ADHB</td>
</tr>
<tr>
<td>Chris Pegg</td>
<td>Northern DHB Support Agency</td>
<td>Programme Manager – Health of Older People</td>
</tr>
<tr>
<td>Dr Gavin Pilkington</td>
<td>WDHB</td>
<td>Clinical Head – Mental Health Services for Older People (MHSOP)</td>
</tr>
<tr>
<td>Sue Thomson</td>
<td>Northern DHB’s</td>
<td>Northern Regional Dementia Behavioural Support and Advisory Coordinator</td>
</tr>
<tr>
<td>Anne Williamson</td>
<td>East Health Trust PHO</td>
<td>ElderCare – Coordinator of services for Older People</td>
</tr>
<tr>
<td>Dr Richard Worrall</td>
<td>ADHB</td>
<td>Clinical Head – Mental Health Services for Older People (MHSOP)</td>
</tr>
</tbody>
</table>
8.3 ADHB Dementia Care Pathway
Auckland/Waitemata District Health Board

DiSAC Board

DiSAC Meeting

Health of Older People

<table>
<thead>
<tr>
<th>Date</th>
<th>27 February 2013</th>
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<tbody>
<tr>
<td>To</td>
<td>Auckland and Waitemata DHB - DiSAC Committee</td>
</tr>
<tr>
<td>From</td>
<td>Tim Wood, Funding &amp; Planning Manager, Denis Jury, Chief Planning and Funding Officer</td>
</tr>
<tr>
<td>Author</td>
<td>Richard Worrall, Clinical Director MHSOP, ADHB</td>
</tr>
<tr>
<td>Functional Group</td>
<td>Auckland and Waitemata DHB Funding and Planning Managers</td>
</tr>
<tr>
<td>Subject</td>
<td>DiSAC Quarterly Report on the Auckland DHB Dementia Care Pathway</td>
</tr>
</tbody>
</table>

**Purpose**

To provide DiSAC with an update on the Auckland DHB Dementia Care Pathway.

**Recommendation:**

1. **Endorse** the trial of the ‘This is Me’ and ‘Living Well Plan’.
2. **Note** the ‘This is Me’ tool
3. **Note** the Lining Well Plan

**Background**

Prior to Ministry Directives for Dementia Care Pathways there was already some dementia service development underway:

In recent years Auckland DHB has developed and continues to refine a memory clinic which is a joint initiative between Health of Older People and Mental Health Services for Older People. This service has used a multi-disciplinary approach to standardise the assessment process and post diagnosis care. There is a good working relationship with Alzheimer’s Auckland who are part of the clinic team. In addition, the memory clinic continues to develop research initiatives.

Health of Older People, Neurology, and Mental Health Services for Older People provide diagnosis with cross referral between services when appropriate.

**Progress to Date**

Auckland DHB is in the final stages of establishing a dementia services governance group. In acknowledgement of the broad reach of dementia service provision and the growing demand and impact of services the governance structure will include the Chief Executive Officer, the Chief Planning and Funding Officer, and key clinical expertise including primary care.

Subject matter experts and project teams will work beneath this governance group to deliver service development in priority areas.

The Auckland DHB hospital dementia project has continued over the past year or more. This currently...
includes the running and evaluation of a pilot to screening all people over 75 admitted to hospital. For those screening positive, we are implementing a standardized pathway of care within the hospital, using the ‘This is me’ (Appendix 1) tool to support person-centred and shared planning, geriatrician support for diagnosis, and a standardized discharge plan. Project management support through the Performance Improvement team has been essential to the progress of the project. If the measures are able to be implemented hospital-wide with the earlier diagnosis there is potential for significant progress towards an improved standard of care in hospital, harm minimisation, and improves supports post discharge.

Links between the hospital dementia project, memory clinic and the regional dementia workgroup have meant that the clinical services have contributed to, and are becoming testing grounds for tools such as “This is Me” and the “Living Well Plan” (Appendix 2) which we hope will be adopted more broadly.
This is me
...dignity and safety for older people

For help to complete This is me please refer to the guidance notes at the end of this document

Section 1: Personal Details

First name: ______________________________________________________
Last name: ______________________________________________________
I like to be known as: _____________________________________________

I currently live at: ________________________________________________

My carer or the person who knows me best: __________________________
Their contact details are: __________________________________________

My Enduring Power of Attorney is __________________________________
Their contact details are: __________________________________________

The other people you should keep informed about my progress are:
_________________________________________________________________

Things I would like you to know about me

My home and family and things that are important to me
_________________________________________________________________
_________________________________________________________________

My life so far: ____________________________________________________
_________________________________________________________________

My hobbies and interests: _________________________________________
_________________________________________________________________

Other things I would like you to know: _______________________________
_________________________________________________________________
_________________________________________________________________

_________________________________________________________________
Section 2: Things to know when providing medical care

Things which may worry or upset me:


The best way to relax and calm me is:


Agreed support, to be completed with health staff:


My hearing and eyesight:


Agreed support, to be completed with health staff:


My communication:


Agreed support, to be completed with health staff:
My mobility:

Agreed support, to be completed with health staff:

My sleep:

Agreed support, to be completed with health staff:

My personal care:

Agreed support, to be completed with health staff:

My toileting needs:

Agreed support, to be completed with health staff:
My eating and drinking: 

Agreed support, to be completed with health staff:

My medication: 

Agreed support, to be completed with health staff:

My current support at home: 

Agreed support, to be completed with health staff:

If you have an Advance Care Plan where will we find a copy 

Patient or carer/family signature: Date: 

Health team signature: Date:

This is me is based on an original plan developed by Alzheimers UK and the Nursing Council UK
**Better Brain Care Plan**

This is for use for people with known dementia, past or current history of delirium or who have a positive GP COG (Cognitive Impairment Screening). This should be used alongside the information in This is me.

<table>
<thead>
<tr>
<th>Preventive care</th>
<th>Practice guide</th>
<th>Action/checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person and family centred care</td>
<td>Involve family in care</td>
<td>□Complete This is me</td>
</tr>
<tr>
<td></td>
<td>Need interpreter Y/N</td>
<td>□Enduring Power of Attorney (copy requested)</td>
</tr>
<tr>
<td></td>
<td>Delirium brochure</td>
<td>□Advance Care Plan (copy requested)</td>
</tr>
<tr>
<td></td>
<td>Flexible visiting</td>
<td></td>
</tr>
<tr>
<td>Ensure hydration and nutrition</td>
<td>Record food intake</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fluid balance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Assist and protect mealtimes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dentures Y/N</td>
<td></td>
</tr>
<tr>
<td>Assess and treat pain</td>
<td>Use regular pain relief</td>
<td>□monitor and record pain score</td>
</tr>
<tr>
<td></td>
<td>Paracetamol to start</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avoid prn regimes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Use LOW doses opiates to start</td>
<td></td>
</tr>
<tr>
<td>Mobility and falls assessment</td>
<td>Maintain mobility twice daily walk</td>
<td>□Falls assessment</td>
</tr>
<tr>
<td></td>
<td>Ensure usual aids available</td>
<td>□PT review</td>
</tr>
<tr>
<td>Continence plan</td>
<td>Replicate usual pattern or</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Regular toileting schedule</td>
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</tr>
<tr>
<td>Sleep</td>
<td>Quiet and comfort , usual settling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>routine, avoid caffeine , offer snacks</td>
<td></td>
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<tr>
<td>Medications</td>
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<tr>
<td></td>
<td>Avoid unnecessary hypnotics</td>
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<tr>
<td>Hourly rounding</td>
<td>Regular checks , risk assessment</td>
<td>□Consider need for observation room</td>
</tr>
<tr>
<td>Maintain function and routine</td>
<td>Do with, not for</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□Minimise moves</td>
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</table>

**Delirium Risk**

Patients on this care pathway are usually at high risk.

<table>
<thead>
<tr>
<th>Pre-morbid risk factors</th>
<th>Precipitating factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual impairment</td>
<td>WARNING: these factors increase risk</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>• Mechanical restraint</td>
</tr>
<tr>
<td>Severe illness –physical or depression</td>
<td>• Malnutrition</td>
</tr>
<tr>
<td>Dehydration</td>
<td>• 3 new medications added in 24hrs</td>
</tr>
<tr>
<td></td>
<td>• IDC</td>
</tr>
<tr>
<td></td>
<td>• iatrogenic event(procedure, infection, complication, fall etc)</td>
</tr>
</tbody>
</table>

**Monitor for delirium**

You should note any change in behaviour and ask the family/carer if they note any change from normal, for example if the patient becomes more withdrawn, variable attention, more or less sleepy, disorganised thinking, hallucinations, fluctuations from shift to shift. Request the following if you note change

<table>
<thead>
<tr>
<th>Date</th>
<th>+ve change</th>
<th>Medical review</th>
<th>Family history</th>
<th>Physical exam</th>
<th>Medication review</th>
<th>bloods</th>
<th>MSU</th>
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</table>

See the delirium policy for more information.
Discharge planning check list
Use this as a checklist to make sure ongoing care and support is available to keep the patient safe after discharge.

Is there adequate support at home, with meals, personal care, domestic help, transport, finances?  

Has the patient been assessed by OT, PT, Social worker or other?  

Has the patient been given information on EPOA if they still have mental capacity?  

Is the person medically fit to drive? YES / NO, advice given  

Is there support in place to manage medication?
  - Yellow card  
  - Blister pack  
  - Someone to pick up prescription  
  - What supervision is needed/available for medications  
  - Plan for antipsychotic reduction  
  - Acetylcholinesterase inhibitor  

Are the family aware of discharge date and time and has transport been arranged?  

Have any family and carer concerns been discussed and met?  

Have you checked and noted who the appointment details for clinic follow ups should be sent to?  

Have you arranged follow ups for example with GP, OPH, MHSOP  

Has a referral been made to Alzheimers Foundation?  

If this is a new diagnosis, has the alert form been completed and faxed to Clinical Records  
(this will ensure that an alert and link to the Care Plan is included on the patients electronic record)  

Registrar/Consultant signature:  

Date:
Information for Health Care Staff: Our principles of care

It is important that we maintain the dignity of our patients and treat them with respect at all times. Following these principles of care will help us to do this and make sure we provide a safe and caring environment for patients with a cognitive impairment.

Person centred care.
- Use the information in This is me to make sure you enhance the care of patients whilst they are in an unfamiliar environment
- The patient and their family are central to care involve them wherever possible.
- Life history and experience will impact on behaviour and emotion, be aware of the information in This is me to seek any support required
- Relax visiting times
- Use a calm tone of voice and do not argue
- Avoid sensory overload and deprivation
- Minimise the number of moves and maximise continuity of care
- Try and ensure patients have their own clothes and other familiar items.

Reorientation
- Help patients settle into the unfamiliar environment
- Clearly explain to patients where they are, why they are here, who you are and what is happening. Use simple language and explain one step at a time
- Try and have a visible clock and calendar in place
- Remember the 3Rs
  - Repetition: you will need to repeat yourself, this is OK

Establish diagnosis
Be as accurate as possible with the diagnosis and avoid terms like “confusion” and “cognitive impairment.”
- A detailed cognitive history is mandatory
- Use IQCODE
- Use standard cognitive assessment tools (MMSE, MOCA, ACE-R)
- Remember to check executive function (ADHB Executive Screen or Exit)
- CT head if this has not been done previously
- Make a further referral if the patient
  - Is living alone and has functional impairment - refer to a Geriatrician
  - Is showing behaviours that challenge - refer to Psychiatry
  - Has Atypical features –refer to geriatrician, psychiatrist or neurologist
  - Is still working – refer to

Family communication and information
- The family should be kept informed of the diagnosis and prognosis
- The family should be provided with information about support services available (NASC/SW)
- Tell family members they have a right to a carers assessment to identify support for them and provide Social Worker contact details.
- Refer to Alzehmers Foundation
Guidance for completing This is me

This is me should be completed by or with the older person, if they are able or someone who knows them best. Nursing staff may have to telephone a family member or carer to help complete This is me.

When This is me has been completed Nursing staff should discuss the patient needs and agree support required during their stay in hospital with the person and their family or carer. This should be documented in the purple boxes.

This is me is intended to provide information about the person as an individual. This will enhance the care and support provided while the person is in an unfamiliar environment.

This is me is about the person just before they came to hospital or got sick.

Guidance notes on each of the sections

Where I currently live: The address where you live. Include how long you have lived there, and where you lived before.

Carer/the person who knows me best: This may be a spouse, relative, friend or carer. Please include contact details along with those of any other people who need to be informed about progress.

Enduring Power of Attorney: Include the name and contact details of the person who has this for welfare and property. Include if this has been formally activated with a certificate of incapacity. A copy of this will need to be provided for the patient records.

My home and family and things that are important to me: Include marital status, children, grandchildren, friends, pets, any possessions or things of comfort. Include any religious or cultural considerations.

My life so far: Place of birth, education, work, history, travel, or anything else that helps us understand more about you as a person.

My hobbies and interests: Past or present, for example, reading, music, television, radio, crafts, cars.

Other things I would like you to know: anything you feel is important and will help staff to get to know and care for you, for example you have never been in hospital before, you don’t like the dark, you are left handed, or anything else you think we should know that is not included in other sections.

Things which may worry or upset me: Anything that may cause anxiety such as, money, family concerns, or being apart from a loved one, or a physical need, for example, being in pain, constipated, thirsty or hungry.

The best way to relax or calm me is: Things which may help if you become unhappy or distressed. What usually reassures you, for example, comforting words, music or TV. Do you like company and someone sitting and talking with you or prefer quiet time alone? Who could be contacted to help, include when and how.

My hearing and eyesight: How well you hear and if you need a hearing aid. How is it best to approach you? Is the use of touch appropriate? Do you need eye contact to establish communication? Do you wear glasses or need any other vision aids?

My communication: How you usually communicate, when you are in pain, discomfort, thirst or hunger or example, verbally, using gestures, pointing or a mixture of both. Can you read and write, does writing things down help? Include anything else that may help staff identify your needs.

My mobility: Are you fully mobile or do you need any help, including walking aids and hand rails. Is your mobility affected by surfaces, can use stairs? Can you stand unaided from a sitting position, do you require a special chair or cushion. Anything that makes you more comfortable for example raising your feet.

My sleep: Include your usual sleep patterns and bedtime routines. Whether you like a light left on, if you find it difficult to find the toilet at night, position in bed, any special mattress, pillow, and if you need a regular change of position.

My personal care: Include your normal routines and preference, level of assistance required in the bath or, shower or other. Include here if you prefer a male or female carer. Anything we should know about soaps used, cosmetics, shaving, teeth cleaning and dentures.

My toileting needs: What is your usual bladder and bowel routine. Do you need help at night. What continence products you use, if any. If you need a urinary, a commode or take laxatives.

My eating and drinking: Tell us if you need assistance to eat or drink, do you need any adapted aids for eating and drinking? Does your food need to be cut into pieces or liquidised? Do you wear dentures to eat or have any swallowing difficulties? Likes, dislikes or special dietary requirements. Include information about your appetite and whether you need help to choose food off a menu.

My medication: Include here any help you need to take medication, for example if you need tablets crushing or you prefer to take liquid medication.

Advance care plans: If you have made an advance care plan please show us this. We will discuss all treatment with you and your family but if you are unable to make your own decisions we will be guided by your advance care plan.
This care plan will help you support me during my hospital stay. Please return it to me when I leave.

First name: _______________________________
Last name: _______________________________
I like to be known as: _______________________________

You may wish to include a photo of yourself here
1. Decision making

I can and would like to part of making my own decisions, so please ask me first. However, if, I lack capacity (unable to make decision when it is necessary), the following will apply:

a) Do I have a legal representative? Yes / No

My legal representative is:

______________________________________________________________________________

Full Name:

______________________________________________________________________________

Legal relationship: (e.g. welfare guardian, enduring power of attorney etc.)

______________________________________________________________________________

Telephone Mobile Fax: ______________________________

Email _______________________________________________

b) Do I have advance directives? Yes / No

My advanced directives can be found at: (e.g. on my medical file, in cupboard at home, I have given verbal directives to my wife etc.)

______________________________________________________________________________

______________________________________________________________________________

c) I do not have a legal representative or advance directives and trust than any decision concerning my care and welfare will be made appropriate by appropriate professional/s in my best interests after taking into account my views if they are known, or consulting people who know me and

I am supported in this by_________________________________________

Who is my (relationship) ___________________________________________

They visit (regularity) _____________________________________________

To (help me to) _____________________________________________

NOTES FOR PERSON COMPLETING THE CARE PLAN

- Completing this care plan is optional. You may decide how much information you want to give under each section and may even choose not to complete some sections of the care plan.
- If you are unsure what to write in a particular section, please refer to the Guide to completing the Living well with Dementia Care Plan
1. This is what I want to tell you about myself

I currently live at:
You can contact them at

Other people you should keep informed of my progress:

My home and family, and things that are important to me

My life so far (early life, education and career, important events that have shaped who I am, achievements I am proud of)

NOTES FOR MEDICAL AND SUPPORT STAFF

- If you are involved with my care and support, please read this care plan
- This is not my Medical Record. This Living Well with Dementia Plan gives information about:
  - Things you MUST know about me
  - Things that are important to me
  - Other useful information
My hobbies and interests

Some people might do things that others find difficult to understand. Things I may sometimes do:-
(examples might include: walking about with potential to get lost, getting upset or angry more easily, saying things without thinking through how others might feel, or being over familiar with others).

<table>
<thead>
<tr>
<th>For e.g. When I am</th>
<th>I may get easily frustrated or angry</th>
</tr>
</thead>
<tbody>
<tr>
<td>When I am</td>
<td>I may</td>
</tr>
<tr>
<td>When I am</td>
<td>I may</td>
</tr>
<tr>
<td>When I am</td>
<td>I may</td>
</tr>
<tr>
<td>When I am</td>
<td>I may</td>
</tr>
<tr>
<td>When I am</td>
<td>I may</td>
</tr>
</tbody>
</table>

Other things that may worry or upset me:
(This may include tiredness, hunger, constipation, ill health or if someone speaks to me in an abrupt way or hurries me along etc).

The best way to help me to become relaxed and calm is to:-
(This could be making sure my environment is not overwhelmed by noise, that I eat regular meals, that I am treated with respect and dignity, help me to direct my attention to some thing pleasant such as music massage etc)
3. My communication

A. My first (or preferred) language is:

..................................................................................................................................................

B. I can also speak

..................................................................................................................................................

C. I do/don’t need an interpreter in this language

..................................................................................................................................................

D. I communicate best with people using: (e.g. gestures, facial expressions, picture charts, hearing aids, etc.)

..................................................................................................................................................

..................................................................................................................................................

..................................................................................................................................................

E. Things you need to know when communicating with me:
   (E.g. speak slowly, face me, tap my shoulder for attention, turn on my hearing aid etc.)

..................................................................................................................................................

..................................................................................................................................................

..................................................................................................................................................

..................................................................................................................................................

..................................................................................................................................................

..................................................................................................................................................
4. Things to know when providing medical care for me

A. You would know when I am in pain when: e.g. I can tell you, my mood changes, I rock my body etc.)

____________________________________________________________________________________________________

B. I am allergic too: e.g. medication, food, perfume

____________________________________________________________________________________________________

C. When giving me medication, please (e.g. crush my medication)

____________________________________________________________________________________________________

D. When conducting a medical examination, please:
   (e.g. be aware that I may not understand what is happening, may not like the process)

____________________________________________________________________________________________________

____________________________________________________________________________________________________

E. Other things you need to know about my medical care: (please provide other information not already covered that staff must know about you)

____________________________________________________________________________________________________

____________________________________________________________________________________________________

____________________________________________________________________________________________________
5. Day to Day

a) My hearing and eyesight:

b) My mobility:

c) My sleep:

d) My eating and drinking:

e) Medication

f) Personal Cares (Showering, dressing, toileting)
The Living well with dementia care plan should be completed by or with the older person, if they are able or someone who knows them best. Nursing staff may have to telephone a family member or carer to help complete Living well with dementia care plan.

When the Living well with dementia care plan has been completed Nursing staff should discuss the patient needs and agree on support required during their stay in hospital with the person and their family or carer. This should be documented in the yellow boxes.

The Living well with dementia care plan is intended to provide information about the person as an individual. This will enhance the care and support provided while the person is in an unfamiliar environment.

The Living well with dementia care plan is about the person just before they came to hospital or got sick.

Guidance notes on each section

Decision making: Include the name and contact details of the person who has this for welfare and property. Include if this has been formally activated with a certificate of incapacity. A copy of this will need to be provided for the persons medical records.

My home and family and things that are important to me: Include marital status, children, grandchildren, friends, pets and possessions or things of comfort. Include any religious or cultural considerations.

My life so far: Place of birth, education, work, history, travel, or anything else that helps us understand more about you

My hobbies and interests: Past or present, for example, reading, music, television, radio, crafts, cars.

Other things I would like you to know: Anything you feel is important and will help the staff get to know and care for you, for example Do you like company and someone sitting and talking with your or do you prefer your own company?

My hearing and eyesight: How well you hear and if you need a hearing aid. How is it best to approach you? Is the use of touch appropriate? Do you need eye contact to establish communication? Do you wear glasses or need any other vision aids?
8.4 WDHB Dementia Care Pathway
**DiSAC Meeting**

**Health of Older People**

<table>
<thead>
<tr>
<th>Date</th>
<th>27 February 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>To</td>
<td>Auckland and Waitemata DHB - DiSAC Committee</td>
</tr>
<tr>
<td>From</td>
<td>Tim Wood, Funding &amp; Planning Manager, Denis Jury, Chief Planning and Funding Officer</td>
</tr>
<tr>
<td>Author</td>
<td>Tim Wood</td>
</tr>
<tr>
<td>Functional Group</td>
<td>Auckland and Waitemata DHB Funding and Planning Managers</td>
</tr>
<tr>
<td>Subject</td>
<td>DiSAC Quarterly Report on the Waitemata DHB Dementia Care Pathway</td>
</tr>
</tbody>
</table>

**Purpose**

To provide DiSAC with an update on the Waitemata DHB Dementia Care Pathway.

**Recommendations**

1. **Note** the development of a draft primary care cognitive impairment pathway.
2. **Endorse** the pilot and evaluation of the primary care cognitive impairment pathway.
3. **Note** that the pilot and the evaluation will be reported to the committee.
Under the Specialised Services for Older Adults (SSOA) work programme there has been a focus on dementia pathways. The initial work focus on the development of a model of care as represented in the following diagram.

Subsequent to this the development of a detection and diagnostic pathway (see following) has been completed.
DETECTION AND DIAGNOSTIC PATHWAY FOR DEMENTIA

(Diagram includes dealing with BPSD)

UNCOMPLICATED ASSESSMENT
IN PHO

FORGETFULNESS
PERSONALITY
CHANGES

BPSD

ACUTE
CONFUSION
DELIRIUM

TRIGGERS IDENTIFIED IN
MEDICAL/SURGICAL/ECC

FORGETFULNESS
PERSONALITY
CHANGES

BPSD

ACUTE
CONFUSION
DELIRIUM

UNSURE

NO
Dementia

NO
Dementia

NO
dementia

NO
dementia

Short-term
Education &
Support

Short-term
Education &
Support

Short-term
Education &
Support

OTHER AGREED
TESTS

STANDARDISED
ASSessment,
E.g. GP COG,
BLOODS, CT
Scan

Standardised
Assessment,
E.g. GP COG,
bloods, CT Scan

Standardised
Assessment,
E.g. ACE-R

History
Physical exam

Standardised
tests
E.g. ACE-R

History
Physical exam

TRIGGERS IDENTIFIED IN
MEDICAL/SURGICAL/ECC

STANDARDISED
ASSessment,
E.g. CPCOG/
MMSE

UNSURE

YES
Diagnosis

YES
Diagnosis

YES
Diagnosis

NO
Dementia

NO
Dementia

NO
Dementia

BPSD with
Complexity

BPSD with
Complexity

BPSD with
Complexity

MHOSA

INTEGRATED CONTINUUM OF CARE, NGO INVOLVEMENT, ON-GOING MANAGEMENT

MORE COMPLEX SECONDARY-LEVEL ASSESSMENT

MHSOA

COMPLEX TERTIARY-LEVEL ASSESSMENT
Progress to Date
Since the development of the model of care and the detection and diagnostic pathway a clinical reference group has been formed. The clinical reference group has representation from primary care, and secondary care. This group has overseen the development of the draft primary care cognitive impairment pathway (Appendix 1). It is planned that final sign off of this pathway will occur at the next clinical reference group meeting. When the pathway is approved the intention is to pilot the pathway with 60 patients across 12 GP practices (6 ProCare and 6 Waitemata PHO practices). The pilot will include training of general practitioners and practice nurses involved in the pilot of the appropriate tools and referral pathways.

The pilot will be formally evaluated. The pilot and its evaluation will be reported to the committee when available.

The pilot and the evaluation outcomes will then inform the next development steps and decisions on the rollout of the pathway or not.
APPENDIX 1
Patient / Family / Whanau / GP Receptionist / Other alerts GP that patient has memory & /or personality & / or behavioural changes.

**GP 1st Visit**
- History including to exclude delirium, depression, medication side-effects, alcohol / substance dependency
- Physical including neuro exam to exclude Stroke / Parkinsons etc.
- Cognitive Screen with Mini Cog

**Preparation for GP 2nd Visit**
- To exclude dementia:
  - IQ Code - request family / carer to complete before next appt
- Bloods & Urine, order:
- Cognitive Assessment - refer for MoCA by Practice Nurse or Alzheimer's Auck

**GP 2nd Visit**
- Results: GP discusses IQ Code, Bloods & Urine, MoCA results with patient and carer / family / whanau
- If results inconclusive and no other pathology diagnosed, repeat the preceding tests in 6 months
- If MoCA ≤ 26 & no CT Head over period of cognitive decline, consider referral for CT Head (waiting list approx 6 weeks)
- If MoCA ≤ 22, refer for functional assessment by Community Occupational Therapist

NOTE: If after 12 months the diagnosis is still uncertain refer to Geriatrician and enclose all results of the 6 month and 12 month assessments.
If mild cognitive impairment or non-complex dementia is diagnosed this can be managed by GP in partnership with Alzheimers Auckland & Community Health Services.

At GP 2nd Visit

- As well as explaining diagnostic results, emphasise importance of patient-centred multidisciplinary care plan to help slow down cognitive decline or progression of dementia.
- Medication: decide re commencement of Donepezil.
- Refer to Alzheimers Auck for patient & carer education and support.

Care Planning Meeting

- Patient, Carer / Family / Whanau, Alzheimers Auckland, Community OT (if involved) & other key services (if any involved) meet, agree care plan, with Alzheimers Auck Key Worker usually the best placed to be Care-Plan Co-ordinator.
- Care Plan to include: referral to NZTA for on-road driving safety test; EPOA (enduring powers of attorney); WINZ for disability allowance.
- At appropriate stage agree who will determine with patient their advanced care wishes.

Care Plan Review/s

- Full group meet 1 year later, sooner if required, to review and patient and carer needs, determine any required changes to care plan and agree respective responsibilities.
- Complete any ‘tests’ referrals required and ensure patient / carer, family / whanau understand the results and follow up required.
- Set next review date for Care Plan.

NOTE: With mild cognitive impairment there is a 10% chance every subsequent year of converting to dementia, usual risk is 1%.
If diagnosis is complex or advanced dementia, or diagnosis is uncertain GP is to refer patient to secondary care services.

FAX REFERRAL TO 09 486 8997 and include results of: IQ Code, MoCA, Bloods, Urine, CT Head (if done), OT Functional Assessment (if done), and state whether patient has been referred to Alzheimers Auckland.

- **Referral likely to be triaged to Gerontology Nurse Specialist (GNS) or Geriatrician if:**
  - If further Cognitive assessment is required (e.g. ACER etc)
  - Medical co-morbidities (e.g. Parkinsons, CVA etc)

- **Referral likely to be triaged to Memory Service if:**
  - early age onset, familial
  - Advanced dementia

- **Referral likely to be triaged to Mental Health Services Older Adults (MHSOA) if:**
  - behavioural or psychological (BPSD) symptoms
8.5 Waitemata PHO Dementia Care Pathway
Auckland/Waitemata District Health Boards
Auckland & Waitemata DHBs
DISAC Meeting
Health of Older People

Date 13 March 2013

To Auckland and Waitemata DHB - DISAC Committee

From Tim Wood, Funding & Planning Manager,
Denis Jury, Chief Planning and Funding Officer

Author Rachael Calverley (Director of Nursing and Workforce Development, Waitemata PHO) & Lynelle Dagley (Gerontology Nurse Specialist, Waitemata PHO)

Functional Group Auckland and Waitemata DHB Funding and Planning Managers

Subject DISAC Quarterly Report on activities in Auckland & Waitemata DHBs

Purpose
To provide an overview of the Waitemata PHO Integrated Gerontology Nurse Specialist in Primary Care Project – Phase II.

Recommendations:
1. The committee notes the content of this paper.
2. The committee notes and endorses the development of an electronic tool to enable earlier recognition of dementia.

Background
Phase I
- This was a feasibility study to assess the effectiveness of a Gerontology Nurse Specialist (GNS) working in a primary care setting.
- The model employed a GNS who led a proactive risk screening process using the Brief Risk Identification for Geriatric Health Tool (BRIGHT) screen for older people living at home.
- This also explored the potential of the GNS role for upskilling the primary care workforce.

The BRIGHT screening tool was used to “case find” people over 75 years who at risk. The ‘at risk’ group received a full geriatric assessment in their home by the GNS. A person-centred care plan is then developed for each person and their family.

Phase 1 outcomes
- The BRIGHT screen was a cost-effective tool for systematic screening of the older adult population.
- The GNS integrated model was effective in leveraging geriatric specialist skills in primary care.
- The GNS role was effective model for the delivery of comprehensive care as well as building gerontology expertise in primary care.
- Patient and practice responses were positive.

Phase II
This ongoing project is jointly funded by Health Workforce NZ (HWNZ), Waitemata DHB and Waitemata PHO. This is a partnership between all parties, in association with the University of Auckland. The University of Auckland will be undertaking the evaluation.

Phase II extends the first study to cover ethnically and socioeconomically diverse populations (these high needs groups include Maori, Polynesian, rural and quintile 5). Integration with Maori workforce
development is an integral element to this project.

The project commenced 1 December 2012 with three components:

1. Demonstrate the effectiveness of the GNS in Primary Care with the high needs older population. This will be achieved by the GNS undertaking home visits to patients recently discharged from hospital. The GNS is currently working with 3 Integrated Family Health Centres (IFHC).
2. Development of the Dementia Toolkit: including education and up-skilling of general practice teams, development and trialling of an electronic dementia decision support tool.
3. Demonstrate the benefits of GNS home visits to patients from the Waitemata DHB Transition of Care project.

### Progress To Date

#### GNS in Primary Care – High Needs Population
- 494 older people with high needs were identified from the Integrated Family Health Centres practices.
- 3 Integrated Family Health Centres practices have been identified for the project, one of these has agreed to participate.
- Invitation letters and the BRIGHT screen questionnaire have been translated into Maori, Samoan and Tongan.
- The BRIGHT screen questionnaires have been posted to selected patients. The responses will be recorded in a purpose built database.

#### Transition of Care (TOC)- A previous Waitemata DHB project
Processes are in place to identify patients from the TOC project who may require a home visit from the GNS in Primary Care Project.

#### The Dementia Toolkit
The dementia toolkit aims to provide electronic decision support for primary and secondary services. In the first instance this will be available via the Health Workforce New Zealand website.

General Practices have been identified for trialling the dementia toolkit, with education and teaching sessions scheduled. One education session for GPs and RNs was well attended. A smaller workshop group has been held with one IFHC that received a positive evaluation. A second workshop is scheduled.

#### Evaluation
There is a three month evaluation that consists of 3 elements:

1. Effectiveness of the GNS in Primary Care
2. Monitoring the rate of rehospitalisation
3. Implementation of the dementia toolkit, including IT tool-usability/training needs/workforce impact.

The evaluation framework includes:

1. Impact and implications for the primary/secondary workforce
2. Impact and implications for patients
3. Service/system design
4. Learnings from the process.

#### Steering group
This is well established, Waitemata DHB and Waitemata PHO colleagues and senior clinicians are integral to the group. This enables connections to the wider plan of work focussed on older adult care and management, currently being undertaken at the DHB.

#### HWNZ
Waitemata PHO remains well connected to and communicating with HWNZ, monthly reporting is in place to manage the challenges of the project.

A full report of the evaluation will be presented to the committee with advice on the next steps at the end of the pilot.
9.1 Action Points for next DSAC Meeting

9.2 DSAC Feedback to Board
GENERAL BUSINESS

Topics List

Strategic Priorities
- Mental Health of Older People
- Dementia Pathway
- Aged Residential Care
- Implementing the Northern Region Health Plan
- Disability – Annual Plans

Improving Access
- ADHB Accessibility Review
- Universal Access for Carers
- Funding Boundaries
- Cultural and Attitudinal Shifts
- Physical Infrastructure Environment
# MEETING DETAILS

**Time and Date**  
1:00 pm – 4:00 pm, Wednesday, 13 March 2013

**Venue**  
Training Room, CCS Disability Action, 14 Erson Avenue, Royal Oak

**Members ADHB & WDHB**  
Sandra Coney (Chair), Dairne Kirton, Jan Moss, Jo Agnew, Dr Lester Levy, Marie Hull-Brown, Max Abbot, Michelle Cavanagh, Pat Booth, Robyn Northey, Susan Buckland, Susan Sherrard, Russell Vickery.

**Apologies**

**In Attendance**  
Dr Dale Bramley, Dr Denis Jury, Sue Waters, Dr Debbie Holdsworth, Ronnelle Baker, Linda Harun, Kate Sladden, Katrina Lenzie-Smith, Tim Woods, Ian Bell.

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**Item 1: Introductions**

**Item 2: Attendance and Apologies**

**Item 3: Conflicts of Interest**

**Item 4: Confirmation of Minutes 14 November 2012**

**Item 5: Action Points 14 November 2012**

**Item 6: Chairpersons’ Report**

**Item 7: Improvement Activities**

- 7.1 Quarterly Report on the Implementation of the NZ Disability Strategy
- 7.2 Quarterly Report on Activities
8 Papers
8.1 National Dementia Cooperative
8.2 Regional Dementia Workgroup
8.3 ADHB Dementia Care Pathway
8.4 WDHB Dementia Care Pathway
8.5 Waitemata PHO Dementia Care Pathway

9 Confirmation
9.1 Action Points for next DSAC Meeting
9.2 DSAC Feedback to Board

10 General Business

Topics List

Strategic Priorities
- Mental Health of Older People
- Dementia Pathway
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- Implementing the Northern Region Health Plan
- Disability – Annual Plans

Improving Access
- ADHB Accessibility Review
- Universal Access for Carers
- Funding Boundaries
- Cultural and Attitudinal Shifts
- Physical Infrastructure Environment
- Respite and Transitional Care for Disabled Youth

NEXT MEETING

Time and Date: 1:00pm – 4:00pm, Wednesday, 5 June 2013
Venue: Training Room, CCS Disability Action, 14 Erson Avenue, Royal Oak, Auckland

Hei Oranga Tika Mo Te Iti Me Te Rahi
Healthy Communities, Quality Healthcare