



Disability Support Advisory Committee Meeting

Wednesday 27 August 2014

1.30pm

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

Hei Oranga Tika Mo Te Iti Me Te Rahi

Healthy Communities, Quality Healthcare

Published 20 August 2014



Agenda

Disability Support Advisory Committee

27 August 2014

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

Time: 1.30pm

ADHB and WDHB Members	ADHB and WDHB Staff	
Sandra Coney (Chair)	Dr Dale Bramley	Chief Executive Officer Waitemata District Health Board
Jan Moss	Ailsa Claire	Chief Executive Auckland District Health Board
Max Abbot	Carolyn Simmons	Allied Health Director, Adult Medical/Cancer and Blood Community Engagement Manager
Jo Agnew	Carlsson	
Judith Bassett	Sue Copas	Disability Strategy Coordinator Waitemata District Health Board
Pat Booth	Samantha Dalwood	
Marie Hull-Brown	Dr Debbie Holdsworth	Director Funding – Auckland and Waitemata District Health Boards
Dairne Kirton	Katrina Lenzie-Smith	Programme Manager, Health of Older People
Dr Lester Levy	Kery McIlroy	Professional Leader Dieticians and Nutritionists
Robyn Northey	Marty Rogers	Maori Health Gain Manager
Russell Vickery	Kate Sladden	Funding and Development Manager, Health of Older People
	Marlene Skelton	Corporate Business Manager
	Sue Waters	Chief Health Professions Officer
	Tim Wood	Funding and Development Manager, Primary Care
	Other staff members who attend for a particular item are named at the start of the minute for that item	

Apologies Members: Lester Levy

Apologies Staff: Tim Wood, Sue Waters, Leanne Catchpole, Ailsa Claire, Fionnagh Dougan, Judith Catherwood, Dale Bramley

Register of Interests

Does any member have an interest they have not previously disclosed?

Does any member have an interest that may give rise to a conflict of interest with a matter on the agenda?

Agenda

Please note that agenda item times are estimates only

- | | | |
|--------|----------|--|
| 1.30pm | 1 | ATTENDANCE AND APOLOGIES |
| | 2 | CONFLICTS OF INTEREST |
| | 3 | CONFIRMATION OF MINUTES 4 June 2014 |
| 1:35pm | 4 | ACTION POINTS 4 June 2014 |
| | 5 | CHAIRPERSON'S REPORT |

- 6 PRESENTATION**
- 1:40pm 6.1 What the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) contains and how New Zealand is meeting its obligations under the convention – Ezekiel Robson, Salubrious
- 2:10pm 6.2 Patient Experience Manager, Jay O’Brien – Providing an overview of short to medium term goals for service
- 7 IMPROVEMENT ACTIVITIES**
- 2:20pm 7.1 [Health of Older People Quarterly Report on Activities in Auckland and Waitemata DHBs](#)
- 2:40pm 7.2 [Implementation of the NZ Disability Strategy in Auckland and Waitemata DHBs Update Report](#)
- 3:10pm **8 CONFIRM**
- 8.1 Action Points for next DSAC Meeting
- 8.2 DSAC feedback to CPAC
- 8.3 DSAC feedback to Board
- 9 GENERAL BUSINESS**

Next Meeting	Wednesday 19 November 2014 at 1.30pm Training Room, CCS Disability Action, 14 Erson Avenue, Royal Oak, Auckland
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Hei Oranga Tika Mo Te Iti Me Te Rahi

Healthy Communities, Quality Healthcare

Attendance at Disability Support Advisory Committee

	12 March 2014	4 June 2014	27 August 2014	19 November 2014					
Attendees									
Sandra Coney (Chair) (WDHB)	1	1							
Jo Agnew (Deputy Chair) (ADHB)	1	1							
Max Abbott (WDHB)	x	x							
Judith Bassett (ADHB)	1	1							
Pat Booth (WDHB)	1	1							
Dr Marie Hull-Booth (Appointed)	1	1							
Dairne Kirton (Appointed)	1	1							
Lester Levy (Ex-officio) (ADHB/WDHB)	x	1							
Jan Moss (Appointed)	1	1							
Robyn Northey (ADHB)	1	1							
Russell Vickey (Appointed)	1	1							
x absent									
# leave of absence									

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.

This sheet provides summary information only - refer to clause 36, schedule 3 of the New Zealand Public Health and Disability Act 2000 and the Crown Entities Act 2004 for further information (available at www.legislation.govt.nz) and “Managing Conflicts of Interest – Guidance for Public Entities” (www.oag.govt.nz).

Register of Interests – Disability Support Advisory Committee

Name of Member	Organisation	Latest Disclosure
Sandra CONEY (Chair)	Chair – Waitakere Ranges Local Board, Auckland Council	12 Dec 2013
Jo AGNEW (Deputy Chair)	Professional Teaching Fellow - School of Nursing, Auckland University Appointed trustee Starship Foundation Casual Staff Nurse - ADHB	1 Mar 2014
Max ABBOTT	Pro Vice-Chancellor (North Shore) and Dean – Faculty of Health and Environmental Sciences, Auckland University of Technology Patron - Raeburn House Board Member - Health Workforce New Zealand Board Member - AUT Millennium Ownership Trust Chair - Social Services Online Trust Board Member - The Rotary National Science and Technology Trust	28 Sept 2011
Judith BASSETT	Fisher and Paykel Healthcare Westpac Banking Corporation	14 May 2014
Pat BOOTH	Consulting Editor - Fairfax Suburban Papers in Auckland	24 June 2009
Lester LEVY (Ex-officio)	Chairman - Waitemata District Health Board Chairman - Auckland Transport Independent Chairman - Tonkin & Taylor Deputy Chairman – Health Benefits Ltd Chief Executive - New Zealand Leadership Institute Professor (Adjunct) of Leadership - University of Auckland Business School Trustee of the Well Foundation (ex-officio member as Waitemata DHB Chairman) Advisor - Orion Health Director and sole shareholder – Brilliant Solutions Ltd	15 Aug 2014
Robyn NORTHEY	Self-employed Contractor - Project management, service review, planning etc. Board Member - Hope Foundation Trustee - A+ Charitable Trust	20 June 2012
Marie HULL-BROWN	Employee - Mental Health Foundation of NZ	25 Mar 2014
Dairne KIRTON	Northern Regional Representative - CCS Disability Action National Board Grants Committee Member – Variety the Children’s Charity	25 Mar 2014
Jan MOSS	Co-ordinator - Complex Carer Group Board Member YES Disability Centre, Albany Member - SSOAS Stakeholders Group, WDHB Reference Group Member - MOH Disability Workforce NZ & Choices in Community Living	25 Mar 2014
Russell VICKERY	None declared	12 Mar 2014



Minutes

Disability Support Advisory Committee

4 June 2014

Minutes of the Disability Support Advisory Committee meeting held on Wednesday, 4 June 2014 in the Training Room, CCS Disability Action, 14 Erson Avenue, Royal Oak commencing at 1:30pm

ADHB and WDHB Members	ADHB and WDHB Staff
Sandra Coney (Chair)	Samantha Dalwood Disability Strategy Coordinator Waitemata District Health Board
Jan Moss	Dr Debbie Holdsworth Director Funding – Auckland and Waitemata District Health Boards
Jo Agnew	Kate Sladden Funding and Development Manager, Health of Older People
Judith Bassett	Marlene Skelton Corporate Business Manager
Pat Booth	Sue Skipper Operations Manager, Older Adults and Home Health
Dr Marie Hull-Brown	Sue Waters Chief Health Professions Officer
Dairne Kirton	Gilbert Wong Director Communications
Dr Lester Levy (Arrived during item 7.1)	
Robyn Northey	
Russell Vickery	
	Other staff members who attend for a particular item are named at the start of the minute for that item

1 ATTENDANCE AND APOLOGIES

That the apology of Committee Member Max Abbot be received.

That the apologies of staff members, Ailsa Claire, Dale Bramley, Judith Catherwood, Tim Wood, Marty Rogers, Fionnagh Dougan and Linda Huran be received.

[Secretarial Note: Jo Agnew was present at the 12 March 2014 meetings as noted in the minutes but the attendance sheet needs to be amended to reflect this. Marie Hull-Brown requires “Dr” to be removed from every instance where her name appears on the attendance sheet and the agenda page.]

2 CONFLICTS OF INTEREST

There were no declarations of conflicts of interest for any other items on the agenda.

The register of Interests requires updating to reflect interests held by Russell Vickery.

3 CONFIRMATION OF MINUTES 12 MARCH 2014 (Pages 7-14)

Resolution: Moved Judith Bassett/Seconded Jo Agnew

That the minutes of the Disability Support Advisory Committee meeting held on 12 March 2014 be confirmed as a true and correct record with an amendment to item 9 to read “..Maori girls in years 12 and 13 to be part of a programme...”

Carried

4 ACTION POINTS 12 MARCH 2014 (Pages 15 – 16)

There was no comment with regard to action points from the meeting of 12 March 2014.

5 CHAIRMANS REPORT (Pages 20 - 22)

Appointed Member Vacancy

Current Committee members were asked to provide recommendations for consideration for the remaining vacancy. One recommendation has been submitted. In order to be seen to be transparent it has been decided that public notification of the vacancy should be undertaken.

The Auckland and Waitemata Joint Terms of Reference provide for membership as follows:

- Three members from Waitemata District Health Board
- Three members from Auckland District Health Board
- The Board Chair as an ex officio member
- Six external members

The total membership is twelve persons excluding ex officio membership. The Boards are to endeavour to appoint, as members of the Committee, persons who together will provide a balance of skills, experience, diversity and knowledge to enable the committee to carry out its functions.

The Boards are to ensure that the Committee includes representation for Maori in accordance with Section 34 of the Act and for Pacific people.

The Terms of Reference state that the Boards will appoint any external appointees as members in accordance with the following process:

- The Chair and Deputy Chair of each Board together with the respective Chief Executive Officer will evaluate potential members in accordance with the criteria determined by the Boards and make recommendations to the Boards as to the proposed appointments.
- The Boards will make the final appointments (if any) to the Committees.

Public notification would follow a prescribed advertising programme in the public notice section of the regions Community Newspapers. Contact could also be made directly with the Deaf Association of NZ, the Royal New Zealand Foundation of the Blind, the Stroke Foundation of New Zealand the Disabled Persons Assembly, IHC and CSS.

Matter covered in discussion of the report and in response to questions included:

- Agreement that one of the vacant positions should be allocated to representation for Maori in accordance with Section 34 of the Act. It was also noted that it would be good if Pacific representation could also be accommodated when considering the

advertising for the remaining vacant position.

- A request that the advertisement be circulated to Committee Members before being released.

Action

That the Corporate Business Manager follows the prescribed process for requesting Maori representation on the Committee and proceed with the advertising required for the remaining vacant position.

Terms of Reference

Committee members noted that the Terms of Reference did not give the required emphasis to the New Zealand Disability Strategy and that there were other strategies that should perhaps be mentioned. A review was requested.

Action

That a review of the Terms of Reference be undertaken to ensure a more positive reference is included to the New Zealand Disability Strategy and other relevant strategies.

Resolution: Moved Russell Vickery/Seconded Jo Agnew

That the Chairpersons report be received.

Carried

6 PRESENTATIONS

6.1 Delivery of Respite Care – Estelle Muller (Page 24)

Estelle Muller was newly appointed to her role as Contract Relationship Manager, National Health Board when she last addressed the Disability Advisory Committee in August 2013. Estelle was been invited back to give a more detailed update relating to questions asked by committee Members on what is happening with delivery of respite care.

Respite Care

When will respite care be able to be accessed through Individualised funding?

There are delays in setting this up and a timeframe is unknown at this point. Work is being done to ensure that the allocation is correct as there is a need for respite care to be as flexible as possible and that hasn't been able to be achieved yet. Estelle was certain that it could be achieved.

What provision is there for respite for young people with serious on-going medical conditions?

This is available through NASC. If Committee members are aware of young people unable to access respite Estelle urged them to use the hot line or as a last resort to let Estelle herself know.

Carer Support

How is the review of Carer Support going?

The review work is still on-going and has yet to be finalised. At this stage Estelle commented that she had no new information for the committee members.

What process and support exists to find suitable carers?

There is direct matching of carers to people requiring alternative care. In 2011 the model was reviewed and it was found that service coverage and quality was not what was required. In 2013/14 work got underway to address identified issues and further improve the model. An assessment takes into account the home situation and other services currently being received in order to determine what an individual requires and is provided with. A number of these people have high and complex needs. Often these situations fail because a competent carer cannot be found. The situation for children is even more complicated as to be eligible for personal care they must be in the category of high and complex needs.

Key Initiatives

What are some of the key initiatives/projects that you are involved in that will, in your opinion, make a difference in respite care over the next two to five years?

Individualised funding – the Bay of Plenty model of enhanced individualised funding collective has had positive results and it is hoped that this can be rolled out further.

Also of interest is the pilot occurring in Christchurch which is allowing the amalgamation of funding so that families can be given the total budget and then apply it as they require. There has been a strong demand for this pilot to be extended.

Matter covered in discussion of the presentation and in response to questions included:

- Advice that for people to find a carer they need to do so through contracted agencies who vet applicants. It is not known what percentage of the matching is actually successful. However, it is known that the current contracts do need improving in the areas of service, coverage and meeting national indicators.

That Estelle Muller be thanked for her presentation.

6.2 Age Residential Care Health Utilisation Study (ARCHUS) – Professor Martin Connolly (Page 24)

Professor Martin Connolly and Joanna Broad attended the meeting. Professor Martin Connolly made a presentation on the Age Residential Care Health Utilisation Study (ARCHUS); the first randomised controlled trial of multi-disciplinary intervention into residential aged care facilities with the aim of reducing avoidable hospital admissions.

In brief:

- Auckland has an aging demographic with people living longer. The productive segment of the population is diminishing and the percentage of people living beyond 85 is increasing.
- Dependency ratios are increasing. In 2011 for every 100 people aged between 15 and 65 there were another 20 aged over 65. By 2031 it is estimated that this will be 40 aged over 65.

- In 2006 over 8% of older people in New Zealand lived in institutions, one of the highest rates in the OECD countries.
- The OPAL study undertook surveys in 1988, 1993, 1998 and 2008 and found that there were 8000 residential beds (the number remaining relatively static through the years) What is occurring though is that people are entering residential assisted care later in life and when they do enter hospital they are usually classified as medically acute.

Matter covered in discussion of the presentation and in response to questions included:

- Comment that mainstream services are discharging older people too quickly, on average after three or four days stay. This was seen as a funding and resourcing issue. However, it was also noted that longer stays brought other inherent complications to the fore. It was best not to have to be admitted in the first instance.
- It was noted that 60 to 70% of older people who enter hospital go directly to residential care from hospital. In terms of rest homes it is only half that number.
- Good generic management of conditions substantially lowers admission rates. This is an issue that needs addressing between GPs and rest homes.

Resolution: Moved Sandra Coney/Seconded Robyn Northey

That Professor Martin Connolly and Joanna Broad be thanked for their attendance and that Professor Martin Connolly be thanked for a very informative presentation.

Carried

7 IMPROVEMENT ACTIVITIES

7.1 Health of Older People – Quarterly Report on Activities in Auckland and Waitemata (Pages 25 – 31)

Kate Sladden, Programme Manager Funding Team asked that the report be taken as read highlighting as follows:

- The Ministry of Health provided District Health Boards with a guidance document for developing Paid Family Carer (PFC) policies in April 2014. It recommended that PFC policies only enable District Health Boards to permit some family members to be paid, in exceptional circumstances, for providing home-based support services (HBSS) to disabled family members.

It was agreed that the three metro Auckland District Health Boards would develop a policy to be used across the region. The management arrangement agreed upon was to pay family carers via contracted HBSS providers rather than through a host agency or paying directly. The HBSS provider is responsible for ensuring statutory employee rights are not breached and working as a HBSS employee means family carers have more access to peer support from other non-family carers to ensure that they are not exploited by the family member they are caring for.

Currently across the three metro Auckland District Health Boards there is a practice of HBSS providers employing family carers in extenuating circumstances. The

number is small.

The metro Auckland District Health Boards' PFC policy has been reviewed by the Ministry of Health and has received sign-off.

- The Auckland District Health Boards Home Based Support Services model has had an increase in the proportion of clients classified as 'complex'; from 27% in January 2013 to 37% in January 2014. There has also been a shift up the eight complex categories from what was originally modelled using client data in 2012. Both these shifts have funding implications.

There is no convincing reason for the shift in complexity nor has there been an indication from providers that the level of service they are required to provide has taken a sudden or marked step increase.

However, there has been an increased proportion of patients now being assessed (using the interRAI Home Care assessment) in hospital prior to their discharge rather than in their homes. The increase in hospital based assessments began in mid- 2012 and potentially could be inflating a patient's acuity.

An audit of all HBSS clients assessed in hospital started in May 2014. The audit will determine if there has been a reduction in a client's complexity/acuity since they returned home.

Matter covered in discussion of the report and in response to questions included:

- Advice that in relation to the financial model for long term support for chronic health conditions, in 2014/15 and future years, it has been regionally agreed that District Health Boards will continue to manage their own risks and utilisation costs through their respective PBFF and adopt the national process for IDFs. IDFs relate to those persons out of their area of domicile.

Resolution: Moved Sandra Coney/Seconded Marie Hull-Brown

That the quarterly report of the Health of Older People be received.

Carried

7.2 Implementation of the new Zealand Disability Strategy 2013-2016 (Pages 32 – 39)

Samantha Dalwood, Disability Strategy Coordinator Waitemata District Health Board asked that her report be taken as read highlighting as follows:

- That she had inspected the accessible car parking available at North Shore Hospital and concurred with Russell Vickery that it was not satisfactory. Arrangements are being made to have the defects remediated.

Matter covered in discussion of the report and in response to questions included:

- Lester Levy advised that a new shuttle service had started between Waitakere and

North Shore Hospitals. Alternative arrangements were in place for those requiring wheelchair access.

Action

That information be provided via email to committee members as to how the new shuttle service between Waitakere and North Shore Hospitals operates.

Resolution: Moved Jan Moss/Seconded Marie Hull-Brown

That the Disability Support Advisory Committee receives the update report on the implementation of the NZ Disability Strategy in Auckland and Waitemata District Health Boards.

Carried

8 PAPERS

8.1 Auckland District Health Board Accessibility Report Update (Pages 40 – 60)

Sue Waters, Chief Health Professions Officer asked that her report be taken as read.

Matters covered in discussion of the report and in response to questions included:

- Advising that toilet design was managed by the Facilities Team who were reviewing toilets as each new build or upgrade occurs to ensure that the correct design principles were applied for disabled access.
- Judith Bassett requested that item 17 on page 46 carry a timeframe rather than the word “ongoing”. Sue Waters advised that accessibility of the content in MOODLE modules was reviewed at least annually and as required when content was updated.
- Russell Vickery asked whether any thought had been given to the use of voice description. Gilbert Wong advised that it had been considered and it would be good to have but that Auckland District Health Board was not in a position to implement it at this time. Concentrated effort had gone into including all impaired groups in any initiatives.

Action

The ADHB Accessibility Report Update was accepted with a request for a further update on; Autism related facilities – a verbal update to provide information on what has been done to accommodate those with severe autism and/or cognitive impairment.

Resolution: Moved Russell Vickery/Seconded Jan Moss

That the report be received and that the Disability Support Advisory Committee (DSAC):

- 1. Note the continuation of the 2012 work plan tabled.**

2. Note and accept the progress of work in this update.

Carried

8.2 Accessibility of Information for People with Disabilities (Pages 61 – 64)

Gilbert Wong, Director of Communications, asked that his report be taken as read.

Matters covered in discussion of the report and in response to questions included:

- Advising that in making District Health Board information as accessible as possible to people with disabilities an approach has been adopted that is suitable for both print and web-based communications. Feedback was initially sought via email with the option of electing other media to place feedback, for instance, via phone.
- It was acknowledged that the Auckland District Health Board website was not ideal and did not meet accessibility standards. Plans are underway within the next 12 months to rebuild the website to address deficiencies in providing information about hospital services for patients, visitors and family. It will address the issue of providing information in the three main official languages. It is hoped to eventually run video on the website opening up a whole new host of opportunities.

The Chair thanked Gilbert Wong for the report and asked that a quarterly progress report be provided to the Committee.

Resolution: Moved Sandra Coney/Seconded Jo Agnew

That the report be received.

Carried

9 CONFIRM

9.1 Action Points for next DSAC Meeting

Shuttle service between Waitakere and North Shore Hospitals

That information be provided via email to committee members as to how the new shuttle service between Waitakere and North Shore Hospitals operates.

Severe Autism and/or Cognitive Impairment.

That the next Auckland District Health Board Accessibility Report Update provide information on what has been done to accommodate those with severe autism and/or cognitive impairment.

Putting People First

That the Corporate Business Manager arrange for Pam McNeil from the Ministry of Health to attend the next meeting of the Committee to address how recommendations from the

Putting People First” report are to be implemented.

Queen’s Birthday Honours

That a letter of congratulations be sent to Minnie Baragwaneth on the conferment of a QSO.

Appointed Member Vacancy

That the Corporate Business Manager follows the prescribed process for requesting Maori representation on the Committee and proceed with the advertising required for the remaining vacant position.

Terms of Reference

That a review of the Terms of Reference be undertaken to ensure a more positive reference is included to the New Zealand Disability Strategy and other relevant strategies.

9.2 DSAC feedback to CPAC

There was none.

10 General Business

“Putting People First”.

Jan Moss advised that the Ministry have stated that they will be instituting all the recommendations in the 2013 report. This Committees role should be one of a watchdog to ensure that these recommendations are put into effect. Pam McNeil has been newly appointed to the Ministry to oversee this area and as the first step in monitoring progress she should be invited to attend a meeting to inform members of what is intended.

Queen’s Birthday Honours

That a letter of congratulations be sent to Minnie Baragwaneth on the conferment of a QSO.

The meeting closed at 3.30pm.

Next Meeting

The next ordinary scheduled meeting will be held:
1:00pm, Wednesday, 27 August 2014
Training Room, CCS Disability Action, 14 Erson Avenue, Royal Oak, Auckland

Signed as a true and correct record of the Disability Support Advisory Committee meeting held on Wednesday, 4 June 2014

_____ Chair _____ Date

Action Points from Previous DiSAC meetings

As at Wednesday 4 June 2014

Meeting and Item	Detail	Designated to	Action by
Carried forward	The Secretary was to follow up with Colleen Brown on organising a meeting with the Auckland Council Disability Group.	Sandra Coney	Deferred until Committee carries full membership
Item 6.2 12 March	That the WDHB Patient Experience Manager be invited to the August meeting to provide an overview of his or her role and goals in the short to medium term.	Debbie Holdsworth	See item 6.2 on this agenda
Item 6.2 12 March	That a presentation be provided to a future meeting on what the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) contains and how New Zealand is meeting its obligations under the convention.	Samantha Dalwood (Linda Harun)	See item 6.1 on this agenda
4 June 2014 Item 7.2	Shuttle service between Waitakere and North Shore Hospitals That information be provided via email to committee members as to how the new shuttle service between Waitakere and North Shore Hospitals operates.	Debbie Holdsworth	Completed
4 June 2014 Item 8.1	Severe Autism and/or Cognitive Impairment. The ADHB Accessibility Report Update was accepted with a request for a further update on; Autism related facilities – a verbal update to provide information on what has been done to accommodate those with severe autism and/or cognitive impairment.	Sue Waters	Verbal report to be given
4 June 2014 Item 10	Putting People First That the Corporate Business Manager arrange for Pam McNeil from the Ministry of Health to attend the next meeting of the Committee to address how recommendations from the "Putting People First" report are to be implemented	Marlene Skelton/ Debbie Holdsworth	November 2014
4 June 2014 Item 10	Queen's Birthday Honours That a letter of congratulations be sent to Minnie Baragwaneth on the conferment of a QSO.	Marlene Skelton	Completed
4 June 2014 Item 5	Appointed Member Vacancy That the Corporate Business Manager follows the prescribed process for requesting Maori representation on the Committee and proceed with	Marlene Skelton (with Lester Levy who is	August 2014

	the advertising required for the remaining vacant position.	currently discussing appointment process with Naida Glavish)	
4 June 2014 Item 5	Terms of Reference That a review of the Terms of Reference be undertaken to ensure a more positive reference is included to the New Zealand Disability Strategy and other relevant strategies.	Marlene Skelton/ Debbie Holdsworth	November 2014

HEALTH OF OLDER PEOPLE QUARTERLY REPORT ON ACTIVITIES IN AUCKLAND & WAITEMATA DHBS

Recommendation:

That the Disability Support Advisory Committee receives the Health of Older People quarterly report.

Prepared by: Kate Sladden (Funding and Development Manager Health of Older People), Katrina Lenzie-Smith (Programme Manager Health of Older People)

Endorsed by: Dr Debbie Holdsworth (Director Funding, Waitemata and Auckland DHBS)

7.1

Glossary

ARRC	-	Age Related Residential Care
DHB	-	District Health Board
DSS	-	Disability Support Services
FLS	-	Fracture Liaison service
HBSS	-	Home Based Support Services
HCSS	-	Home and Community Support Services
LTCF	-	Long term Care Facility
LTS-CHC	-	Long Term Support for Chronic Health Conditions
MoH	-	Ministry of health
PG	-	Psychogeriatric
RACIP	-	Residential Aged Care Integration Programme

1. Purpose

The purpose of this report is to provide an update to DISAC on the progress and activities occurring across Auckland and Waitemata DHBS for Health Older People. The report includes material common to both DHBS and where appropriate material specific to an individual DHB.

2. Background

Health of Older People (HOP) services are directed by the Minister of Health, the 2014/15 Northern Region Health Plan, Waitemata and Auckland DHB Annual Plans and the Māori Health Plan. We have finalised our 2014/15 Annual Plan and will continue to work with community providers and primary care to deliver integrated services for older people to support safe and independent living at home. There is a focus on avoiding hospital admissions and ensuring appropriate provision of care after a hospital discharge. Following the development process, we now need to implement our dementia care pathways. We will also support age residential care in adopting interRAI Long Term Care Facility (LTCF) Assessment as their primary assessment tool.

3. The Northern Region Health Plan (NRHP)

Major achievements for the Health of Older People Clinical Network over the last quarter were the Ministry of Health approval of 2014/15 Health of Older People Northern Regional Plan, endorsement of the Terms of Reference (from lead CMO – Health of Older People), addition of further falls initiatives and more traction on dementia strategies.

There are now five regional subprojects relating to falls within First Do No Harm, Health of Older People and the Age Related Residential Care (ARRC) sector. These are:

- aiming for a 20% reduction target for major falls and pressure injuries in ARRC
- the national falls campaign
- the national hip fracture registry
- DHB Fracture Liaison Services
- St John's Falls Referral Project

The Hip Fracture Registry and St John's project are likely to be piloted in the Northern Region. There has also been a slight increase in ARRC providers submitting falls data and we are hopeful that strategies to increase participation are working. For the last quarter 30% of ARRC providers met the criteria that constituted implementation of a 'falls reduction programme'.

The 40% target for long term Home Based Support Services (HBSS) clients receiving an interRAI assessment within 12 months has been exceeded and is sitting at 55% for the quarter ended 31 March 2014. DHBs have made significant and steady progress throughout the year to achieve this pleasing result.

The Northern Region dementia projects are reported in section 5.

4. Home Based Support Services (HBSS)

4.1 Auckland DHB

As previously reported the ADHB HBSS model had an increase in the proportion of clients classified as 'complex' from 27% in January 2013 to 37% in January 2014. There was no convincing reason for the shift in complexity of the client population to the extent that it occurred, over such a short time period and drivers of the shift are being investigated. The increase in the proportion of complex clients had funding implications. Therefore, in order to remain in budget for 2013/14 a bulk funding arrangement was agreed with providers and used from 1 January 2014 to 30 June 2014.

The cost model has been realigned for 2014/15 by the University of Auckland Business School, who developed the original cost model, to reflect changes in the client mix. However, within the 2014/15 HBSS Agreement there is provision for the case mix cost model to be recalculated in November 2014 for any material changes in the client acuity mix and the average hours per acuity category. Although, all parties to the Agreement acknowledged that

total HBSS funding payable by ADHB to all contracted providers is capped at a set budgetary amount.

The four HBSS providers submitted reports for the final six months of the MoH Complaints Categorisation Pilot. ADHB is one of three DHBs participating in this pilot to develop standardised approaches to complaints categorisation and reporting. The overall objective is to ensure that older people receiving HBSS are able to share concerns and that the pilot tests assumptions about the level of detail required for DHBs to identify potential risks for further follow up.

The previous five year Agreement with the HBSS providers expired on the 30 June 2014. The Audit and Finance Committee recommended to the Board that the contract was extended for one year to 30 June 2015 and that the option of having a joint procurement process with Waitemata DHB was investigated. A joint planning process between ADHB and Waitemata DHB is now underway for HBSS.

4.2 Waitemata DHB

Waitemata DHB is focused on ensuring all HBSS patients have a current needs assessment and accordingly are allocated the appropriate package of care.

All individuals on the wait list (the wait list was people screened as having low needs) have now been needs assessed; 57% of these people did not require allocation of HBSS. The reasons for this included the person had: recovered and had no current need; been admitted to hospital; wanted to retain their private arrangements; and moved out of the DHB. The results have prompted the DHB to review how it manages its needs assessment and re-assessment processes.

With completion of the wait list needs assessments the focus is now on updating the overdue re-assessments of current HBSS patients.

5. Dementia Care Pathway

5.1 Northern Region

Progress on regional dementia projects:

- The Northern Region Cognitive Impairment Pathway has been updated and agreed by all four DHBs –the static version is being converted into HealthPoint. The Portfolio Manager-Regional Work Programme (Pathways) has fed back that this pathway is very good with respect to content and process.
- A dementia forum aimed at primary care (200 places available) is being arranged for 1 September 2014. We have been fortunate to secure Professor Henry Brodaty as the keynote speaker. He is an internationally recognised authority on ageing and dementia with an interest in primary care, based in Sydney.
- We continue to participate in a national Ministry of Health project to develop education resources for people with dementia and caregivers. Feedback is currently being sought by the Australasian Colleges of Geriatricians and Psychiatrists on the new Fact Sheets.

- A Driving and Dementia Guide (Appendix 1) has been developed for Primary and Secondary Care use and is published on a number of websites e.g. HealthPoint, National Dementia Cooperative and DHB intranets. Feedback has been positive.
- Implementation of the recommendations arising from the Psycho-Geriatric (PG) Bed Review is progressing. A draft regional protocol for the admission, review and discharge of a PG resident is currently being tested by the DHBs and ARRC providers. Funding options for clients in the regional Mental Health Unit for Older People (at Counties Manukau DHB) have been sourced from other regions and are being evaluated for adoption in the Northern Region.

5.2 Auckland DHB

The following four work streams for the Dementia Care Pathway have provided input into the development work undertaken over the last year:

1. Carer Workstream (support for carers)
2. Integration Workstream (integration between services and agencies, diagnostic processes)
3. Support Suite Workstream (support services e.g. respite care, day programmes, home based support)
4. Foundation Workstream (workforce competency and understanding roles and accountabilities).

Progress over the last quarter:

- A carer assessment form has been finalised and development of a project plan for training and implementation is underway.
- A key issue for carers and people with dementia is around knowing who to contact when things go wrong and knowing who is responsible for coordinating their care. The Foundation Workstream has been clarifying and documenting the roles of all members of the care team and a mechanism for identifying which service will take the lead role and therefore be responsible for overall care coordination.
- The Shared Care Record Pilot continues. The Shared Care platform is not accessible to all community providers, which may have some short term impacts. The nature and scale of the issues are being investigated. A dementia assessment template has been developed for the Shared Care Record and is currently being tested by clinicians via the test environment with plans to go on to the production site once approved. One training session on the shared care record has been held with further sessions booked.
- Competency requirements for staff working in dementia care have been developed along with a training stocktake and a gap analysis of training needs.
- An Auckland Dementia Network Service Directory has been compiled and is currently being reviewed and refined.

5.2 Waitemata DHB

The Waitemata DHB Cognitive Impairment Clinical Pathway has completed its nine month Pilot; the last day was 31 July 2014.

The full complement of 12 GPs from six practices and their 20 Practice Nurses enrolled, with their informed consent, 60 patients and their key next-of-kin (carers) in this Pilot.

The secondary care clinicians and pilot General Practitioners (GPs) and their Practice Nurses participated in four action research meetings to discuss and amend the Cognitive Impairment Clinical Pathway. The discussion focused on *'what was working / what was not working / and agreeing the changes to be made'*. The June action research meeting endorsed the pathway changes made at the previous meeting as the recommended pathway to rollout to the 300 GPs across Waitemata DHB.

The evaluation by the University of Auckland, Department of Geriatric Medicine is underway. The patients and the carers were all interviewed soon after diagnosis and again 6 months after diagnosis. The interviews use validated tools to evaluate depression, anxiety, quality of life and carer stress. The participant GPs, Practice Nurses, Alzheimer's Auckland key worker, and participant secondary care clinicians are all being interviewed for the evaluation. The DHB will receive the final evaluation report by 31 January 2015. The results and recommended way forward will be presented for Board approval during February March 2015.

The Project methodology utilised for this Project has resulted in a high level of commitment from all participant health professionals. Anecdotal feedback from the patients and carers suggests satisfaction with the care, education and support they have received; the definitive feedback will be in the evaluation report.

There will be nothing new to report from this Project until after receipt of the evaluation report in early 2015.

6. Aged Related Residential Care

6.1 Auckland DHB

All ADHB aged residential care facilities are engaged in interRAI training as follows:

- 19 fully competent (required number of nurses trained)
- 17 competent (at least one nurse trained)
- 5 in training
- 1 scheduled for training
- 30 engaged (signed an engagement agreement with MoH)

The ARRC cluster group model continues to make progress. There is a bimonthly Steering Group meeting with the cluster groups meeting in the alternate months. The focus has been on achieving the First Do No Harm targets to reduce pressure injuries and falls by 20%. However, a range of other initiatives have also been implemented through this model and are listed below.

- The Quality Care for Older People website (www.qualitycare4olderpeople.org.nz) providing information on better assessment and care has been completed. Additionally, the website provides a data collection function that enables facilities to submit falls and pressure injury data, which can also be used for benchmarking between facilities.

- An Early Warning System for residential care is being trialed. The concept behind this is to detect changes in a resident's health early by detecting small changes in status. This means that treatment can begin earlier and can potentially avoid hospital admissions.
- ADHB introduced non-slip socks to help prevent falls and through negotiation with the preferred supplier, residential care facilities can purchase these socks at the ADHB negotiated prices.
- Initiated roll out of an Incident Management System, which enables facilities to understand common causes of their incidents and then take proactive steps to address these issues. Smaller facilities don't have the resources to purchase a system and this is provided free.
- In facility IV service has been trialed and implemented. This involves the service provider visiting the facility to deliver IV antibiotics rather than an individual being sent to the hospital for treatment. It has only limited success as the providers can't offer a 24 hour service and generally 6 or 8 hour IVs are required. The possibility of expanding the service is being investigated.

The specialist team had 280 consultations with aged residential care over this quarter. Key reasons for these consults included: wound care, complex residents, complex discharges from Auckland City Hospital, care planning guidance, advice on falls and pressure injuries, behaviours of concern, change in level of care, interRAI, support for facility (manager/clinical manager), meeting with families (if complaint or facility needing support).

A study day held for aged residential care registered and enrolled nurses had 125 attendees from 43 facilities. Topics covered were: catheter management, recurrent UTIs and constipation in older adults, palliative care case study, managing residents with COPD and heart failure management.

6.2 Waitemata DHB

All Waitemata DHB ARRC facilities are now engaged with interRAI training as follows:

- 12 fully competent (required number of nurses trained)
- 21 competent (at least one nurse trained)
- 13 in training
- 13 scheduled for training.

The 60 ARRC facilities continue meeting bi-monthly as part of the Residential Aged Care Integration Programme (RACIP).

RACIP Projects

- Dementia Decision-making Journey is a resource for family members of people with advanced and end-stage dementia living in residential care. The resource supports families to understand end stage dementia, advance care plans and appropriate and inappropriate interventions. The booklet (Appendix 2) is at the printers and a launch will be organised for the near future. An electronic version will soon be freely downloadable from the RACIP website www.wdwb-agedcare.co.nz.
- Development of two resources: one for end stage lung disease and one for end stage heart disease. These will be similar in principle to the dementia booklet. The RACIP work group is preparing the content.

- Project Toru - the partnership between Seadrome residential care facility, Kelston Girls College and Waitemata DHB, is on-going. Early outcomes include increased levels of communication from the Kaumatua and also between the groups.
- The quarterly off site education topic was Infection Prevention and Control; 252 registered nurses and health care assistants attended.
- Onsite education topics are offered bimonthly and ARRC facilities can choose to have an alternative or an additional topic according to need. The focus during April and May was urinary tract infection assessment and intervention for registered nurses. An additional topic was wound care by the Wound Care Nurse Specialists; 613 staff in ARRC (mainly registered nurses) received the education.
- Cluster groups were formed in response to the targets set by First Do No Harm to reduce pressure injuries and falls by 20%. We have four cluster groups that represent 20 ARRC facilities in the DHB. As a result of this collaboration an incident data collection tool has been developed and made available to other ARRC facilities. This enables staff to recognise patterns and causes of incidents.

6.3 Additional Charges in Aged Related Residential Care Facilities

Last year the public was consulted on whether DHBs should fund premium-only facilities. The outcome of the consultation was that premium only facilities was not supported, however the reality is that such facilities do exist and are increasing, as part of overall sector development. The Minister then asked DHBs, aged residential care providers and consumer groups to come up with pragmatic solutions to premium charging that are, on balance, fair to all parties. Key principles accepted by all parties were:

- The need to ensure that all older people who are assessed as requiring aged residential care will be able to access care, regardless of whether they wish to pay additional charges.
- The need to always have 'local' availability of beds, without an additional charge.
- The principles need to be enduring – that is no detailed schedules which simply enable people to work around the principles. This applies to the provider, the funder and to the older person.

To this end all parties have developed and agreed rules for how subsidised residents will be charged, or not, for premium rooms or additional services. These have been included in the 2014/15 ARRC Agreement. Application of these rules will be closely monitored by ADHB and Waitemata DHB and any issues will be reported to DHB Shared Services.

7. Long-Term Supports for Chronic Health Conditions (LTS-CHC)

For the 2014/15 year LTS-CHC has transitioned from a regional risk share to each DHB managing their own risk and utilisation costs through their respective PBFF. A regional IDF process has been established for the LTS-CHC residential care services.

Due to the transition away from the regional risk share ADHB and Waitemata DHB have been through a process of replicating formerly held regional contracts including an Individualised Funding Contract with Manawanui In Charge (MIC). MIC act as an agency which administers

the fund for the client for a small fee (between 6-8%) but the client themselves are responsible for managing and employing staff to meet their care needs.

The lack of consistent methodology when determining dual funding agreements and the need to reduce dual assessments of clients has been raised at the National LTS-CHC and Disability Support Service (DSS) Resolution Panel as an issue to be considered and addressed. The National Panel has agreed to look at the various LTS-CHC and DSS guidelines to provide better clarity between LTS-CHC and DSS eligibility criteria.

Work is ongoing to develop and implement a model of care for LTS-CHC rehabilitation clients. This will set standards for clients to have equal access to rehab services, corresponding service coordination and planned clinical follow-up and review.

A Request for Quote is being prepared for an ADHB patient at Auckland City Hospital with complex requirements who will transition to residential care. The patient will spend three months at Rehab Plus before transitioning to the community.

8. Fracture Liaison Service

There is a Ministry of Health requirement for all DHBs to establish a Fracture Liaison Service (FLS). This Service provides secondary preventative care, for people presenting at Hospital with fragility fractures, through assessment and treatment of osteoporosis.

8.1 Auckland DHB

A Fracture Liaison Nurse (FLN) was appointed in March 2014. A decision has been taken for the FLN to focus on Fracture Clinic patients initially. Prior to the clinics the FLN screens all patients on the list to identify appropriate candidates to interview about falls prevention and fracture prevention. She is interviewing 6 to 14 patients per week and referring about 5-7 for bone density assessment by DEXA and 2-3 for further falls prevention assessment.

Testing is underway for a method to record all people with fractures over the age of 50 years that attend ED and are either admitted or discharged. We will then be able to identify not only the total demand but also the number that subsequently attend Fracture Clinic.

8.2 Waitemata DHB

The service continues to develop and now includes inpatient assessment with the support of the Ortho/Geriatric team. All patients go through selected laboratory investigations, with a large proportion (aged between 50 and 75 years) requiring DEXA to aid treatment decision. Complex cases, especially those with recurrent or multiple fragility fractures, are arranged to be seen in Endocrine outpatient clinic.

The service is actively working with the quality team to establish methods of embedding FLS in practice and with the Enhanced Recovery after Surgery (ERAS) team to promote FLS.

The Service attained 'Bronze' status from the International Osteoporosis Foundation's Capture the Fracture campaign on the basis of its 2013/14 work – the first of any DHB in NZ.

9. Waitemata DHB Partners in Care Project

In conjunction with the Health Quality and Safety Commission Partners in Care Programme, Waitemata DHB invited 12 Maori elders living in West Auckland and their whanua to an 'In your shoes' session as part of 'older persons healthcare experience: from listening to action'. A summary report of this session and findings are provided in Appendix 3.

10. Action Points - Item 9.1

At the DiSAC meeting on the 28 August 2013 it was recorded in the minutes that *"there were changes to the WINZ Benefit System in July, an update detailing how this is impacting on the ADHB/WDHB population is requested."*

Outlined below are the changes to the benefit system that occurred in July 2013. However, it is not possible to detail the impact of these changes on the ADHB and Waitemata DHB populations as data has not been collected for this purpose. Anecdotally, relevant DHB services appear to have had no significant issues relating to the benefit changes or queries/concerns from patients and the public. The most recent Ministry of Social Development report (released April 2014) titled '2013 Benefit System Performance Report' is for the year ended 30 June 2013 i.e. prior to the changes.

In July 2013, three new benefits replaced most of the previous benefits. These new benefits are:

- Jobseeker support – for people who can usually look or prepare for work. It also includes people who can only work part-time or can't look for work at the moment e.g. because they have a health condition, injury or disability
- Sole Parent Support – for sole parents with dependent children under 14 who can look or prepare for part-time work
- Supported Living Payment – for people who have or care for someone with a health condition, injury or disability that severely limits their ability to work on a long term basis.

Benefits that remain include: Emergency Benefit, Emergency Maintenance allowance, Youth Payment and Youth Parent Payment.

The supported Living payment (SLP) includes two pre July 2013 benefit categories:

- Invalids Benefit
- Domestic Purposes Benefit-Care of Sick and Infirm

The number of recipients of SLP increased by 2% nationally between June 2013 and June 2014. The number of people receiving SLP in June 2014 in the Auckland region was:

- SLP for health condition or disability – 20,589
- SLP for caring – 3,606

Dementia and Driving Safety

A Clinical Guideline



Driving with Dementia Working Group
Auckland, Counties Manukau, Waitemata and Northland DHBs –
Revision - 2014



Citation

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This document is available electronically at www.healthpoint.co.nz; <http://www.healthnavigator.org.nz/>>

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Executive Summary

As health clinicians we are under an obligation to consider the driving safety of our patients and to deal with any risk to themselves or others from unsafe driving, especially in those who suffer from Mild Cognitive Impairment (MCI) or Dementia. Many will have already voluntarily ceased driving when diagnosed but a significant number continue to drive.

This guideline is designed to assist clinicians, in both primary and secondary care settings, in the sometimes fraught decision-making process around those people who have some form of cognitive impairment and are also continuing to drive a motor vehicle. A review of driving risk should be part of the standard assessment of all those with cognitive impairment.

People who have moderate or severe dementia should be told that they must cease driving, and if they refuse to do this, there is an obligation to notify the New Zealand Transport Agency (NZTA) under Section 18 of the Land Transport Act.

Those who have MCI or Mild Dementia are more difficult to assess and many are safe to continue driving, at least in the short-term. Clinical bedside testing is a poor guide to deciding on a person's driving safety, and they should be asked if they will undertake an Occupational Therapist (OT) Driving Assessment through one of the local agencies. These are unfortunately not funded. Following such an assessment, recommendations regarding driving should be communicated with the person, their family and the NZTA, where necessary. Remember that drivers can be approved to continue driving, or clinicians can recommend restricted driving such as only driving close to home and in non-busy daylight hours. However, for some the outcome will be that they must cease driving.

If a person with MCI or Mild Dementia declines an on-road test or cannot afford one, then we need to make the best decision we can based on an extended clinical assessment. This might include a combination of further cognitive testing, consideration of functional capabilities, review of mental and physical health issues, and a focused review of markers indicating that driving safety might be of concern, including inspecting the car. Questionnaires can be administered to both the person and their family. These can be combined with an alternative and cheaper forms of driving assessment, such as the On-Road Safety Test or using an AA driving instructor, but these tests are not as rigorous as the OT driving assessment, nor are they targeted at a potentially impaired group. Nonetheless they may all be helpful in reaching a clinical decision about driving safety. Occasionally neuro-psychological tests may be recommended.

The results of these further investigations should then be reviewed and a clinical decision made about driving safety. Although this testing will not provide the same degree of certainty as the results of an OT Driving Assessment, they will inform us in making the best clinical decision we can about the issue of driving safety.

When the clinical decision is for the person to stop driving or restrict their driving, this should be documented and discussed with the person and their family. If they do not comply with this direction, then we are obligated to notify the NZTA under Section 18. If the person continues to drive in spite of having had their licence revoked, we again must notify the NZTA, as well as confronting them and their family. If a person is assessed as safe to drive, then a suitable review period should be defined.

Remember driving safety is an important part of assessing and managing clients with Dementia. However removal of someone's driving licence has a major impact emotionally and on their lives.

Dementia and Driving

Part 1: Guidelines for using the Driving Assessment Protocol

Introduction:

This guideline is designed to assist all clinical staff in assessing the driving safety of a person who wishes to continue driving in the context of having cognitive impairment¹. It is important to stress that these decisions can be made either in primary or secondary care health services, or after consultation between these sectors. The guidelines reference the step-by-step flow diagram (*Appendix 1*). The guideline is aimed at those clients under our care who have cognitive impairment² or dementia³; however there are numbers of other common medical reasons⁴ which may be a reason for people needing to stop driving.^{5 6} (A list of some of the more common ones we encounter is provided in *Appendix 2*.)

Many people with Mild Cognitive Impairment (MCI) or dementia have already voluntarily limited or ceased driving⁷. However some have not; and it becomes our clinical and legal responsibility to make reasonable efforts to determine that those who are continuing to drive are safe to do so⁸.

A person should be warned in advance that driving safety is one factor that we have to consider in all cases where there are memory problems⁹. This may be done by highlighting the issue in the information package or pamphlet about the service, sent out prior to the person's initial assessment. Otherwise it needs to be explained directly to all those who are being assessed for problems with their memory¹⁰. It also needs to be emphasised both to the person and their families, when necessary, that we have a legal obligation to do this for the sake of both their safety and that of the other drivers on road¹¹.

We should explain to people and their families that there is a clear link between memory impairment, dementia and unsafe driving, and that this is the reason for our concerns and

¹ Carr, D., Duchek, J., Morris, J (2000) Characteristics of Motor Vehicle Crashes of Drivers with Dementia of the Alzheimers type

² Classen, S., Levy, C., McCarthy, D., Mann, W., Lanford, D., Waid Ebbs, K (2009) Traumatic Brain Injury and Driving Assessment: An Evidence Based Literature review

³ Australian and New Zealand Society for Geriatric medicine (2009) Position Statement No 11 – Driving and Dementia

⁴ Molnar, F (2010) Approach to assessing fitness to drive in patients with cardiac and cognitive conditions

⁵ McKenna, P., Bell, V (2007) Fitness to drive following cerebral pathology: The Rockwood Driving Battery as a tool for predicting on-road driving performance

⁶ McKenna, P (1998) Fitness to drive: A neuropsychological perspective

⁷ Man Son Hing, M., Marshall, S., Molnar, F., Wilson, K (2007) Systematic Review of Driving Risk and the Efficacy of Compensatory Strategies in Persons with Dementia

⁸ Beran, R (2005) Personal viewpoint – Analysis and overview of the guidelines for assessing fitness to drive for commercial and private vehicle drivers

⁹ Bieliauskas, L (2005) Neuropsychological assessment of geriatric driving competence

¹⁰ Odenheimer, G (2006) Driver safety in older adults – The Physicians role in assessing driving skills of older patients

¹¹ Molnar, F., Byszewski, A., Rapoport, M., Dalziel, W (2009) Practical Experience Based Approaches to Assessing Fitness to Drive in Dementia

apparent focus on driving safety. This is particularly important for those clients who have a Mild Cognitive Impairment (MCI) or similar, and whose condition may worsen over the years ahead. They should be warned about the prospect of becoming unfit to drive in the future, if this is a real prospect for them. All these discussions should become a normal part of our clinical interaction with patients¹².

We need to be aware that some people may be unsafe to drive in spite of having a reasonable cognitive testing performance¹³. Not all those with impairment have progressive cognitive decline. Some may have specific neuro-cognitive deficits such as visuo-spatial problems¹⁴ following a stroke, or prominent executive dysfunction which leads to impaired anticipation of hazards, a lack of concern for road rules or impulsive decision making. Others may be unsafe to drive because of their mental health or addiction issues. We need to listen to the concerns expressed by family members about a person’s driving.

Six things to remember:	
1.	We cannot make a perfect prediction of driving safety even with OT Driving Assessments. We have to make a reasonable clinical decision “on the balance of probabilities” about driving safety and be consistent in our practice. We cannot “do nothing” because we are not sure – we have to be seen to be making a definitive clinical decision about a person’s safety to drive on the road amongst other drivers.
2.	These are guidelines; we have tried to create a user-friendly framework, but as each case is very different, clinicians need to use their judgement and use the guidelines in a flexible manner.
3.	If clinicians are sufficiently concerned about a person’s driving safety then action should be taken immediately to make sure that the person is not driving.
4.	The most useful assessment of driving safety remains the OT Driving Assessment (including an on-road assessment) and throughout the interaction with a person and their family, we need to be encouraging them to undergo this form of assessment if there is any uncertainty about their driving safety.
5.	That assessing someone as being “not safe to drive” is not the same thing as being able to predict who will have an accident in the next year. Accidents and especially fatalities are rare events, and we have to understand that we cannot predict these in advance. However if someone is not safe to drive then other drivers on the road are safer through our actions.
6.	Lastly, if all those that we refer for an OT Driving Assessment fail that test, then our threshold for referral is too high and there will be unsafe drivers on the road – we need to be comfortable with asking people to have the test, even though some will pass.

¹² McKenna, P., Jefferies, L., Dobson, A., Frude, N (2004) The use of cognitive battery to predict who will fail an on – road driving test

¹³ Dawson, J., Anderson, S., Uc, E., Dastry, E., Rizzo, M (2009) Predictors of driving safety in early Alzheimer Disease

¹⁴ Ball, K., Owsley, C., Sloane, M., Roenker, D., Bruni, J (1993) Visual Attention Problems as a Predictor of Vehicle Crashes in Older Adults

Why invest our energy in doing extra testing on people?

The question is asked as to why we should use our own resources to get a better understanding of a person's driving safety. Why not send letters to the NZTA¹⁵ on the entire group of those with mild cognitive impairment or mild dementia, thereby forcing the individual to have the testing if they wish to recover their licence? The answer is that, although we have a duty to protect the person and other road users, we also have a duty not to do harm. This means we cannot put them through the trauma, cost and inconvenience of having their licences revoked without due cause¹⁶. We are also required to have a reasonable level of concern if we are to break our usual duty of confidentiality to the person. Therefore we need to have sound clinical reasons for making such a recommendation to NZTA, and that will not be the case unless we have completed a comprehensive assessment, including a review of driving safety¹⁷. However we have made an effort in this guideline to limit excessive testing which will not offer us any more certainty about a person's driving safety. We have also tried to rely as far as possible on that information which is completed as part of a normal comprehensive assessment, with a few additions when required.

Those patients who refuse to cooperate

Some people do refuse to cooperate with our assessment of their driving safety. In these cases, where there are sufficient grounds for concern (whether from history, cognitive testing to date or reports from family members), we can legitimately notify the NZTA under Section 18, if all other avenues of seeking cooperation with the person have failed. It is not uncommon for the therapeutic relationship between the person and their clinician to breakdown in the course of this process. People are often outraged at the suggestion that they might be unsafe to drive any longer, and sometimes "sack" their clinicians.

Initial assessment or review:

When a person is assessed as having problems with memory or dementia, or has received this diagnosis in another service, then there should be a thorough review of their condition. A comprehensive assessment should include questions about their mental and physical health; functional status, medications and a standardised cognitive test should be administered such as the MMSE, MOCA, RUDAS, ACE-III or equivalent. (*See Box below.*) Appropriate blood tests and scanning should be requested. Collateral history should be sought from family or carers. At the conclusion of the assessment, which may take place over more than one visit, and may require phone calls to family members for information, clinicians should be able to make the diagnosis and make an assessment of the likely dementia stage or severity (see below), and hopefully will have some idea about the most likely aetiology of the dementia. (It is hoped that this clinical decision-making process will be supported in the near future throughout Primary Care, with the introduction of some form of computerised Cognitive Impairment Assessment Tool and Pathway).

As part of the assessment, there needs to be a specific enquiry about the person's driving and the safety of this. This will involve asking the person and their family about their driving

¹⁵ Ministry of Transport (2008) Risk on the road; Ongoing New Zealand Household Travel Survey 2003-2007

¹⁶ Ott, B., Daiello, L (2010) How does dementia affect driving in older patients?

¹⁷ Ott, B., Anthony, D., Papandonatos, G., D'Abreau, A., Burock, J., Curtin, A., Wu, C., Morris, J (2005) Clinician Assessment of the Driving Competence of Patients with Dementia

history and the safety of the person's driving, looking at the person's car and finding out about the person's typical use of their car. There should be some specific enquiry about accidents or near-misses, and episodes of getting lost when out driving or walking. There should also be some attempt to ascertain the likely consequences of a person losing their licence and the impact on them and their family¹⁸.

Remember that this guideline deals specifically with those suffering from memory problems or dementia. Most of those under consideration will be of an age where other medical problems are an issue. For those that already have limitations in other respects such as visual impairment or mobility restrictions, having cognitive problems may start to cause a person's driving to become unsafe earlier than it would have otherwise. The disabilities should be viewed as additive and likely to compound each other. Hence the clinician should be even more cautious about assuming that someone is driving safely.

Cognitive Testing: Notes

The following tests have been included in the discussions in this document, as they are the commonly used tests clinically. The tests described are manageable bedside tests that can be used in both Primary and Secondary care. They each have their strengths and weaknesses, and none is specifically recommended. (However it needs to be noted that the MMSE is now under copyright and theoretically clinical users could be charged for using this as their preferred test.) Nonetheless, it is the test most clinicians are familiar with and is widely used still. It is recommended that clinicians familiarise themselves with the alternative tests (and move away from using the MMSE).

MMSE: Mini-Mental State Examination (scored out of 30)

MOCA: Montreal Cognitive Assessment (scored out of 30)

RUDAS: Rowland Universal Dementia Assessment Scale (scored out of 30)

ACE-III: Addenbrooke's Cognitive Examination – version 3. (Scored out of 100)

If a person requires further or more comprehensive testing, then a huge variety of Neuro-Psychological tests are available through Secondary Care Mental Health or Health of Older People Services, or through private Clinical Psychologists. Most tests used are pen-and-paper-type tests; others may employ computerised testing. This guideline mentions a few such tests such as the **Mazes Test, Trails Test A and B**: these are short tests which can be employed by many clinicians.

¹⁸ Classen, S., Horgas, A., Awadzi, K., Messinger-Rapport, B., Sheckman, O., Joo, Y (2008) Clinical Predictors of Older Driver Performance on a Standardised Road Test

Dementia Staging and the Clinical Dementia Rating Scale

The following table (*Table 1*) is designed as the start of a clinical assessment of a person's likely driving safety. The staging shown is based upon the categories used in the Clinical Dementia Rating scale¹⁹ and other similar scales, and is designed to be a descriptive and realistic picture of the severity of a person's cognitive and functional impairment. Indicative scores on typical cognitive testing scales are given, but much of the staging information comes from collateral history about the person's level of function (in personal cares, household tasks and outside responsibilities), usually obtained from a person's family or carers. Staging Dementia can be challenging, especially in those clients who are still able to provide a convincing affirmation in clinic of having full functional capabilities, but who are often found to be more impaired when a collateral history is obtained²⁰.

The CDR structure was chosen, over alternatives such as the FAST (Functional Assessment Scale²¹) and the GDS (Global Assessment Scale of Deterioration²²), as it is well validated and commonly used in research, and has the advantage of a relatively simple structure. Also, some other Driving safety guidelines have based their recommendations upon this structure, such as those from the American Academy of Neurology.

Accordingly, once a person is identified as having MCI or Dementia, the clinician should attempt to allocate them to one of the CDR stages of Dementia severity. This is so that decisions about driving safety may be commenced, but is also a useful way of ascertaining or estimating a person's need for other interventions such as packages of care or medications such as Donepezil.

It is important to note that we are not using the CDR in a research or rigorous manner; instead we are using the structure of staging of dementia, as defined in that rating scale. The proper CDR uses a formal semi-structured interview (which takes around 45 minutes to complete). It has to be emphasised that we are not suggesting that clinicians complete this process. Rather, it is recommended that clinicians use the results of the person's cognitive testing and information about their level of functional capacity from the clinical and collateral history, to estimate a person's dementia severity or its stage, using a staging structure as defined by the CDR. This is less rigorous than using the formal test, but most of us have neither training nor permission to use the formal test. Nor the time to administer it to our patients. Also, for some people we do not have the luxury of collateral information being available, and therefore our staging decision will always be limited in its accuracy.

¹⁹ Morris, J. (1993) The Clinical Dementia Rating (CDR): Current vision and scoring rules

²⁰ Whelihan, W., Di Carlo, M., Paul R (2004) The relationship of neuropsychological functioning to driving competence in older persons with early cognitive decline

²¹ Sclan, S., Reisberg, B (1992) Functional Assessment Staging (FAST) in Alzheimers disease: reliability, validity and ordinality

²² Reisberg, B., Ferris, S., de Leon, M., Crook T (1982) The global deterioration scale for assessment of primary degenerative dementia

Table 1. Dementia Staging

Dementia Stage	Typical Cognitive Scores*	Cognitive and Functional levels
No Dementia	MMSE:> 27/30 ACE-III:> 90/100 MOCA :> 26/30 RUDAS:>26/30	No cognitive impairment: Normal memory and cognition Independent function Competent in home, work and hobbies
Mild Cognitive Impairment	MMSE: 24 – 27/30 ACE-III: 80-90/100 MOCA:18 – 26/30 RUDAS: 23-26/30	A mild but noticeable decline in cognition: Mild forgetfulness Mild disorientation Mild impairment in problem solving Generally independent in most activities May struggle with complex tasks
Mild Dementia	MMSE:18-23/30 ACE-III: 65-76/100 MOCA : 11-17/30 RUDAS: 17-22/30	Definite cognitive decline and impairment Moderate memory loss and disorientation Impaired problem solving Mild impairment in household tasks / personal cares Requires prompts or supervision with some tasks Complex tasks and roles no longer possible Social interactions often well preserved
Moderate Dementia	MMSE:10 – 18/30 ACE-III: 35 -64 /100 MOCA : 6 – 10 /30 RUDAS: 10 – 16/30	Significant impairment of cognition/function Marked memory loss Disorientation to time and place Decreasing ability to make judgements Decreasing ability to engage socially Decreasing ability to function independently Needs assistance with personal cares Requires supervision when leaving home May get lost when away from home Limited capacity to complete tasks in home No longer able to participate in usual activities
Severe Dementia	MMSE:<10/30 ACE-III: <35 /100 MOCA : <6 /30 (or not testable) RUDAS: <10/30	Profound impairment of cognition / function Severe memory impairment / disorientation Spoken language limited or lost Incontinence No capacity for making judgements High dependency on others for personal cares Unable to contribute to household chores Often unable to recognise family members Increasing loss of psychomotor skills Frequent behaviour or psychiatric complications

*The cognitive testing scores provided are indicative. The tests included are those commonly employed in New Zealand in both primary and secondary care. The MMSE is well validated and there are also studies completed showing typical scores in the different stages of dementia such as the CDR stages. However, there is still variation between different studies in this regard. (Complicating the use of the MMSE is the fact of its copyright status, and potential for cost to clinicians using this test. Accordingly, many services have already switched to other forms of testing such as the RUDAS, ACE-III and MOCA). In contrast to the MMSE, while the RUDAS, the ACE-III and the MOCA have been validated to define thresholds between normal, MCI and Dementia cases, they have not been studied further to link scores with the different stages of established Dementia. As a result, the staging scores (especially between mild, moderate and severe dementia) given in the table are based more on clinical experience than research studies. All the tests suffer from both ceiling and floor effects to different degrees (i.e. they are not sensitive to mild degrees of impairment and cease to be useful before the end of the illness). The correlation between scores and staging is compounded by factors such as age, language spoken, education, baseline intellectual functioning, specific cognitive issues such as dysphasia, and according to the aetiology of dementia. In particular, those with Fronto-temporal dementia may have relatively well-preserved scores on tests such as the MMSE in spite of quite high levels of impairment and behavioural disturbance.

(A recent study by Gary Cheung et al (personal communication: not yet in print) suggested that the cut-off scores for ACE-III and MOCA, dividing those with mild dementia from controls was lower in New Zealand clinic populations, than in the usual validation studies. They found that the validated RUDAS scores was similar to the results in the clinic population. Hence the scores in the above table may yet be amended over the next year, and should be further seen as “indicative.”)

Other services may be employing other cognitive tests not listed in this table, such as the SLUMS or informant questionnaires such as the IQCODE. However, it is important to recognise that, regardless of the test used, much of the useful information that allows clinicians to determine CDR-type staging comes from the combination of a full clinical assessment of the person, and from a reliable source of collateral information about the person.

Dementia Staging and Driving Safety

The purpose of making an assessment of the person’s dementia severity or stage, is that clinical decision-making about driving safety follows on from this. The following Table (*Table 2*) is a summary of clinical recommendations about driving safety according to Dementia Stage/Severity (and by implication, shows the clinical advice re continuation, restriction or cessation of driving).

Table 2. Dementia Stage and Driving Recommendations

Dementia Stage	Driving Recommendation
No Dementia	<p>May continue to drive Check for Other Medical Conditions</p>
Mild Cognitive Impairment	<p>Most people Safe to Drive Consider OT driving assessment, Restricting or stopping driving if:</p> <ul style="list-style-type: none"> • Family concerns • Recent accidents or near-misses • Functional impairment in some complex tasks • Behavioural disinhibition – “risk-taking” • (Notify NZTA)
Mild Dementia	<p>Driving Safety is Uncertain: Some people safe, others unsafe to drive Safety not predicted by Cognitive testing / Dementia Stage</p> <p>Person needs further investigation / review:</p> <ul style="list-style-type: none"> • OT Driving Assessment ** (Preferred and Recommended) • Further Collateral History • Clarification of Function level in other areas • Driving Questionnaires • Further cognitive testing • Alternative on-road driving assessment • Second Opinion <p>Clinical Decision needs to be made!</p> <ul style="list-style-type: none"> • Continue Driving – Review Date, • Restricted Driving – Review Date, or • Stop Driving Immediately • Notify NZTA
Moderate Dementia	<p>Must Stop Driving! Notify NZTA</p>
Severe Dementia	<p>Must Stop Driving! Notify NZTA</p>

7.1

For those without Dementia and those with Moderate or Severe Dementia, the recommendations are relatively clear and uncontested. Those people not suffering from MCI or dementia may continue to drive as long as other medical conditions are no obstacle. Those with Moderate or Severe Dementia must cease driving, as they will be no longer safe to do so, and will certainly have some of the impairments described in the Medical Aspects of Fitness to Drive. These clients should be asked to stop driving immediately, and the NZTA should be notified (A letter template to the NZTA is included below in *Appendix 3*.) There is nothing to be gained from referring these groups for an OT Driving Assessment, as they are unlikely to pass and should not be put through the trouble and expense. There will be a few individuals who will demand the right to such an assessment, and a clinical decision regarding the usefulness of this will need to be taken, including whether the medical practitioner would still consider the person unfit to drive even if they were to pass the assessment.

For those with Mild Cognitive Impairment, most will be safe to drive for the immediate future, but should be specifically reviewed by a clinician in six months or one year. However, it is worthwhile checking with families or carers to see if they have any concerns about the person's driving safety. Specific questions should be asked about recent accidents, behaviour when driving, near-misses, getting lost and early impairment in other areas of complex task completion (e.g. cooking or managing finances). If there are concerns, the person may be asked to restrict their driving to non-rush hour driving times and to not drive outside a radius of around 5km from their home. If restrictions are recommended, then the NZTA should be notified so that the person's driving licence can be amended accordingly (*Appendix 3*). Rarely a person will be advised that they should cease driving, often in the context of compounding impairment from physical illness or behavioural disinhibition making their driving unsafe. For those who are assessed as safe to drive, it is worth telling the person and their family that MCI does in some cases progress to dementia, and that driving safety will need to be reviewed at that point. (However they do need to be reassured that for many people, MCI does not show any such progression.) If the clinician is uncertain about the person's driving safety or feels unable to make a decision, then further investigations may be completed, as per the group with Mild Dementia (see below).

Those with Mild Dementia (those with mild memory and cognitive impairment and a clear functional loss) are unfortunate in that their driving safety is uncertain and cannot be inferred from their cognitive test results, diagnosis and clinical stage. Studies have shown that some of these individuals drive as well as their non-demented age-peers. However, others are definitely unsafe to drive, will fail an on-road driving assessment and are at risk of causing a potentially fatal road accident. The difficulty is that these two groups cannot be distinguished by looking solely at their cognitive testing scores and/or level of functional impairment. On occasion, clinicians may feel confident that a person is not safe to drive, especially if they are impaired in a number of other functional areas, or there is a clear history of concern from family already expressed. If this is the case, then the clinician may proceed with making their recommendation about driving, on the basis of that clinical view.

However, most often, the driving safety of a person with Mild Dementia will be uncertain, and further review and investigation is required before a clinical decision can be made. Having said which, the clinician must make a definite decision about driving safety in someone who has Mild Dementia, such that this can be documented and communicated with the person and their family. The situation and decision about a person's driving cannot be "parked" and events allowed to evolve.

The following section describes some of the further investigations that may be undertaken in either primary or secondary care settings (or a combination of both), to further inform the clinical decision making about a person's driving safety.

Driving Safety in those with Mild Dementia: Further Investigations

This section describes some of the options available to clinicians who are trying to ascertain the driving safety of someone with Mild Dementia (if this is not already apparent). The suggestions made below are not prescriptive, and are often not clinically possible as described. For example, many clinicians do not have access to easy sources of collateral information about a person's driving (or the person may have a family with a vested interest in the retention of their driving licence). In other cases, what is possible in the way of further testing may be limited by the person's ability or willingness to pay, availability of testing or the person's absolute refusal to cooperate. In such cases, clinicians should gain what information they can and make the best decision possible in the circumstances.

The further investigations have been divided into two different stages:

First Stage: Seeking Readily-available Information.

Further clinical review should be undertaken to gather some of the following information or review associated issues. This may be completed by the assessing clinician or another person in the service.

- Standard cognitive testing may be checked, repeated or extended. For example, if testing was done in hospital in the context of delirium, then the tests should be repeated. If the diagnosis was made on the basis of an MMSE score, then perhaps either MOCA or ACE-III testing could be completed.
- Collateral history should be sought from families regarding the dementia severity, and overall functional capacity, observed driving behaviour, traffic violations, accidents and near misses. Asking if family are comfortable travelling as passengers (or allow grandchildren to be passengers) is often a telling indication of concern. The Driving Questionnaires can be administered (see *Appendices 4 & 5*)
- Other medical problems, physical disabilities or medication risks can be reviewed with the person.
- Mental Health factors, medication and use of alcohol or other substances should be considered.
- There should be some discussion about car usage and availability of alternative forms of transport or other drivers in the household. The practical impact of losing one's driving licence needs to be explored. The person should be asked if they have already restricted their driving voluntarily and why.
- If the person's car is available (e.g. parked outside), it should be inspected for signs of damage. (It is not uncommon to find that the car is significantly damaged.)

At the completion of the First Stage, the clinician may feel that there is now sufficient extra information to allow them (or their team) to make a decision about the person's driving safety. If this is the case, then the person should have this discussed with them, and if their driving is to be restricted or stopped, then the NZTA should be notified accordingly. If a clinical decision cannot be made comfortably, then specific review required to investigate the likely safety of the person's driving, as described under the Second Stage below.

Second Stage: Specific Driving-Related Investigations

In this stage, clinicians need to seek information that is more specific to actual Driving Safety, and which will allow a definitive decision to be made regarding the continuation or restriction of driving. The best information that can be sought is for the person to undergo an Occupational Therapy (OT) Driving Assessment by one of the specialised services providing for this. An OT Driving Assessment normally includes both off-road testing and, if recommended, an on-road driving test which is standardised and rigorous. These tests are not funded in most parts of New Zealand, and the total cost of both parts of the assessment can be in excess of \$500. This cost is frequently an impediment to clients going onto having these tests completed.

In making a referral to an OT Driving Assessment agency, relevant clinical information should be included such as history and cognitive test results, highlighting those most pertinent to driving. (A letter template for the Auckland region is included in *Appendix 6*.)

It needs to be emphasised that although OT Driving Assessments are regarded as the most reliable indicator of driving safety, this form of testing is not without its critics. The different companies offering this service use different tests and scoring protocols, and the equivalence of their testing is therefore uncertain. Furthermore, the companies operate in different ways and the level of cooperation with the referring clinician can be variable. Lastly, the testing does still not test how a person is likely to react in an emergency situation. Therefore, while the results of OT assessments should be viewed as being the strongest available evidence about a person's driving ability, they should not necessarily be viewed as the last word on the matter (see Cochrane Review of driving and dementia)²³.

Where people are unwilling or unable to undertake an OT Driving Assessment, clinicians need to turn to alternative but less informative sources of information about the person's driving skills. This includes other forms of On-Road driving assessment, further collateral information about driving, and / or more extensive cognitive testing. It is also possible to investigate the person's performance in other activities of daily living: if they have obvious impairments in complex tasks such as cooking, managing their finances, paying bills, and shopping, these impairments may provide an indication of their likely performance in driving. It is also possible to obtain a second opinion, possibly from a colleague or from another service such as a specialised memory or dementia service. None of these options will provide a definitive answer to the question of driving safety, but may be useful in informing the clinical decision in this regard. The alternatives are summarised in *Table 3* below.

All of the proposed alternatives have their limitations. The problem with other forms of On-Road driving assessment is that the testing is not as rigorous and the testers do not have the clinical insights into the conditions of those being tested. Further collateral information can be useful, for example filling in the Driving Questionnaires (*Appendices 4 & 5*), but literature shows that family members are not totally reliable in assessing the driving safety of a person, and are often conflicted about what response to give the clinician. Many have a vested interest in the person continuing to drive, or believe that if they are present as a "guiding and directing" passenger, then no major accident is likely. Further cognitive testing can be useful in identifying cognitive deficits, but these forms of testing, even those that are

²³ Martin, A., Marottoli, R., O'Neill, D (2009) Driving assessment for maintaining mobility and safety in drivers with dementia (Review)

completed in driving simulators, do not reliably separate those clients who will not pass an OT Driving Assessment from those that will pass²⁴. Other forms of functional impairment can be helpful, but are only suggestive of driving capabilities. Lastly, a second opinion from a colleague or someone experienced in dealing with this situation can be helpful, but their clinic-based assessments are still likely to be less accurate than the OT Driving Assessment. Nonetheless, if the person will not undergo an OT Driving Assessment, these other sources of information have to be the basis on which a clinician must make their clinical decision (however imperfect that may be) about whether someone with MCI or Mild Dementia should still be driving.

The alternative forms²⁵ of testing can all be employed in making the decision. An on-road driving test with an AA instructor can be requested at the same time as asking a family member to complete a Driving Questionnaire, looking at the person's car, **and** completing Trails tests A and B. A clinical decision can then be made using all that information collected.

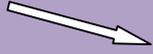
Remember that we are able to recommend three options to people

1. That they can continue to drive for the moment
2. That they can only drive under certain limitations such as time of day and/or in their local area; or
3. That they must cease driving altogether.

²⁴ Brown, L., Stern, R., Cahn-Weiner, D., Rogers, B., Messer, M., Lannon, M., Maxwell, C., Souza, T., White, T., Ott, B (2005) Driving Scenes test of the Neuropsychological Assessment Battery (NAB) and on-road driving performance in aging and very mild dementia

²⁵ Innes, C., Jones, R., Dalrymple-Alford, Hayes, S., Hollobon, S., Severinsen, J., Smith, G., Nichols, A., Anderson, T (2007) Sensory – motor and cognitive tests predict driving ability of persons with brain disorders

Table3: Further Investigation of those with Mild Dementia

Drivers with Mild Dementia: Further Reviews needed	
First Stage: Review / Seek Readily-Available Information	<ul style="list-style-type: none"> ➤ Review / repeat Cognitive Testing ➤ Obtain Collateral History ➤ Review other medical issues / medication ➤ Address MH issues / substance abuse issues ➤ Discuss car usage and restriction ➤ Inspect car where possible
<p>Can a Clinical Decision be Made about Driving Safety?</p> <p>Yes  Discuss with person and family. Notify NZTA as required</p> <p>No  Go to Second Stage (Below)</p>	
Second Stage: Specific Driving-Related Investigations	<p>Preferred option: ** Referral for OT On-Road Driving Assessment</p> <hr/> <p>Alternatives: Other On-road driving assessment</p> <ul style="list-style-type: none"> ➤ On-Road Safety Test ➤ Driving Instructor e.g. AA Driving School <hr/> <p>Alternatives: Further cognitive / functional testing</p> <ul style="list-style-type: none"> ➤ Trails A & B and/or Mazes test ➤ Neuropsychological Testing ➤ Computerised testing in simulator ➤ OT assessment of other functional skills – IADLs <hr/> <p>Alternatives: Further information:</p> <ul style="list-style-type: none"> ➤ Inspection of car ➤ Driving Questionnaires (<i>Appendices 4&5</i>) <hr/> <p>Alternatives: Referral for another opinion:</p> <ul style="list-style-type: none"> ➤ Referral to Secondary Care service ➤ Referral to colleague
<p>Make Definitive Clinical Decision re Driving Discuss with Person and their Family. Notify NZTA where necessary.</p>	

Notes about Referrals for an On-Road Driving Assessments

These notes are included because of the issues that arise when referring someone for an On-Road Driving Assessment, especially where the person is required to pay for that assessment out of their own pocket. Where the person is paying and is clearly the “customer” of the agency performing the testing, it is nonetheless vital clinically for the information obtained through testing to come back to the referrer. This issue applies whether the referral is for an OT Driving Assessment or to another agency such as a driving instructor.

As a result, it is crucial for the referrer to have agreed with the person being tested for there to be communication between the testing agency and the referrer. This must be agreed at the time the referral is made, and permission sought from the person to allow the information to be sent back to the referrer. The clinician needs also to be clear about whether driving should cease until the testing has been completed. A formal referral letter then should be written explaining the situation, confirming that the person has consented to release of the testing results, and asking for an opinion on driving safety (including whether a restricted driving license would be suitable). If a clear opinion has not been made by the testing agency, then the referrer should feel free to contact the tester to discuss the performance in the driving test. (A sample letter template has been included in the *Appendix 6*.)

When the testing has been completed, a follow-up appointment needs to be made so that the results can be discussed and recommendations made about driving. If the person is deemed unfit to drive or is advised to restrict their driving (usually to between 10am and 2pm, and to only drive within 5km of their house), then the NZTA should be notified accordingly. This is to formalize the decision and make sure that the person’s license details held by the NZTA are up-to-date.

When the person has consented to an OT Driving Assessment, then a referral should be made to one of the local agencies providing this. Currently, in the Northern Region, there are a number of alternative agencies providing these tests and the person and their family should be provided with the opportunity to choose. If a person passes the OT Driving Assessment, then the report will be sent back to the referrer. However, when a person fails the test, it is the practice of most OT Driving agencies to notify the NZTA directly. We would prefer that there is a discussion between the referrer and the OT Assessor prior to this step being taken; however this would require a change of protocol in some of the agencies. In contrast, the other testing agencies such as Driving Instructors will not notify the NZTA about fail results.

Some people, having failed one On-Road Driving test may undertake further testing, and may pass that assessment. We are not always aware of this process as referrers. If clinically, our assessment remains that the person is probably unsafe to drive, then we should seek to have their licence revoked by the NZTA, under Section 18 of the Land Transport Act.

Not all the OT Driving Assessments available use the same testing protocol or scoring system. We need to be aware that there are differences between the available tests. The OT Driving Assessment also has its limitations and cannot predict accidents or fatalities with any certainty. No available testing process will evaluate directly how a person may respond in a real emergency situation.

Making a Decision about Driving Safety

Following assessment of the person's dementia, and investigation into their likely driving safety, the clinician needs to make a decision about whether the person can continue to drive as before, or to recommend that their driving be restricted or cease altogether²⁶. As discussed, where the person has no evidence of dementia or has moderate or severe dementia the decision is relatively straightforward. Where the person has MCI, driving is usually possible, but restrictions may be recommended if there are concerns from family or about behaviour. Rarely, people with MCI may be asked to stop driving. However, for those clients who have Mild Dementia, a definitive decision often can only be made following further investigation into likely driving safety as outlined above.

The preferred option is for the person to undertake a formal OT Driving Assessment. However in many cases, especially when the person would not consent to an OT Driving Assessment, the decision can only be based on the information obtained, clinical judgement and a balance of probabilities. However, clinicians do have a clinical and legal responsibility to make a clear decision in these cases, and cannot defer or ignore the issue in front of them.

Once the decision has been made, it is critical to communicate this with the person and their family, clearly document the decision and notify any other clinical teams involved, and notify the NZTA so that appropriate changes can be made to the person's licence details. It is possible, in view of the threat to therapeutic relationships caused by removal of someone's licence, for the clinician to write to the NZTA and have that agency make the "final decision." Research completed at Auckland DHB suggested that families prefer that any change to a person's driving status or permission is communicated to the NZTA. This makes it easier for families to remind the person that they are no longer able to drive or have restrictions in place, when the person may have forgotten the conversation and their promise to abide by the clinical advice²⁷.

When the NZTA receives a clinical recommendation that the person is no longer safe to drive, the Agency will write to the driver giving them the opportunity to surrender their licence voluntarily in the following two weeks. If this does not happen, then the person's driving licence will be formally revoked by the Agency. A person who has had their driving licence revoked by the NZTA, may challenge that decision by virtue of making an appeal to the District Court under Section 106 of the Land Transport Act (1998).

If the clinical decision is that the person should stop driving, then there are further recommendations, listed in the section below.

Following assessment as not safe to drive

For those clients who have their licence revoked or driving stopped due to their cognitive impairment, the impact can be devastating, both emotionally and in terms of their ability to

²⁶ Alexandersen, A., Dalen, K., Bronnick, K (2008) Prediction of driving ability after inconclusive neuropsychological investigation

²⁷ Chakko, E (2013) Driving Assessment and Beyond: An Observational Study (DABOS). Dissertation submitted to Royal Australian and New Zealand College of Psychiatrists - Faculty of Psychiatry of Old Age Training Programme.

maintain their independence.²⁸ The capacity to drive is a potent personal symbol of freedom and autonomy, and clinicians should not be surprised at the hostility that often results from suggesting that someone's driving should be restricted or stopped altogether. It is not uncommon for people to become depressed following having had their driving licences revoked. There is also some suggestion that removal of a person's licence may hasten placement into care. Certainly social isolation, diminished community engagement and feelings of loss may occur. There is also a marked handicap for those who have lost their licence in completing tasks such as shopping or attending appointments.

Key workers will need to help the person and their family manage their new situation. It is critical that any concerns and decisions are communicated sensitively and with family present. It is also vital that the person is offered emotional and practical support, including:

- Counselling and support
- Providing the client with written information / pamphlets / local resources
- Engaging with client's family / whanau to seek their assistance with transport
- Transport advice, including access to Gold Cards and information about public transport
- Referral to Age Concern for Total Mobility Transport Subsidy (Half price taxis)
- Information about services such as Driving Miss Daisy

Many people reject the advice to stop driving when this is recommended. A small number will request second opinions or further testing. In general, if the person has moderate or severe dementia, then the clinician should attempt to dissuade them from further testing (which is likely to be a futile exercise and a waste of money.) If the person has mild dementia, then having conflicting results from repeated testing becomes a possibility and leaves all parties uncertain as to making any clinical decision on driving safety.

A person who refuses to stop driving:

Some patients refuse to stop driving even after receiving notification from the NZTA that their driving licence has been revoked. When this happens the following are recommended:

- The person should be reminded of their licence status (this should be followed by a letter to them and their family).
- They should be informed that they will be effectively uninsured if they drive
- The assistance of the person's family/Enduring Power of Attorney should be enlisted, where possible, to help with situation (disabling or removal of vehicle etc)
- Notification of authorities. Where a person has had their driving licence revoked due to dementia, but is continuing to drive against medical advice, it is recommended that a letter be sent to either the police and/or the NZTA. This breach of confidentiality is allowed under Principle 11(f) of the Health Information Privacy Code, where the disclosure is necessary to "prevent or lessen a serious threat" to either public safety or the life and health of the individual. We have had conflicting advice regarding whether clinicians should notify the police directly about someone continuing to drive without a licence. It is the NZTA's view that clinicians should send a letter to the Agency alone, and that the Agency will alert the police to the situation. It is the view of the NZTA that

²⁸ Liddle, J, Bennett, S, Allen, S, Lie, D, Standen, B (2013) The stages of driving cessation for people with dementia: needs and challenges.

clinicians may be more vulnerable to complaints about breach of confidentiality or privacy, if they go directly to the police. However, the contrary view has been expressed in a legal opinion obtained in preparing this update; in the view of this opinion, it is reasonable for clinicians to notify the police directly, where a person is clearly a risk to others and themselves because of continued driving following the removal of their licence. It is therefore recommended that the clinician certainly notify the NZTA in all cases of someone continuing to drive having had their licence revoked; it is also recommended that clinicians notify the local police directly, perhaps where the assessed risk is relatively high. Regardless, the person and their family should be told of the course of action that the clinician is taking. This may be couched in terms of the legal obligations on all clinicians to inform authorities about people who are no longer safe to drive, but are not abiding by that clinician's assessment.

If the clinician is concerned that there might be a potential complaint from the person, following such notification of either the NZTA or police, then it may be advisable to seek legal advice or discuss the case with a colleague – which should then be documented.

Driving and Dementia

Part 2: Clinical and Legal Background

Introduction

7.1

This guideline is designed to assist clinicians in the decision-making process around those people who have some form of cognitive impairment and are also continuing to drive a motor vehicle. This section provides some of the legal background in more detail, and also refers to the research literature relating to issues around driving safety.

People aged 80 and over have the same number of mortalities per kilometre- driven as 16 - 20y olds. This is likely in part to be due to their greater physical fragility, even in slower-speed collisions, but it is also be due to a subset of that age bracket that are driving with cognitive impairment^{1 2} and are therefore at a higher risk of causing a MVA¹⁵.

It is accepted that people with moderate to severe dementia are not safe when driving a car. However it is known that many of those with mild cognitive impairment or in the early stages of dementia may be able to drive at least as safely as their peers. Unfortunately for this latter group there is no fool-proof standardised bedside clinical test³, which can be used to allow a clinician to make the decision about safety of someone's driving¹⁵. It is recognised that as people's performance on cognitive or neuropsychological testing diminishes then their driving safety also does²⁹. However there is generally no definitive "cut-off" point in any test that allows for the accurate identification of the subgroup that is unsafe to drive³⁰. For example, although one study did show that 64% of those with an Mini-Mental State Examination (MMSE) score of <24 failed an Occupational Therapist (OT) Driving Assessment, similar studies have not shown a strong relationship between MMSE score and driving safety³¹. A recent meta-analysis of studies looking for links between cognitive testing, executive functioning and driving safety, found that most forms of testing have only modest predictive value, at best.³² Most bedside or neuropsychological test batteries unfortunately have only modest degrees of sensitivity and specificity when used to predict a person's capacity to pass an OT Driving Assessment. The use of combinations of short bedside cognitive and/or functional assessments may offer some improvement in predictive value.³³ However, the rate of false positives and false negatives are still too high to make the assessments of driving safety with confidence, using only bedside or neuropsychological tests. This also

²⁹ Reger, M, Welsh, R., Stennis Watson, G., Cholerton, B., Baker, L., Craft, S (2004) The Relationship Between Neuropsychological Function and Driving Ability in Dementia: A Meta-analysis

³⁰ Ott, B., Heindel, W., Whelihan, W., Caron, M., Piatt, A., DiCarlo, M (2003) Maze Test Performance and Reported Driving Ability in Early Dementia

³¹ Sylyk, J., Myers, L., Xia Zhang, Y., Wetzel, L., Sharpiro, R (2002) Development and assessment of a neuropsychological battery to aid in predicting driving performance.

³² Asimakopulos, J, Boychuck, Z, Sondergaard, D, Poulin, V, Ménard, I, Korner-Bitensky, N. (2012) Assessing executive function in relations to fitness to drive and their ability to predict safe driving.

³³ Carr, D, Barco, P, Wallendorf, M, Snellgrove, C, Ott, B. (2011) Predicting road test performance in drivers with dementia.

applies to forms of computerised cognitive testing and the use of driving simulators.³⁴ Furthermore, comprehensive batteries of bedside cognitive tests and neuropsychological testing are generally only available in secondary care settings or in private. This guideline hopes to provide some practical guidance for clinicians attempting to make a decision about driving safety, in all health care settings.

Likewise, reports of concern by family members or having had a recent motor vehicle accident⁷ (MVA) can be an indicator of problems with driving, but neither is totally reliable as a guide to making a clinical decision⁸ about someone's safety on the road⁷.

In the absence of an accurate, sensitive and specific bedside or in-clinic test which accurately predicts driving safety, clinicians are nonetheless still faced with the problem of having to decide how safe someone who has mild dementia will be on the road³⁵. Getting this decision wrong, may potentially result in allowing an unsafe driver to continue to drive, or unfairly penalising those who would have been safe to continue driving (for the time being)³⁶.

The test that is regarded as the most accurate and reasonable indicator of driving safety is an on-road driving assessment¹¹, preferably with a trained Occupational Therapist. The OT Driving Assessment usually involves a mixture of off-road testing (either cognitive assessment³⁷³⁸ or in a driving simulator) and a scored on-road driving test³⁹.

In our experience, many people react with more distress and anger to the news⁴⁰ that they can no longer drive than to receiving the diagnosis of dementia itself. Having to tell someone that they can no longer drive is often a challenge to maintaining any therapeutic relationship. This is, in part, because of the loss of insight or appreciation of their illness experienced by a high number of those with dementia. And for many people the loss of their driving licence is a major obstacle to continuing to live independently. In many parts of New Zealand there are few alternative means of transport. (Although half-price taxis are available, after someone gains approval for a Total Mobility card from Age Concern.)

As a result of this reaction to questions about their driving, many drivers refuse to submit to an expensive on-road driving test (or cannot pay to have one). Furthermore, the removal of their driving licence by the New Zealand Transport Agency (NZTA) often does not stop a small subset of drivers continuing to drive (due to either rejection of assessed risk or poor memory for the advice given), and the request by clinicians for intervention by family members may not prevent them driving. It is not uncommon for us to be confronted with a person who is clearly impaired as a driver and who is unlicensed but nonetheless continues to drive¹⁰.

³⁴ Hoggarth, P, Innes, C, Dalrymple-Alford, J, Jones, R. (2013) Predicting on-road assessment pass and fail outcomes in older drivers with cognitive impairment using a battery of computerised sensory-motor and cognitive tests.

³⁵ Molnar, F., Byszewski, A., Marshall, S., Man-Son-Hing, M (2005) In-office evaluation of medical fitness to drive – Practical approaches for assessing older people

³⁶ Iverson, D., Gronesth, G., Roger, M., Classen, S., Dublinsky, R., Rizzo, M (2010) Practice Parameter update: Evaluation and management of driving risk in dementia – Report of the Quality Standards Subcommittee of the American Academy of Neurology

³⁷ Freund, B, Gravenstein, S., Ferris, R., Burke, B., Shaheen, E (2005) Drawing Clocks and Driving Cars – Usage of Brief Tests of Cognition to Screen Driving Competency in Older Adults

³⁸ Elkin-Frankston, S., Lebowitz, B., Kapust, L., Hollis, A., O'Connor, M (2007) The use of the Color Trails Test in the assessment of driver competence: Preliminary report of a culture – fair instrument

³⁹ ACC (2004) Computerised Off-Road Driving Assessment

⁴⁰ Kay, L., Bundy, A., Clemson, L (2009) Predicting Fitness to Drive in People With Cognitive Impairments by Using DriveSafe and DriveAware

Availability of testing in New Zealand

The Ministry of Health ceased funding for on-request OT driving assessments in 2003. The OT Driving Assessment currently costs a person around \$170 - \$230 for the preliminary testing (a driving simulator test or computerised cognitive testing), and up to a total of \$400-700 if this is combined with the on-road test. These tests are available locally through a number of different agencies. However many drivers refuse to pay these costs or are in no position to do so ⁴¹. This fact is one of the major obstacles we face in making an accurate assessment of someone's driving safety. (Some District Health Boards in New Zealand do fund a small number of tests, but these are not available to the vast majority of people.)

Due to the costs of the OT Driving Assessments, some DHBs may refer patients to local driving instructors or equivalent. This certainly can be a cheaper option for an assessment of driving ability but lacks the rigor, validation and standardisation of the OT driving assessments. Nonetheless, for some people, this may be the only form of On-Road testing that can be negotiated with the person or their family ⁴².

Drivers are obliged to have their driving licence renewed at ages 75, 80 and every two years after that. This may be approved in clinic by their GP. However they may be referred for an "On-Road Safety Test" by their GP if there are any concerns about their potential driving safety⁴³. This is an NZTA-approved on-road driving assessment, that involves driving with an assessor (not an OT) in the car on the road. This costs around \$60-70 including the cost of the new drivers licence and it is the driver's responsibility to organise this. The New Zealand Transport Agency (NZTA) advises that this system can be used at any point over the age of 75, to test people's driving, and not just at the point at which the person's existing driving licence is due to expire. We can make referrals ourselves through this system. However the ability to access this facility is not widely known amongst practitioners and it is clearly a much less rigorous test than the OT Driving Assessment. The testing is much less sophisticated than the OT driving assessments but is nonetheless clearly regarded as adequate for driver relicensing by NZTA. This testing is more likely to detect drivers who are obviously unsafe but may pass some who would fail an OT test, creating the potential for false reassurance of the client and unease in clinicians. Drivers under 75 have no access to this source of testing.

⁴¹ Wagner, J., Muri, R., Nef, T., Mosimann, U (2011) Cognition and driving in older persons

⁴² Lococo, K., Tyree, R (2010) Functional Abilities and Safe Driving *Medscape CME Pharmacists* 08/04/2010 Retrieved from <http://www.medscape.com/viewarticle/578231>> October 2013

⁴³ New Zealand Transport Authority (2009) Medical aspects of fitness to drive – A guide for medical practitioners

Legal considerations: “Medical Aspects of Fitness to Drive (2009)”:

The NZ Transport Agency defines two main legal obligations on medical practitioners (and by implication on other health professionals) under the Land Transport Act (1998)⁴⁴. These are:

- Consideration of any medical or other problems an individual may have when conducting an examination of an individual’s fitness to drive (or the implications of any newly diagnosed problems on their driving)⁴⁵, and
- To report to the NZTA any individual who continues to drive when advised not to (under Section 18 of the Land Transport Act).

Medical practitioners may recommend that drivers stop driving completely or may recommend that they drive only in accordance with certain limitations (e.g. only driving during daylight hours or in a localised area)⁴⁶. If a person voluntarily abides by our clinical recommendation, then there is no legal requirement to notify the NZTA but it is our belief that the NZTA should be notified by the clinicians involved. (This is because we believe that it is helpful for the person to receive a letter with the changes outlined from the NZTA, reinforcing and crystallising the clinical decision.) This should all be documented in the person’s clinical file. It may also be helpful if the person receives a copy of the letter of notification to the NZTA.

The Medical Aspects of Fitness to Drive (2009) makes the following statements about individuals with dementia:

- **“Driving may be permitted in cases of early dementia, provided that the medical practitioner is satisfied that there is no significant loss of insight or judgement and an individual does not show signs of disorientation or confusion.”**
- **“A driving assessment with an occupational therapist is recommended in all cases where there is some doubt about driving ability, especially should family members have concerns”⁴⁷.**
- **“(Individuals with confirmed dementia or cognitive impairment from whatever cause should not drive.” *This only applies to commercial or special licences.*)**

These statements highlight that those drivers with mild or early dementia may be permitted to drive but clinicians (with the assistance of OT Driving Assessments) have the responsibility of identifying the driving safety or otherwise of this group⁴⁸. Those with moderate or severe dementia can be assumed to lack judgement and/or display confusion and disorientation, and therefore should not be driving.

⁴⁴ Kumar, S., Pickering, B (2001) “Fitness to drive” in New Zealand: psychiatric aspects and the clinicians role

⁴⁵ Langford, J (2007) Usefulness of Off-Road Screening Tests to Licensing Authorities when Assessing Older Drivers Fitness to Drive

⁴⁶ Langford, J (2007) Usefulness of Off-Road Screening Tests to Licensing Authorities when Assessing Older Drivers Fitness to Drive

⁴⁷ Lincoln, N., Taylor, J., Vella, K., Bouman, W., Radford, K (2010) A prospective study of cognitive tests to predict performance on a standardised road test in people with dementia

⁴⁸ Molnar, F., Patel, A., Marshall, S., Man-Son-Hing, M., Wilson, K (2006) Clinical Utility of Office-Based Cognitive Predictors of Fitness to Drive in Persons with Dementia: A Systematic Review

Ethical considerations:

There are a number of conflicting principles that need to be reconciled in dealing with a person who may have some degree of impairment in their driving.

- We want to encourage the person’s own expression of autonomy in any decision-making about their future driving. To this end the clinical relationship aims to be inclusive and with the goal of person being comfortable with the choice, along with their family, to stop driving or undertake the more definitive OT driving test if required ²⁹.
- We need to consider the implications of forcibly stopping someone from driving. This includes both their emotional reaction and the practical implications of no longer having a driving licence. The latter is critical in those people who have little access to other forms of transport ⁴⁹.
- We have an ethical responsibility to ensure the safety of the person themselves, as well as other road users, in those situations where there is clear or highly suggestive evidence that the person’s driving is no longer safe.
- If we are going to breach our duty of confidentiality to someone, in the above situation (by notifying the NZTA or others), then we need to have clear indication of concern, which requires a thorough assessment of the client and complete honesty about our actions.

Summary:

In summary, we all have a responsibility to consider the safety of all individuals under our care when they are driving. This guideline is focussed upon the context of cognitive decline but attention needs also to be given to those with cerebrovascular disease, diabetes, visual impairment, cardiac problems and those impaired by mental health disorders or medication. Those who are at increased risk of having an accident when driving should be asked to stop driving, and if they will not accept this advice then notification of the NZTA is legally required. It is often difficult to assess the safety of an individual’s driving when the cognitive impairment is relatively mild. Cognitive testing does not provide a definitive assessment of driving safety although deteriorating scores on testing do correlate with a worsening performance on driving assessments. An on-road Occupational Therapy driving assessment remains the accepted “gold-standard” in terms of assessment of driving skills and safety, and we need to be encouraging clients to “take the test”. Unfortunately these are not funded and are expensive. We all need to be mindful of the likely emotional reaction to deciding that someone is no longer safe to drive, as well as the practical implications for them continuing to live independently.

⁴⁹ Carr, D., Ott, B (2008) The Older Adult Driver with Cognitive Impairment “It’s a Very Frustrating Life”

Glossary

MHSOP	Mental Health Services for Older People
MCI	Mild Cognitive Impairment
NZTA	New Zealand Transport Agency
OT	Occupational Therapy / Occupational Therapist
MMSE	Mini-Mental State Examination
MOCA	Montreal Cognitive Assessment
RUDAS	Rowland Universal Dementia Assessment Scale
ACE-III	Addenbrooke’s Cognitive Examination – version 3
CDR	Clinical Dementia Rating scale
FAST	Functional Assessment Scale
GDS	Global Assessment Scale of Deterioration
SLUMS	St Louis University Mental Status Examination
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
IADLs	Instrumental Activities of Daily Living
On-Road Safety Test	NZTA-approved on-road driving assessment for driving licence renewal
AA	Automobile Association
EPOA	Enduring Power of Attorney
GP	General Practitioner
CVA	Cerebro-vascular accident
TIA	Transient Ischaemic Attack
CTO	Compulsory Treatment Order
LTA	Land Transport Act (1998)

Useful Resources

- New Zealand Transport Agency

<http://www.nzta.govt.nz/resources/supporting-older-drivers/docs/supporting-senior-drivers.pdf>

Pamphlet “Supporting older drivers – Help your older friend or relative stay mobile safely”

<http://www.nzta.govt.nz/resources/total-mobility-scheme/docs/total-mobility-around-new-zealand.pdf>>

Brochure – National Total Mobility Scheme

<http://www.nzta.govt.nz/resources/keeping-moving/docs/keeping-moving.pdf>.

Booklet – Keeping Moving: the positive guide for senior road users

- New Zealand Association of Occupational Therapy

<http://www.nzaot.com/about-occupational-therapy/driving-assessments.php>

Website description of OT Driving Assessments

- Office for Senior Citizens

<https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/research/coping-without-a-car/how-will-you-get-around-without-a-car.pdf>

Pamphlet “How will you get around when you stop driving – plan ahead so you can still do the things you enjoy”

- The Hartford – Insurance and Financial company USA

<http://www.thehartford.com/sites/thehartford/files/dementia-warning-signs.pdf>

Pamphlet “Warning signs for drivers with dementia”

<http://www.thehartford.com/sites/thehartford/files/1287779111224.pdf>

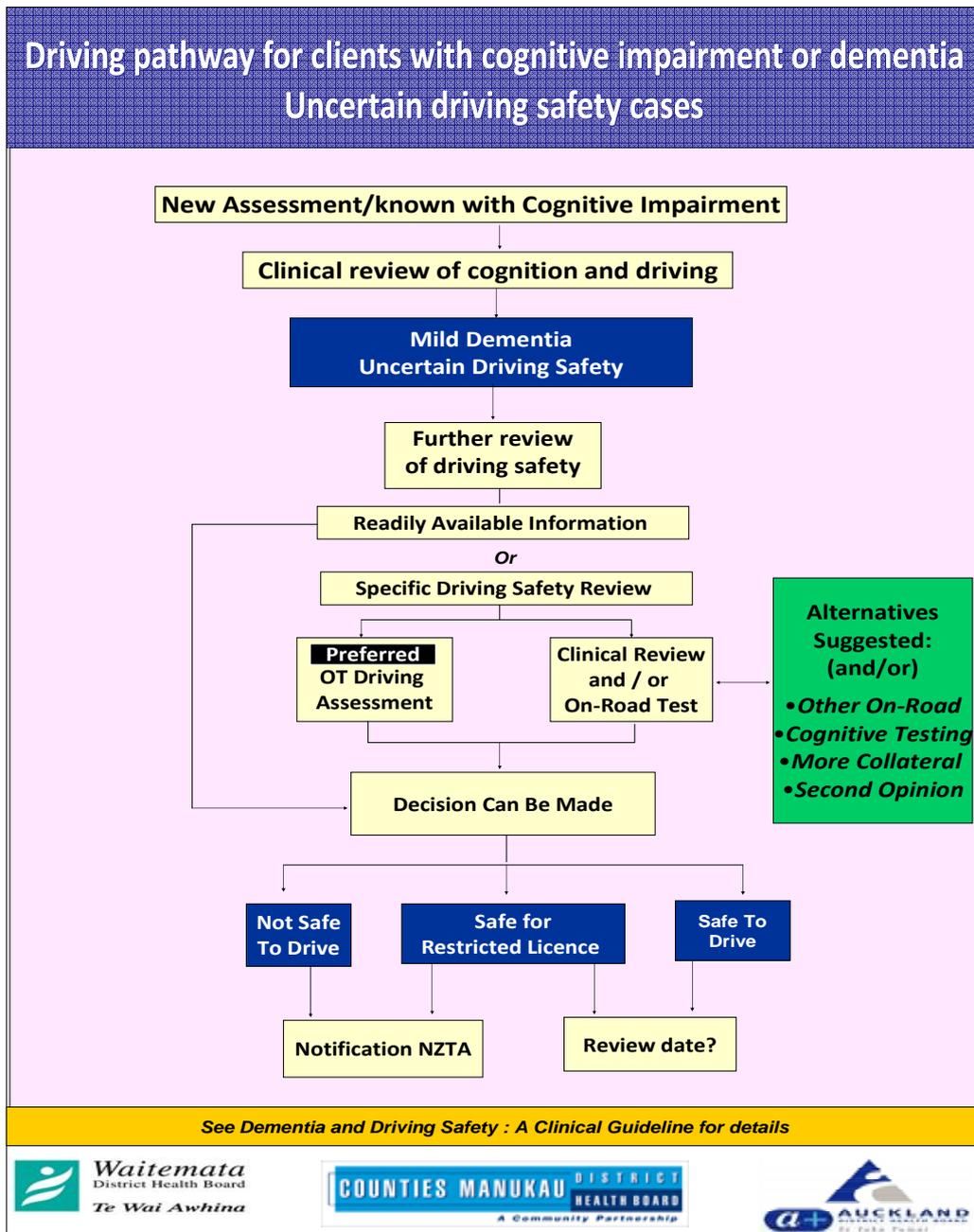
Pamphlet “Conversation Planner: How can I have good conversations about not driving”

- The Stroke Foundation

<http://www.stroke.org.nz/resources/Driving%20after%20a%20stroke.pdf>

Pamphlet “Driving after a stroke or TIA”

Driving pathway for clients with cognitive impairment or dementia



Other conditions affecting driving

This table contains a summary of some of the common conditions seen in practice. For a full description of the details of driving restrictions for these disorders and many others please consult Medical Aspects of Fitness to Drive (MAFTD) 2010. Remember that regardless of the cause, if an individual appears unsafe to drive it may be because of a combination of disorders and action needs to be taken. The following summary only applies to ordinary driving licences and not to commercial driving licences.

Conditions	Restrictions on Driving (Medical Aspects of Fitness to Drive)
CVA	An individual should not drive until clinical recovery is complete, with no significant residual disability affecting their ability to drive. They cannot drive within 1 month of the CVA. Individuals with residual disabilities should be assessed by an OT driving test. Those with homonymous hemianopia should not drive.
TIA	An individual should not drive for 1 month after a single TIA. For those with recurrent TIAs, they may resume driving after being symptom-free for 3 months.
Collapse	Individuals should not drive for 2 months following a collapse (syncope or cardiac arrest)
Angina	Individuals with angina at rest or on mild exertion should not drive. They may resume driving once they are free of angina on mild exertion provided there are no other conditions (e.g. arrhythmias) that would exclude them from driving.
Myocardial infarction	An individual should not drive for 2 weeks following an uncomplicated MI. They can resume driving following a specialist assessment.
Epilepsy/ Seizure	Individual should not drive following single seizure or since their last seizure for those with epilepsy for one year. Generalised and partial seizures are not treated in the same manner. Period may be shortened if there was a particular factor causing seizure and recurrence is unlikely. Individuals with sleep epilepsy may drive after three years of establishing this pattern.
Visual Impairment	Visual acuity needs to be 6/12 in both eyes together, with or without correcting lenses. For those with marked impairment in one eye or visual field defects specialist assessment is required.
Vertigo/ Meniere's	Where the attacks of vertigo or giddiness are sufficiently disabling to impair an individual's ability to drive, they should not drive until the condition is treated.

Diabetes	<p>Diabetes is generally not an obstacle for driving unless the person is having hypoglycaemic attacks. Where these are recurrent and the person has poor hypoglycaemic awareness, they should not drive until this is managed.</p> <p>An individual who has a hypoglycaemic attack while driving should not drive for one month until remedial action is taken.</p>
Advancing age	<p>Advancing age is not an obstacle to driving per se. However if there are concerns about an individual's driving safety due to a combination of medical, cognitive, medication or biomechanical issues, formal OT driving assessment should be sought.</p>
Severe Mental Disorder	<p>When an individual has a severe enduring mental disorder affecting their ability to drive safely due to impairments in cognition, behaviour, impulsivity or mood, they should not drive until treated for a period of at least 6 months.</p> <p>The NZTA should be notified about all individuals subject to an Inpatient CTO under Section 19 of the LTA. These individuals are still permitted to drive unless they are assessed as unsafe to do so.</p>

This letter template is designed to be adapted to a variety of uses:

- Letter to client / GP approving driving but suggesting review in six months
- Letter to OT Driving Assessment Agency requesting OT driving assessment
- Letter to NZTA making recommendation about restriction on, or withdrawal of clients driving licence

Service Logo

Date CC Client
CC GP

Dear

Patient Details

Driving Assessment Letter

Problem List:

- 1 Driving Safety issues
- 2 Cognitive Impairment
- 3 (Recent MVAs)
- 4 Relevant Medical issues

Delete paragraphs (and numbering) as required:

1. Mr/Mrs has voluntarily agreed to stop driving following medical advice. It is not likely that driving will be possible safely in the future, and it is my recommendation that his/her licence is revoked at this time by the NZTA.
2. Mr/Mrs has voluntarily agreed to restrict his/her driving following medical advice. I have suggested that he/she does not drive outside the hours of 10am to 2pm, and should not drive further than 5km from his/her home. I would recommend that his/her licence is amended accordingly at this time by the NZTA.
3. Mr/Mrs has been advised by me that he/she should no longer be driving due to the medical conditions described. Unfortunately, he/she has not agreed to stop driving, and I am therefore notifying the NZTA under Section 18 of the Land Transport Act, with the recommendation that his/her driving licence be revoked.
4. Mr/Mrs no longer has a driving licence but is continuing to drive a motor vehicle on roads. I would be grateful if you would communicate with him/her regarding this and with a reminder that his/her licence is no longer valid. (I believe that there is some significant risks associated with him/her driving, and I would recommend that the NZTA ask the local police to visit Mr/Mrs about driving.)

Background Information:
 (Relevant supporting clinical information.....)

Driver's Questionnaire

This questionnaire addresses historical features with Level A, Level B or Level C evidence of relevance to driving competency, as well as selected items from the Manchester Driver Behaviour Questionnaire. It is only intended to be used in the qualitative determination of driving risk in elderly patients and patients with dementia, and has not been validated for use in the quantitative determination of driving risk.

1.	How many times have you been stopped or ticketed for a traffic violation in the last three years? (0, 1, 2, 3, 4 or more)	
2.	How many accidents have you been in, or caused, within the last three years? (0, 1, 2, 3, 4 or more)	
3.	In how many accidents were you at fault in the last three years? (0, 1, 2, 3, 4 or more)	

Use this scale to answer the following questions below:

1 = strongly disagree, 2 = disagree, 3 = no opinion, 4 = agree, 5 = strongly agree

1.	I have concerns about my ability to drive safely	
2.	Others have concerns about my ability to drive safely	
3.	I have limited the amount of driving that I do	
4.	I avoid driving at night	
5.	I avoid driving in the rain	
6.	I avoid driving in busy traffic	
7.	I will drive faster than the speed limit if I think I won't be caught	
8.	I will run a red light if I think that I won't be caught	
9.	I will drive after drinking more alcohol than I should	
10.	When I get angry with other drivers, I will honk my horn, gesture, or drive up too closely to them	

How many kilometres a week do you drive?	<i>Km</i>
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Family or Caregiver Questionnaire

1.	How many times has the driver been stopped or ticketed for a traffic violation in the last three years? (0, 1, 2, 3, 4 or more)	
2.	How many accidents has the driver been in, or caused, within the last three years? (0, 1, 2, 3, 4 or more)	
3.	In how many accidents was the driver at fault in the last three years? (0, 1, 2, 3, 4 or more)	

7.1

Use this scale to answer the following questions below:

1 = strongly disagree, 2 = disagree, 3 = no opinion, 4 = agree, 5 = strongly agree

1.	I have concerns about the person’s ability to drive safely	
2.	Others have concerns about his/her ability to drive safely	
3.	The person has limited the amount of driving that he/she does	
4.	He/she avoids driving at night	
5.	He/she avoids driving in the rain	
6.	He/she avoids driving in the busy traffic	
7.	The person will drive faster than the speed limit if he/she thinks they won’t get caught	
8.	The person will run a red light if the patient thinks that he/she won’t be caught	
9.	The person will drive after drinking more alcohol than he/she should	
10.	I do not feel safe when being driven by the person	
11.	I would be reluctant to let the person drive my children (or friends)	

How many kilometres a week does the client drive?	<i>Km</i>
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Name of Specialist:	
Phone:	Email:
<u>Reasons for referral / driving concerns</u>	
<input type="checkbox"/> Please contact the referrer for further information.	

<u>Clinical Details</u>	
Diagnosis:	Date of Diagnosis:
Current Psychotropic Medication:	
Relevant Medical & Neurological condition:	
Cognitive Assessment:	
(Addenbrook's) ACE-III	/100
RUDAS / MOCA / MMSE	/30
Eyesight: Right:	Left:

<u>Notification to NZTA</u>	
Phone: 0800 822 422	Fax: (06) 953 6261
Email: mark.pugin@nzta.govt.nz	
1. The patient has been informed to cease driving until he/she has an occupational therapy driving assessment.	
<input type="checkbox"/> YES	<input type="checkbox"/> NO
2. A copy of this referral form has been forwarded to NZTA.	
<input type="checkbox"/> YES	<input type="checkbox"/> NO

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Waitemata
District Health Board

Best Care for Everyone

Dementia Decision-making Journey

Information to support decision making for families of people with advanced and end-stage dementia living in Residential Aged Care.

Manaaki Mana Kaumatua

All-encompassing care, respect, dignity of holding our older ones

This information booklet has been provided by the Residential Aged Care Integration Programme Work Group and Waitemata District Health Board. We hope that this information will assist you to gain a wider understanding of the progressive nature of dementia and its likely impact on your spouse, partner, family/whānau member in the final stages of their illness.

Our aim has been to write about the issues we have noticed that can cause concern for the families/whānau of the person with dementia. It expands on the information given in “Dementia, Decision Making Journey” pamphlet.

Registered nurses are available to further discuss the topics in this booklet and guide you to think about preferences for care. We have also tried to suggest practical ways you can help with the care of your family/whānau member with dementia.

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Gerontology Nurse Practitioner

Nga Kaitiaki Kaumatua

Older Adults & Home Health

Waitemata District Health Board



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Introduction

This booklet is written for family/whānau and friends of people in residential care with advanced and end-stage dementia. It builds on the pamphlet “Dementia, Decision Making Journey.” It has been developed to inform you about what you can expect during the final stages of dementia, which can be distressing for families/whānau and friends. Please ask for an interpreter if this is needed.

The registered nurse and doctor caring for your friend or family member with dementia are able to support and discuss this information with you. Having knowledge of the likely course of the disease gives you and the health care team the opportunity to plan care. The person with dementia may have earlier expressed wishes about their end of life care. Discussing this with the team gives the opportunity for these wishes to be honoured.

There are many disease processes that can cause dementia and it is common to have more than one type of dementia. More important than the diagnosis is the impact it has on the individual, their family and friends. Everyone’s journey with dementia is unique. The disease progression will vary from person to person influenced by the individual’s disease, past medical history, personal skills and life experiences. There is a lot of information about the stages of dementia on the internet and from organisations such as Alzheimers New Zealand (see Supports for family/whānau page 25).

Dementia is an umbrella term. Some examples of the different types of dementia include:

- Alzheimers disease (which is the most common)
- Vascular dementia
- Lewy body dementia
- Frontotemporal dementia.

This is not a complete list of types of dementia (see Supports for family/whānau page 25).

Although the progression of dementia is unique for each person there are usually identifiable stages. Identifying which stage your family/whānau or friend is at can be useful as this supports you and clinicians when planning the goals of care. Overleaf is a framework that will assist you to understand which stage your family/whānau member or friend is at. As the person with dementia moves through the different stages the goals of care will change.

Dementia: Typical progression with typical care goals

Stage	Memory problems noticed by person and/or others	Mild cognitive impairment (memory problems start to impact on person's ability)	Mild dementia (memory problems affect person's ability to manage independently)	Moderate dementia (increasing dependency)	Severe dementia (increasing physical and behavioural problems)	Loss of physical functions	Dying and death	Bereavement
Setting	Community, outpatient and home based services							
Goals of Care	Assessment, diagnosis and monitoring disease progress. Exclusion of reversible causes			Assessment focussed on functioning to inform care needs				
	Patient education. Support to plan ahead eg Enduring Power of Attorney, Advance Directives							
	Caregiver education. Support to plan ahead eg organising Enduring Power of Attorney							
	Try to slow memory decline with treatment							
				Management of behaviours associated with dementia				
				Advance Care Planning, symptom management				
				Diagnosis of dying		End of life care		Bereavement care

The roles of clinical team and family/whānau members

Health care professionals use the information provided by family/whānau and friends to guide the person's care. This includes the values, wishes and feelings the person may have had or the activities they enjoyed.

As well as the registered nurse and doctor there are a variety of people who assist with caring for or supporting you and your family/whānau member or friend with dementia eg health care assistants, physiotherapists, chaplain, or other religious leaders etc.

Who makes decisions?

The person with dementia is able to make decisions regarding their own care and welfare until a doctor has assessed that they no longer have the mental capacity to do so. At this point the person holding Enduring Power of Attorney (EPOA) or a Welfare Guardian (PPPR Act) makes decisions on that person's behalf (see legal definitions Page 26).

- Regardless of capacity the person with dementia should still be supported to take part in discussions about their health and welfare. Their individual preferences and beliefs should be respected and taken into account when making decisions.
- Waitemata DHB's lawyers advise that if there is no EPOA the family should apply to appoint a welfare guardian and possibly a property manager under the PPPR Act. That person will then make decisions on behalf of the person with dementia. These decisions must be in the best interests of the person and would usually be in consultation with other family/whānau and the registered nurse and doctor.

The family/whānau (this may on occasion be a close friend) and health care professionals work as a team, in the best interests of the person with dementia.

- Should any differences in opinion arise around the appropriateness of care, the health care professionals are available to facilitate family/whānau discussion.
- If conflict arises the EPOA/Welfare Guardian makes the final decision.
- Conflict may sometimes arise when there are differences of opinion amongst Individual family/whānau members or between families and the clinical team.

It is most important to have good communication and there are agencies that can support the decision making process eg Alzheimers Auckland, the Advocacy Service, Mental Health for Older Adults team or nurse specialists (Gerontology, Dementia), a Chaplain or religious or cultural groups.

Principles of care

Dementia is a progressive, degenerative disease. Unless the person with dementia dies from another illness there may come a time when they become totally dependent on others for all necessities of life including feeding, moving and hygiene.

Providing comfort and dignity for people with dementia is a priority, especially during the late stage and end of life care. As the brain fails because of dementia, the emphasis moves from prolonging life to providing palliative or comfort care.

The person's ability to process messages will become increasingly impaired. These changes may be reflected in many ways and may include communication difficulties, personality changes and behavioural changes. If English is a second language the person with dementia may start to use their mother tongue. Changes in personality and behaviour may be distressing for you but not for the person with dementia. The person may no longer recognise family/whānau, friends or staff members. Acknowledging the person's uniqueness and personal history by having photographs and life-stories may provide you and the care staff tools which support communication with the person with dementia. Knowledge of the person's cultural, religious and spiritual beliefs will also assist staff and family/whānau or friends to provide individualised person centred care.

A care plan which integrates the cultural, spiritual, religious values and beliefs of the person will assist in providing individualised nursing care specific for that person. Family/whānau and staff may co-operatively plan this care. This may involve a family/whānau representative gathering information about key needs of the person with dementia. This enables open communication and the care plan can then be inclusive of family/whānau input.

There are many things to consider when planning care for those with severe dementia.

As the person's condition deteriorates the role of the team becomes one of support and providing comfort care for the person. There comes a time when active medical intervention either will not improve the person's health, or the burden of the intervention will outweigh any potential benefit. Once this stage of the disease has been reached, it may be appropriate to reduce unnecessary tests or medications. Interventions and observations which are no longer useful will stop. Nursing support and care will continue. It is important to remember

that the person receiving comfort care will continually be assessed for signs such as pain, breathlessness and agitation so that they are comfortable until natural death occurs.

When someone is dying of dementia it is especially important to consider quality of life and plan for the problems that may arise as part of the natural course of the disease process. Some of the most common areas of care to consider are:

1. **Socialising**
2. **Decreasing recognition of time and place**
3. **When is admission to hospital appropriate?**
4. **Resuscitation**
5. **Medicines**
6. **Other medical conditions**
7. **Eating and drinking and weight loss**
8. **Infection**
9. **Pain**
10. **Skin**
11. **Bladder and bowels**
12. **Walking and moving**

The following pages give more details about this. You and the team can talk about these areas when planning care.

1. Socialising

Socialising is an important part of being human and living together in a community. For the person with dementia socialising skills may change and be unacceptable to other residents and families. Examples of this are: wandering in to other resident's rooms, touching or moving other people's belongings, inappropriate sexual behaviour etc. Behaviours such as agitation and aggression are more likely to occur in advanced dementia. Sometimes these behaviours can occur or get worse if the person is unwell, or uncomfortable. It's important to try and manage the behaviours that cause concern.

Strategies:

It is still important for the person with dementia to socialise. This can take many forms but needs to be meaningful for the person. For example:

- culturally appropriate activities that support and enhance the person's cultural background and ethnicity
- activities centred around music
- visitors – such as visiting groups, pets, Aged Concern etc
- physical activities - such as walks around the garden, exercise classes
- spiritual activities – such as church services, visiting chaplains
- reminiscing – use of photos, life histories, photos of residents engaged in current activities, a diary for family/whānau members and staff to write in - this can be useful as points for conversation.

If behaviour is difficult to manage staff will try to find if there is an underlying cause or trigger. This may mean the doctor comes to see them to see if they are unwell. Staff will try different strategies to assist the person to feel less stressed and more comfortable. This will involve a calm non-confrontational approach.

2. Decreasing recognition of time, place and people

The person with dementia loses track of time, place and person. Reorientation is an important part of their care as long as it does not distress them. In the end stage of dementia the person may confuse you with some one else or not recognise you or will talk about another time as if it were the present. Agreeing with the person's experience even though they are confused may cause them much less stress than trying to reorient them.

Strategies:

If re-orientation is helpful there are ways to support this:

- gently remind them of who you are in their life
- use clocks and calendars that they can see clearly
- photographs that you can use in your conversation.

3. When is admission to hospital appropriate?

Unexpected events such as falls, fractures, stroke or infection can occur in anyone's life. Whether the person with dementia needs to go to hospital will depend on the nature of the event and whether it will be of benefit for the person's overall well being.

How unexpected events are managed will depend on the goal of care for the person with dementia. Sometimes going to hospital is necessary to provide treatment which maintains function, or relieves suffering and provides the best possible quality of life. For example a fall may cause a fractured bone which may need treatment, a severe skin tear may need suturing, and a bowel obstruction may need specialist medical intervention.

However in some situations going to hospital may not be in the best interests of the person. Moving a person with an advanced dementia from their care home can cause anxiety, disorientation and further decline of their physical function. An Advance Care Plan may assist in making a decision about when going to hospital is appropriate. The clinical team will advise and guide you about Advance Care Plans.

Residential aged care facilities provide skilled medical and nursing care. Staff are familiar with your family/whānau member and in many situations are able to provide ongoing care in the facility eg urinary tract, chest and wound infections can in most cases be treated in the residential care facility.

Specialist services such as dietitians, physiotherapists, occupational therapists, mental health services, the Alzheimers Association etc can also assist the person with dementia and family/whānau members.

4. Resuscitation

Resuscitation is also known as cardiopulmonary resuscitation (CPR). It is used when a person collapses because their heart stops beating. The heart is massaged by pressing firmly on the chest, and electrical shocks are usually given to try and restart the heart rhythm.

Decisions about resuscitation will be guided by Advance Care Plan/Advance Directives or Welfare Guardians. Where there is no Advance Care Plan/Advance Directives or Welfare Guardians, the family/whānau will be consulted. The person's doctor makes the final decision, taking into account the wishes and beliefs of the patient (if known) and their family/ whānau.

CPR in persons with end stage dementia is usually not successful and therefore may not be appropriate. If you have concerns about this or need further information, please speak to the registered nurse or doctor.

5. Medicines

In the last days or weeks of life medications that were required to control diseases such as heart failure or high blood pressure may no longer be of benefit. The doctor and registered nurse will discuss medications with family/whānau and then make decisions about which ones to stop. Sometimes a new medication may need to be started, for example to manage pain.

Strategies:

- the doctor or registered nurse can assist with symptom management and answer questions about whether your family/whānau member's medicines are of benefit
- Hospice can be called on for complex symptom management, for example pain, breathlessness, restlessness etc
- there may be other health professionals called upon for advice eg physiotherapist
- spiritual and/or cultural advisors can offer support and advice to the person, family/whānau and staff.

6. Other medical conditions

People with dementia can also have other medical conditions which can affect their day to day health eg heart failure, lung conditions, diabetes etc. These conditions also need to be managed by the care team.

Strategy:

- there are specialist services eg hospice available who can advise the doctor on symptom management to ensure your family/whānau member remains comfortable.

7. Eating, drinking and weight loss

Continued decline in memory and cognition will eventually reduce the person's ability to eat and drink causing weight loss. This is a normal part of advancing dementia.

A person with dementia may:

- not recognise food or eating utensils
- not feel hungry or thirsty
- experience changes in taste sensation
- lose their ability to swallow
- be unable to stay focussed long enough to eat.

The team involved in the care of your family/whānau member will try to identify if there is any other reason for weight loss. When a person is dying of dementia they may lose weight in the same way someone dying of cancer or other illnesses do (known as cachexia). When the body is no longer able to get nutrients from food it makes chemicals that cause loss of weight. It can be distressing for family/whānau members when the person with dementia stops eating or drinking or only manages small amounts of food or fluid but there are some things that may help.

Strategies:

- care providers will continue to maintain good oral hygiene to promote comfort
- specialist help is available from speech language therapists and dietitians. If there are concerns about swallowing difficulties a swallow assessment can be arranged with advice about food and fluid texture and safe feeding techniques.

Over time these strategies may become less effective. Alternatives such as tube feeding or subcutaneous fluids are not usually considered to be of benefit for people with advanced dementia as studies have shown they do not prolong life or improve quality of life. These interventions are invasive and distressing for the person. If eating and drinking becomes difficult alternatives can be discussed at that time.

8. Infection

People with dementia may develop infections more easily. The most common are urinary tract infections, chest infections and skin infections. The reason for this is declining health, increasing frailty and reduced ability of the immune system to fight infections effectively.

Strategy:

- decisions regarding the use of antibiotics will need to be made by the doctor with registered nurse and family/whānau input recognising what is appropriate for the person with dementia.

9. Pain

Pain has many causes. For example it can be emotional, spiritual, long term or acute. Examples of the most common causes of pain in the older person are osteoporosis, back pain, constipation, dental problems and infections but there are many others.

People with advanced dementia can and do experience pain due to other conditions they may have. They can also develop new sources of pain for example from skin problems, joint stiffness, because of weight loss etc. They may have difficulty communicating their pain.

Untreated or poorly controlled pain has a significant impact on quality of life and can lead to joint changes and stiffness, loss of mobility, depression and changes in behaviour. If you feel your family/whānau member with advanced dementia is experiencing pain or discomfort, alert the registered nurse involved in their care. Some things to look for are restlessness, agitation, crying, not wanting to move, resisting care, calling out, worried expression or appearing withdrawn.

Strategies:

Some things you could do to assist are:

- provide comfortable clothing that is easy to remove,
- bring music that you know they enjoy,
- use comforting touch or hand massage.

The registered nurse or doctor will assess for pain or discomfort and discuss appropriate and individualised treatment which may involve medication, positioning and pressure relief.

10. Skin

As people grow older their skin becomes more fragile. Older people are at increased risk of skin tears, bruises, pressure injuries, skin infections etc especially if they are incontinent. Skin tears and bruises most commonly occur from falls and bumping into furniture. A person who has difficulty changing their position in bed is at risk of developing pressure injuries especially on their heels, tail bone, hips, elbows, spine and ears. Skin changes also occur with weight loss and decreased fluid and nutritional intake.

Strategies:

- staff will check the skin when providing hygiene. Some people with advancing dementia develop a dislike for showering or bathing. Staff will maintain hygiene using other methods
- the person may need a pressure relieving mattress or seat
- some things you may notice are redness that doesn't disappear, swelling, scratching, rashes or new wounds. If you have concerns about your family/whānau member's skin or notice changes speak to the registered nurse.

If the person with dementia has skin changes or injury, staff will provide skin and wound care that promotes comfort.

11. Bladder and bowels

As dementia increases, the person is likely to lose control of their bladder and bowel. If the person is still mobile they may fail to recognise the toilet. Maintaining your family/whānau member's dignity is most important.

Strategies:

- staff will keep your family/whānau member clean, dry and comfortable using regular hygiene, toileting and incontinence products
- if you have concerns about your family/whānau member's loss of control of bladder and bowels discuss this with the registered nurse.

12. Walking and Moving

In advanced dementia walking and balance may become more difficult. There may be an increase in falls. The person may forget how to use mobility aids such as walking sticks or walking frames. They may forget how to use the call bell for assistance. Eventually the person may be unable to walk or to stand. Some people may even lose the ability to move themselves when in bed.

Strategies:

- if the person is restless and tries to get out of bed staff may lower the bed or place a mattress on the ground
- using restraints may be considered when the person's safety is of grave concern ie a high risk of falling and injury. Examples of restraints are cot sides, safety belts on the toilet or chair. Whether to use restraints will be discussed with the family/whānau. You may be asked to give consent before restraints are used
- if the person with dementia is unable to stand safely staff will use a hoist to transfer and position the person.

Recognising dying

- Dying can be defined as the final or ending phase of physical life. Dementia is now recognised as a terminal illness. The actual cause of death among people who have dementia is often the result of complications of the disease.
- Most people die after a long period of illness with gradual deterioration and an active dying phase at the end. However this process varies from person to person and can be unpredictable, with some people maintaining mobility until the last few days.
- The person's need for food and fluid decreases as is the case for anyone at the end of their life. People who are dying gradually lose the ability to swallow and don't feel thirsty or hungry.
- There is potential for a variety of people to be involved in end of life care. It remains important for family/whānau and friends to be involved at a level that is comfortable for them. Please discuss any concerns with the staff so that they provide the best possible care.
- There may be changes in levels of alertness. The person will become more difficult to wake up and may not respond to talking or physical contact. Some people may still have moments when they recognise family/whānau members.
- The person with advanced dementia gradually loses the ability to move or lift their head up off the pillow. They will need full assistance with all physical cares such as washing, cleaning of the mouth etc.
- There may be changes in the person's physical appearance that can include mottling and discolouration of the skin. There may also be loss of muscle tone which will cause changes in facial expression.

After death

As in life the person's dignity is of the utmost importance. Their beliefs and values will be respected. Specific cultural, religious and spiritual needs should be discussed ahead of time. Discussing the individual and family/whānau preferences early can reduce stress at what is a difficult time eg choice of celebrant, cremation or burial etc.

Supports for Family/Whānau

There are many organisations that can offer support. Here is a list of some of the organisations that are available to support you.

Alzheimers New Zealand: www.alzheimers.org.nz

Alzheimers Auckland: phone (09) 622 4230, www.alzheimers.org.nz/auckland

Age Concern: phone (09) 820 0184, www.ageconcern.org.nz

Advance Care Planning: www.advancecareplanning.org.nz

Amitahba Hospice service: 44 Powell St Avondale phone (09) 828 3321:
www.amitabhahospice.org

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

Grief Centre: phone (09) 418 1457, www.griefcentre.org.nz

Health and Disability Advocacy: advocacy.hdc.org.nz

Hospice New Zealand: www.hospice.org.nz

Hospice West Auckland phone (09) 834 9750, www.wah.org.nz

Hospice North Shore phone (09) 486 1688, www.hospicenorthshore.org.nz

Hospice Hibiscus Coast phone (09) 421 9180, www.hibiscushospice.org.nz

Information for Care Givers (also available in other languages):
<http://caregiver.org/caregivers-count-too-toolkit>

Parkinson's Society: www.parkinsons.org.nz

Stroke Foundation of New Zealand: www.stroke.org.nz

Northern Region phone (09) 475 0070

Waitemata District Health Board: phone (09) 486 8900, 0800 809 342
www.waitematadhb.govt.nz

Needs Assessment and Service Coordinators: phone (09) 486 8945 ext 7171

There are other supports available such as cultural groups, RSA etc.
Facility staff may be able to advise you about local supports.



Appendix: legal definitions

Advance Directive

If the person with dementia already has an advance directive in place, the information in this document will be taken into consideration as part of the care planning process.

Enduring Power of Attorney (EPOA or EPA) and Guardianship

Enduring Power of Attorney (EPOA) cannot be set up once someone has lost mental capacity. An EPOA that was completed when the person was competent is activated once they are assessed by a medical practitioner as incompetent or lacking capacity. This must be written and signed by the medical practitioner activating the EPOA. Ensure that the EPOA is activated by checking with your legal advisor and medical practitioner.

If there is no EPOA the family/whānau should apply to the Court for appointment of a welfare guardian under the Protection of Personal Property and Rights Act. This should be a nominated person from the family or friend who is happy to take on this responsibility for the person once they lose competency. While this is being processed through the Court there should be a nominated person to speak on behalf of the person with dementia. Care decisions would then be made in consultation with health care professionals including the medical practitioner. This will help the health care professionals act in the best interest of the person with dementia. It is important that you are aware of the person's personal wishes, feelings and values to assist in making the best decisions on their behalf. Information about this is available through Age Concern phone: (09) 820 184, www.ageconcern.org.nz

Advance Care Planning

Advance Care Planning is a process that gives the opportunity to plan the health care preferences for the person with dementia, their family and the health care team. It is a way to ensure that the wishes of the person with dementia and their family have been thoroughly discussed and updated on a regular basis. It does not have to be a legalised formal process, but rather part of the care. The person who holds the EPOA for care and welfare makes decisions on behalf of the person with dementia in respect of their care and treatment.

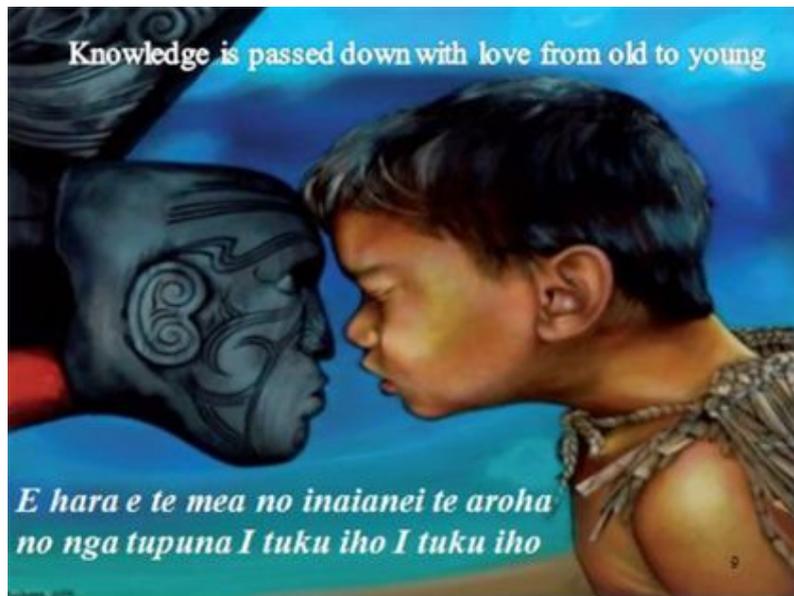
Notes

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Appendix 3



Summary of Partners in Care Project: Margaret O'Sullivan and Jenni Michel Older Persons Healthcare Experience: From Listening to action

During the first week of December 2013, patients and family service users of Waitemata DHB met with members of Waitemata DHB to share their stories through an “in your shoes” session. Feedback from 287 patients provided the project with rich data about their experience e.g. what they want more of and less of and was analysed using the Waitemata DHB values of ‘*Everyone Matters*’, ‘*Compassion*’, ‘*Connected*’ and ‘*Better Best Brilliant*’.

Following this initial session and as part of the Health Quality and Safety Commission Partners in Care Programme, Waitemata DHB invited 12 Maori elders living in West Auckland, and their whanau, onto the Waitakere Marae on 9 May 2014. The Gerontology Nurse Specialist, who is Maori, helped us be true to any cultural needs. She had visited every Maori elder to deliver the invitations and explain the process outlined in the “In Your Shoes” information sheet. Ten patients and their whanau were able to attend.

It was anticipated that much of the learning would emerge in the less formal interactions as well as the structured “In Your Shoes” activity. The structured discussion was facilitated by Waitemata DHB workforce development consultants, who organised listeners / scribes, and the Gerontology Nurse Specialist Dianna McGregor to uphold the Mana of the Kuia and Kaumatua whose voices were to be

heard, as well as Maori staff members attached to the research team to ensure Kawa Whakaruruhau of the kaupapa.

During the session, the Maori elders and their whanau were asked to focus particularly on aspects of their experience following admission to a general ward at either North Shore Hospital or Waitakere Hospital, over the previous eighteen months. In addition, they were asked what they would wish for in terms of service changes, staff practices and behaviours.

What was unique to Maori patients and their families?

- **Close to home** - patients and families greatly value being close to home so that whanau can visit and play an active role in care
- **Whanau helping** – a high emphasis is placed on whanau helping – at the bedside, in care and in bringing food and care items in from home. Whanau also valued when there was support for them in giving care
- **Community support** – presence and support from Kaumatua was very reassuring and allowed patients to have someone to speak up for them when whanau wasn't there or to say that whanau input was important
- **Marae** – being able to visit the Marae had a big impact on patients and helped recovery
- **What's right for me** – patients valued that they were treated as a Maori patient and that staff understood their cultural needs. This was appreciated in staff of all different cultures, not only from Maori staff
- **Expenses** – some whanau found the cost of travel and parking too expensive, as well as sometimes having to give donations to support groups. This could reduce whanau visits and access to support groups

These findings represent values and beliefs of Maori patients and their whanau.

The learning experience gained from our Maori elders and their whanau from West Auckland, at the session included:

- Waitemata DHB behaviours are demonstrated to a good standard on the wards
- Being welcoming and reassuring are behaviours that Maori greatly value, and were mentioned equally in positive and negative comments
- Being helpful is a behaviour that is greatly valued and staff currently excels consistently in this area
- Being efficient and communicating are areas which need greatest attention

We learnt that participants were keen to share their stories and make recommendations for changes in practice. Whilst we facilitated the day to the best of our ability, with advice from healthcare professionals who are Maori, the structure of the day was not acceptable to at least one of the Maori elders present, and this will be taken into account for any future sessions.

Two initial nursing led projects have come from the participants stories and both are related to forming relationships, based on trust:

1. To introduce a communication tool that will ensure greeting that includes making eye contact with the patient, at their level, and acknowledging them by name
2. To introduce, as a pilot, 'named nurse' into the current nursing care delivery model on the Assessment, Treatment and Rehabilitation ward at Waitakere Hospital.

**This project will be available on the HQSC website soon.*

IMPLEMENTATION OF THE NZ DISABILITY STRATEGY IN AUCKLAND & WAITEMATA DHBS UPDATE REPORT

Recommendation:

That the Disability Support Advisory Committee receives the update report on the implementation of the NZ Disability Strategy in Auckland & Waitemata DHBS.

Prepared by: Samantha Dalwood, Disability Strategy Coordinator, Waitemata DHB

Endorsed by: Dr Debbie Holdsworth (Director Funding), Sue Waters ADHB Executive Director Allied Health, Scientific & Technical

Glossary

DHB - District Health Board

1. Purpose

The purpose of this report is to provide an update to DiSAC on the joint Waitemata District Health Board (DHB) and Auckland DHB Implementation Plan 2013-2016 progress report which is attached.

Waitemata DHB and Auckland DHB Implementation of the New Zealand Disability Strategy 2013-2016 Current Status at 1 August 2014





Communication and Information Empowering people through knowledge and understanding
Current Status at 1 August 2014

<u>What</u> we will do... actions	<u>Where</u> we are now...current status
Accessible Communication guidelines developed.	
Review of Web content and presentation.	August 2014 – at the June DSAC meeting Gilbert Wong, ADHB Director of Communications, advised that his intent is to make paper and web-based communication as accessible as possible. Gilbert acknowledged that the Auckland DHB website does not meet accessibility standards. Plans are underway within the next 12 months to rebuild the website to address deficiencies in providing information. It will address the issue of providing information in the three main official languages. It is hoped to eventually run video on the website too.
Increase formats of key documents, e.g. Strategic Plans.	August 2014 – a Joint ADHB/WDHB Health Literacy Steering Group has been set up. The group’s purpose is to provide consistency across both DHB’s, share learning and work collaboratively to identify and implement best practice guidelines that support patients to access services, receive information (verbal and written) in a consumer/culturally sensitive manner that enables opportunities for best health outcomes and is consistent with the values of Auckland and Waitemata District Health Boards.
Review the automated telephone system with regard to access for people with disabilities.	August 2014 – The Contact Centre collaboration project is currently completing a second proposal, which will be open for feedback at the end of August. Initial feedback including the issues of an automated telephone system.
Review the possibility of improved text communication to patients.	August 2014 – The Contact Centre collaboration project is currently completing a second proposal, which will be open for feedback at the end of August.

Continue the implementation of the Health Passport across both DHBs.	August 2014 - Promoting the Health Passport to the Community through the CCS Disability Health & Wellness network. Also presented the Health Passport at Counties Manakau DHB DSAC meeting.
Work with the Deaf community to improve access to interpreters.	May 2014 - WATIS (WDHB Interpreting Service) have recommended improving wifi at the main hospital sites. Improved wifi will allow VRI (Video Remote Interpreting) to happen. VRI gives access to interpreters via an internet video connection.
Encourage the use of interpreters for non-English speaking families.	May 2014 - WATIS have recommended improving wifi at the main hospital sites. This will allow interpreting to be done across the internet, including NZSL interpreting.



Community and Engagement Working within a family and patient centred framework
 Current Status at 1 August 2014

<u>What we will do... actions</u>	<u>Where we are now...current status</u>
<p>Ensure a diverse range of disabled people are identified as stake-holders in all projects and service development.</p>	<p>May 2014 – The Patient Experience Manager has started at Waitemata DHB. The role looks at the improving the experience of all our patients, including disabled people.</p> <p>August 2014 – The Patient Engagement Manager will present at the DiSAC meeting on 27 August.</p>
<p>Engage regularly with the disability sector to develop their capacity to influence decision making and increase DHB responsiveness.</p>	<p>August 2014 – ‘In Your Shoes’ and Values work being done by WDHB & ADHB has actively engaged disabled people.</p>
<p>Ensure the voice of people with learning/intellectual disabilities, particularly people with high/complex needs, is included in consumer reviews of service planning and development.</p>	<p>August 2014 – The WDHB Disability Strategy Coordinator role continuously drives this message. Recent projects include Emergency Department at Waitakere, Maternity upgrades at NSH, Community Renal Service in Mairangi Bay and the improvements to the entrance at Auckland City Hospital.</p>
<p>Continue working with Health Links to increase health literacy through fully accessible patient information.</p>	<p>August 2014 – Health Literacy Steering Group driving this work cross both DHBs.</p>



Employment Opportunities Equal employment opportunities for people with impairments and carers
Current Status at 1 August 2014

<u>What we will do... actions</u>	<u>Where we are now...current status</u>
Encourage the use of supported employment agencies.	
Review all recruitment and employment policies and make recommendations to improve inclusion and employment opportunities for disabled people, as required.	
Collect data on the number of staff with disabilities (at the time of employment and/or when a disability is acquired).	
Work with Hiring Managers to increase disability awareness.	August 2014 – working with Recruitment Manager and Deaf Aotearoa to increase opportunities for Deaf people. This includes looking at safe ways to work in a hospital setting.
Working with HR to look at how the DHBs support staff with Carer responsibilities.	February 2014 – WDHB HR Workforce Development Team and Carers NZ are working on the following three work streams – 1. Carer Aware staff training, 2. a staff survey on caring responsibilities, and 3. Carer information being available on the staff intranet site. April 2014 – reviewed Carers NZ staff awareness training module and made recommendations. May 2014 – first Auckland area cluster meeting between Carers NZ and a small network of employers who want to support family carers in their workplaces.



Disability Responsiveness Educating staff and challenging stereotypes & assumptions
 Current Status at 1 August 2014

<u>What we will do... actions</u>	<u>Where we are now...current status</u>
Work with Dieticians to improve the nutritional outcomes for disabled patients.	August 2014 <ul style="list-style-type: none"> • WDHB Nutritional Charter has been completed and Nutrition Champions have been identified across the wards. • ADHB nutrition services Project group has been set up at to improve food and hydration in patients. • Releasing time to care for patients introduced into surgical wards at ADHB – patients food trays identified that patient needs assistance with feeding • Pilot for Trendcare initiated and ability to identify pt acuity and disabilities which need increased Allied health and nursing time to support these patients.
Develop 'Disability Champion' roles across the DHBs.	August 2014 – ADHB & WDHB working together to look at joint model for Disability Champions. Draft role description completed.
Promote the Disability Awareness e-learning module to all staff across the DHBs.	Ongoing.
Provide a range of disability awareness training, targeting specific services.	May 2014 – The Disability Awareness e-learning module has been reviewed and updated. The changes made are based on feedback from people who have completed the course.
Develop tools to increase staff skills for working with people with communication difficulties.	
Ensure public waiting areas, wards and treatment areas meet the needs of a range of impairments, including people with autistic spectrum disorders.	August 2014 - Values workshops at ADHB with visitors, patients and employees identifying 'things that matter'. Report of findings available in Sept 2014. Disability groups approached for their input and feedback. Continue to raise awareness as part of all projects, eg. Maternity.



Physical Access Overcoming a disabling society
Current Status at 1 August 2014

<u>What we will do... actions</u>	<u>Where we are now...current status</u>
Encourage the use of symbols and pictograms in signage and way finding.	August 2014 – the merger of Auckland & Waitemata DHB Facilities teams is a great opportunity to improve the way finding and signage at the hospital sites. Waitemata have done some good work to improve signage in new facilities.
ADHB Disability Champions will complete the 2-day Barrier Free Training.	
An accredited Barrier Free Advisor will be involved in all new Facilities work.	August 2014 - the merger of the two Facilities teams is a great opportunities to standardise ways of working across all sites.
Adoption of Universal Design principles in all Facilities work.	August 2014 - The Disability Access review is a joint undertaking between the Ministry of Business, Innovation and Employment (MBIE) and the Office for Disability Issues (ODI). The review will look at whether the current building regulatory system meets the needs of people with disabilities. Recommendations from the review were due mid-2014 and we are still waiting for them to come out.
Building standards document developed in ADHB.	August 2014 - Waitemata currently has a standardization document. The merger of the two Facilities teams will mean both DHBs can use the same document.
A review of accessible toilets in ADHB buildings to be completed.	May 2014 – Stage One of the review looking at leaks and plumbing is complete. Upgrades to toilets will be done on an individual project basis when funding becomes available.
Work with Auckland Transport to improve accessible transport between hospital sites.	August 2014 - a six month trial has commenced for visitors to travel between Waitakere & North Shore Hospitals.

Investigate the reported shortage of wheelchairs available - both numbers and sizes.

Completed – 40 wheelchairs were delivered and are in use across the services.