Dysexecutive Syndrome, Anosognosia, and Driver and Carer Evaluation of On-road Driving Performance: Results from a Dementia Driving Clinic

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Declaration

I certify that this thesis does not incorporate, without any acknowledgment, any material previously submitted for a degree or diploma in any university and that, to the best of my knowledge and belief, it does not contain any materials previously published or written by another person, except where due reference is made in the text.

Colin David Field

Date: _____

Dedication

AUDREY VIOLET FIELD

4 November 1928–17 June 2007

‘Keeper of the light’: Thank you for believing in me.

And, in memory of all members of my family who have died in wars declared and undeclared:

Osmond Field (Bob) EDDINGTON
1884–1917
Pte 12th Bn
Hindenburg Line at Noreuil, France, 15 April 1917

Lindsay McRae (Max) FIELD
1893–1917
Sergeant 3rd Australian Battalion Imperial Camel Corps
Second Battle of Gaza, Palestine, 19 April 1917

Gilbert O'Connor EDDINGTON
1889–1917
Gnr 13th Field Artillery Brigade
Ypres, Belgium, 1 October 1917

Alan McDonald BOWMAN
1911–1941
WGCDR, RAF, Western Desert Communications Flight
Gialo, Libya, 30 November 1941

Raymond Victor FIELD
1917–1942
Pte, 2/40 Bn
POW, Timor, 21 February 1942.

Shane Patrick WALSH-TILL
1970–2002
Kuta, Bali, 12 October 2002

'Oh, curséd be those cruel wars, that ever they began,
For they have robbed our country of many's the handsome man'.

—The Banks of the Nile (Tr.) collected by Ralph Vaughan Williams, Norfolk, 1904 (Palmer, 1983), adapted by Sandy Denny 1970.

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  - Professor Maria Crotty, Professor and Head of Division of Rehabilitation and Aged Care, RGH.
  - Ms Angela Berndt OT, formerly at RGH, now at the School of Occupational Therapy, University of South Australia.
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  - The copyright holders of the figures reproduced herein, for their kind permission to reproduce.
  - My cardiologist, Dr Alastair Begg, for keeping me vertical.
  - Mr Peter Cook for his on-road commitment to the cause, despite several near misses and one actual collision.
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Time and life

Fight to the end

But life has to bend

To her makers.

—David Cousins, ‘Time and Life’

Foreword

This thesis presents data derived from the Adelaide Dementia Driving Clinic (2004–present)—a clinical facility based initially at the author's former workplace at the Memory Disorders Study Clinic (MDSU) at the Repatriation General Hospital (RGH), Daw Park (South Australia), and later as part of the author's private practice. At the time of commencing the initial study (mid-1990s), the RGH MDSU was the sole South Australian specialist centre dealing with the diagnosis, treatment and management of dementia (Last, 1994). One major area of concern for this unit was the ability for community dwelling South Australians who had been diagnosed with dementia to manage the instrumental activities of daily living, including testamentary capacity, consent to medical treatment, financial capacity and the ability to safely drive a car. This thesis considers the outcome of 10 years of driving assessments of the Adelaide Dementia Driving Clinic, and subsequently considers various techniques (neuropsychological screening, driver self-rating, informant-spouse/carer ratings and clinician ratings) that have been considered as screening instruments among individuals with known or suspected dementia.

Abstract

This study presents data derived from a specialist dementia driving clinic located in Adelaide, Australia. In Australia, drivers with dementia are not categorically prevented from driving. Licensing authorities typically indicate that, at some stage during the process of a progressive cognitive decline, such as dementia, driving competency will be lost, and individuals with moderate to severe dementia are considered unsafe to hold a licence. The situation is less clear for those with mild dementia or prodromal dementia (mild cognitive impairment), and is further complicated by the likelihood that different subtypes of dementia may be associated with different rates of loss of driving competency. For this reason, it is commonly accepted that the issue of the driver with dementia needs to be considered on a case-by-case basis. It is also recognised that a proportion of individuals suffering from dementia will develop anosognosia (a deficit of self-awareness), which may affect the driver's ability to self-select a time for driving cessation.

It has been widely accepted that a comprehensive on-road driving assessment represents the gold standard by which the driver diagnosed with dementia may be examined. However, given the cost and complexity of such on-road reviews, there has been interest in the ability to screen drivers with known and suspected dementia using in-office tools, including neuropsychological assessment tools and various in-office questionnaires. Using a comprehensive on-road driving assessment as a gold standard, this project sought to examine selected neuropsychological tools (the Mini Mental State Examination [MMSE] and Trail Making Test Parts A and B [TMT-A and -B]), a self-scoring tool for drivers with dementia (Dementia Driver Questionnaire [DDQ]), tools designed to sample informant/carer opinion (Caregiver Questionnaire, based on a series of previously published informant questionnaires) and tools to measure reduced insight in drivers (the Consortium to Establish a Registry for Alzheimer's Disease [CERAD]

Insight Scale, and the Anosognosia Questionnaire—Dementia [AQ-D]), with and their association with the outcome of on-road assessments in this population. This study also had the opportunity to consider several subtypes of dementia (including mild cognitive impairment) and their effect on on-road outcomes, although it is acknowledged that the available sample size (for at least some subtypes of dementia) was limited.

The results of the current study indicate that selected neuropsychological tools vary in their relationship to on-road outcomes. An initial analysis using analysis of variance indicated no statistically significant difference between the pass–fail groups for MMSE, TMT-A *time to completion* and *errors*, and TMT-B *time to completion*, although there was a highly significant ($p = .007$) difference for TMT-B *errors*. However, further analysis using logistic regression indicated that a model incorporating the MMSE score plus driver age was able to distinguish between individuals who passed and failed the test ($\chi^2 = 6.454$, $p = .04$), and explained 10.5% of the variance in pass–fail status (Nagelkerke R^2), although a model using the MMSE score alone was unable to distinguish between individuals who passed and failed the test ($\chi^2 = 2.326$, $p = .127$), and explained 3.9% of the variance in pass–fail status. In contrast, a model incorporating the TMT results was statistically significant ($\chi^2 = 13.523$, $p = .019$) and explained 19.7% of the variance. Receiver operating characteristic (ROC) curves were plotted to demonstrate the optimal sensitivity and specificity for each tool under examination.

Logistic regression analyses indicated that a model incorporating the DDQ driver questionnaire was not statistically significant ($\chi^2 = 1.315$, $p = .252$) and explained 2.9% of the variance in pass–fail status; likewise, components of the Caregiver Questionnaire were not statistically significant ($\chi^2 = 4.864$, $p = .561$), yet explained 41% of the variance in pass–fail status. In contrast, logistic regression analysis indicated that a

model incorporating the CERAD questionnaire was statistically significant ($\chi^2 = 4.807$, $p = .000$) and explained 29.7% of the variance in pass–fail status, and a model containing components of the AQ-D score was once again statistically significant ($\chi^2 = 9.252$, $p = .026$) explained 28.4% of the variance in pass–fail status. For these measures, ROC curves were once again plotted to demonstrate optimal sensitivity and specificity.

This study concluded that the TMT has some association with pass–fail status, and that in-office tools to measure driver insight also have relationship with on-road outcomes. However, the results also indicate that driver opinion and informant opinion—as measured by selected tools—appear to have limited utility in screening for on-road outcomes. This thesis discusses the implications of these findings, and proposes a trichotomous decision tree for cessation of driving among drivers with dementia. This thesis also makes recommendations with respect to future developments.

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List of Abbreviations

ACL	Allen Cognitive Levels
aMCI	Amnestic Mild Cognitive Impairment
ANOVA	Analysis of Variance
AQ-D(D-C)	Anosognosia Questionnaire—Dementia, Driver-Carer versions
AUC	Area under the Curve
CDR	Clinical Dementia Rating
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
DDQ	Dementia Driver Questionnaire
DKEFS	Delis–Kaplan Executive Function System
DSM	Diagnostic and Statistical Manual of Mental Disorders
FAST	Functional Assessment Staging
GDS	Global Deterioration Scale
GP	General Practitioner
IADLs	Instrumental Activities of Daily Living
ICD-10	International Classification of Diseases 10th Edition
IQ	Intelligence Quotient
MCI	Mild Cognitive Impairment
MMSE	Mini Mental State Examination
NART-R	National Adult Reading Test—Revised
OT	Occupational Therapy
ROC	Receiver Operating Characteristic
SD	Standard Deviation
SE	Standard Error
SIMARD	Screen for the Identification of Cognitively Impaired Medically At-risk Drivers

TMT	Trail Making Test
TMT-A	Trail Making Test Part A
TMT-B	Trail Making Test Part B
UFOV	Useful Field of View
US	United States
VORT	Vehicle On-road Test
WAIS-III	Wechsler Adult Intelligence Scale—Third Edition

1. Introduction

1.1 The Older Driver

Driving is an important component of an individual's instrumental activities of daily living—it is important to enable community living individuals to access their environment and resources (Hoggarth, 2011) and is considered important in maintaining independence, feelings of self-worth, and connections to life and society (Donorfio, D'Ambrosio, Coughlin, & Mohyde, 2009). Transport accessibility is a key determinant of the ability of older people to remain healthy and active in their old age, and access services and programs. As such, transport is central to the health of older people (Browning & Sims, 2007). Compared to older individuals who continue to drive, older people who cease to drive have been shown to be more likely to have decreases in physical function (Edwards, Lunsman, Perkins, Rebok, & Roth, 2009), increases in depressive symptomatology (Fonda, Wallace & Herzog, 2001; Ragland, Satariano, & MacLeod, 2005), decreases in community engagement (Marottoli et al., 2000), increased likelihood of entry into long-term care facilities (Freeman, Gange, Munoz, & West, 2006) and increased mortality (Chihuri et al., 2015).

This appears to represent a good *prima facie* reason to encourage older drivers to maintain valid licences for as long as possible, with data for crash risk among older drivers suggesting a low rate in absolute terms (Langford, Methorst, & Hakamies-Blomqvist, 2006). However, when data are controlled for driving exposure, kilometres per year travelled (Baldock, 2004) and risk of injury and death (Braver & Trempel, 2004; Evans, 2000), a disproportionally high risk for older drivers emerges (Fildes, 2004). Most older drivers' accidents occur in situations requiring the perception of several details and complicated information processing (such as busy roads and

intersections). Such crashes typically also involve other cars (Daigneault, Joly, & Frigon, 2002).

Due to Australia's ageing population, an increasing number of older drivers on the road is anticipated, with the fastest growth in the age group of 85 years and over expected in the early 2030s as the early baby boomers enter this age range (Australian Bureau of Statistics, 2009). In addition to the number of older individuals, the number of older drivers is expected to increase due to an increasing proportion of older people with drivers' licences (Hakamies-Blomqvist, Sirén, & Davidse, 2004), a more active and healthy older population, a greater number of disposable incomes, and the growing reluctance of individuals to relinquish licences once they enter retirement (Alsnih & Hensher, 2003; Kostyniuk & Shope, 2003).

Factors thought to contribute to impairment of driving ability and subsequent crash involvement among older drivers relate to the normal biological changes associated with ageing. These have been described in the road safety and gerontological literature, and include gradual decline in vision, hearing, physical mobility and psychomotor performance, and increase in reaction time (e.g., Baldock, 2004; DiStafeno & MacDonald 2003; Stutts, Martell, & Staplin, 2009). As life expectancy has increased—and, with it, an increased number of older people susceptible to the development of dementia—research and clinical concern have focused on the issue of driving safety among older drivers who are cognitively impaired. There is accumulating evidence indicating that one causal factor in the deterioration of older drivers' performance is cognitive deterioration (Anstey, Wood, Lord, & Walker, 2005; Daigneault et al., 2002; DiStefano & MacDonald, 2003)—particularly neurodegenerative and vascular diseases, including dementia, which may be contributing to crash rates (B. M. Dobbs, 2005; A. Dobbs, Triscott, & McCracken, 2004).

1.2 Changes Associated with Ageing

In normal biological ageing, there are well-documented changes in sensory functions, vision, audition and functional performance decline in tasks requiring complex transformations, such as choice reaction time tasks requiring symbolic or spatial manipulation. These are considered to begin to decline between ages 50 and 60, with more pronounced decline beginning between ages 70 and 80 (Harada, Natelson-Love, & Triebel, 2013; Seidler et al., 2010). Ageing causes changes to brain size, vasculature and cognition. The brain shrinks with increasing age and there are changes at all levels, from molecules to morphology (Peters, 2006). The incidence of stroke, white matter lesions and dementia also rise with age, as does the level of cognitive impairment (Peters, 2006; van der Flier & Scheltens, 2005).

1.3 Skills Required for Driving Competence

Driving a car is a complex task requiring coordinated motor sensory and cognitive skills (Anstey et al., 2005; Carr, Barco, Wallendorf, Snellgrove, & Ott, 2011). This task requires mobility, physical strength (Marottoli et al., 1998) and vision, including the ability to cope with glare and contrast sensitivity, as well as intact visual fields (Owsley et al., 1998). Cognitive abilities are also essential to safe operation of a car. Driving involves a number of well-learned visuospatial and praxis skills, which are supervised by the executive function system of the brain (Abood, 2012; Lezak, Howieson, Bigler, & Tranel, 2012; Mathias & Lucas, 2009). Visuoconstructional and executive skills are elicited by environmental demands; thus, the entire process also requires sufficient significant attentional capacity (Ball & Owsley 1991; Mathias & Lucas, 2009; Stalvey & Owsley, 2000) and it is well recognised that these skills decline among older populations (Smith & Rush, 2006; Whalley, 2001). Faults made by drivers with cognitive decline in excess of the decline expected during normal ageing have been suggested as potentially catastrophic (A. R. Dobbs, 1997).

A wide range of error types have been posited in older drivers with dementia, mild cognitive impairment (MCI) or other cognitive deficits. In a group of older drivers with dementia, Hoggarth (2011) described that drivers who failed an on-road drive tended to show decreased awareness of other road users and the environment, lack of scanning techniques, inappropriate gap selection, incorrect use of give-way rules at intersections, slow or incorrect reaction to situations, driving too close to (or over) the left line, and driving above the speed limit. Barco et al.'s (2015) study compared driving errors among people with dementia who passed and failed an on-road test, and found that dangerous actions occurred most often when driving straight and making left turns. Specific driving behaviours associated with road test failure included difficulties in lane position and usage, stopping the vehicle appropriately, attention and decision making, and following the rules of the road.

Berndt, May, and Darzins (2015) defined a range of common driving errors that distinguished drivers with dementia who passed and failed a practical on-road drive. These included errors of traffic signal; left arrow to right arrow; dog-leg signal with traffic signal and lane choice; U-turns; brake with no mirror check; speed and mirror, lane position, right and left lane changes; and zip merge. Drivers with MCI have been described as demonstrating poor scanning and observation of traffic and road signals, an inability to monitor and control car speed, poor positioning of the car on the road, confusion with pedals, and a lack of anticipatory or defensive driving (Snellgrove, 2006). Older cognitively 'at-risk' drivers (drivers with indications of cognitive deficit) have been described as showing error groups including indication (signals), observation (traffic light observance, checking traffic and performing manoeuvres when safe), planning (smoothness of lane change, not hesitating without reason before proceeding, and planning to stop by slowing the vehicle) and speed control (Bowers et al., 2013).

Several models of driving competence have been suggested, with a typical model being the Driving as an Everyday Competence model (described by Lindstrom-Forneri, Tuokko, Garrett, & Molnar, 2010). This model indicates that driving performance and level of competence as outcomes are contributed to by a series of global factors (including health and cognition), environmental factors (both societal and individual), contextual factors (including physical, cognitive and emotional factors) and sensory factors, which are moderated by awareness and self-monitoring. This is detailed in Figure 1.1.

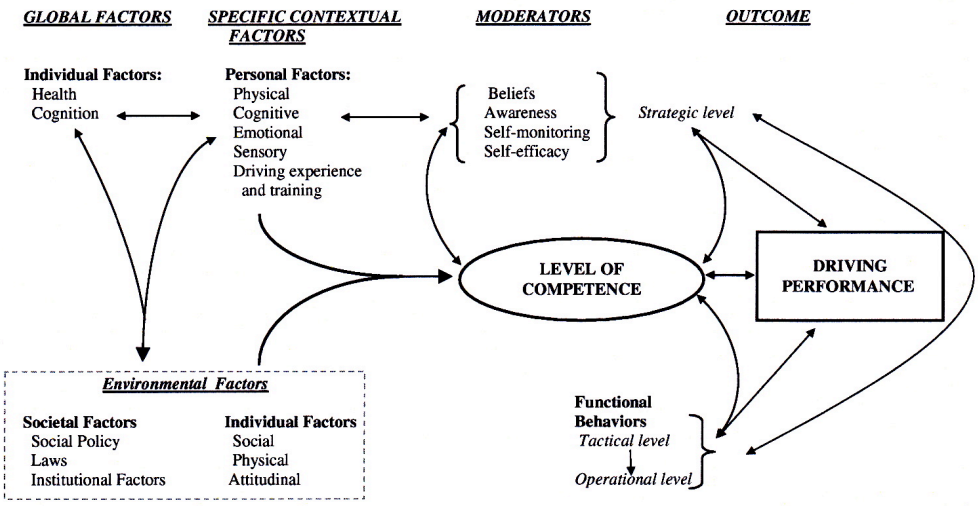

Figure 1.1. Driving as an Everyday Competence model.

Source: Reproduced from Lindstrom-Forneri et al. (2010, pp. 283–297), with the kind permission of Taylor & Francis PPL.

This model incorporates aspects of earlier driving models, including that of Michon (1989), which suggests the presence of three interacting hierarchical levels. The top level deals with strategic processes, such as route choice or consideration of road traffic rules. The middle tactical level involves processes such as planning actions or adapting to the movements of other drivers. The lowest level is concerned with action,

execution and perceptual processing. In their evaluation of the Michon (1989) model, Spiers and Maguire (2007) suggested that all three levels require intact cognitive function. Anstey et al. (2005) also suggested a multifactorial driving model specific to older adults, in which three enabling factors influence driving capacity (ability to drive safely): cognition, sensory functions and physical functioning. Lindstrom-Forneri et al. (2010) suggested that self-monitoring beliefs about driving capacity, in conjunction with actual driving capacity, ultimately determine driving performance. This component appears to relate to Michon's (1989) strategic level, where drivers must be aware of their capabilities to adjust their driving behaviours in response to differing or novel driving situations.

Spiers and Maguire (2007) reported a study using functional magnetic resonance imaging to measure neural substrates of driving behaviour. In a simulated driving exam using normal drivers, they identified different events that characterised the driving process on a second-by-second basis, as well as the brain regions that underlie them. They noted that, by performing specific events during simulated drives, the results provide insight to the brain regions, and confirmed the different components of driving described in Michon's (1989) model of driving. They noted that the category of prepared actions and unprepared actions aligned well with Michon's operational level, action planning and monitoring traffic with the tactical level, and thinking about road traffic rules with the strategic level.

It has been noted that specific brain regions appear to become activated during various aspects of driving performance (Spiers & Maguire, 2007), with the areas of the parieto-occipital cortices, cerebellum and cortical areas involved in perception and motor control becoming more involved during times of increased demand on vision, motor skills and visuomotor integration (Horikawa et al., 2005; Uchiyama, Ebe, Kozato, Okada, & Sadato, 2003). Activity in the frontal, parietal, occipital and thalamic regions

was found to be related to routine driving speed (Horikawa et al., 2005). Additionally, the ability to maintain a safe distance was negatively correlated with activity in the anterior cingulate gyrus (Uchiyama et al., 2003)—an area thought to be intimately involved in performance monitoring and supervisory attention (J. W. Brown & Braver, 2007). It has also been suggested (Horikawa et al., 2005) that the number of simulated crashes is negatively correlated with activity of the posterior cingulate. This is of particular interest, given that metabolic reduction of posterior cingulate activity appears to be specific to probable Alzheimer's disease (Minoshima et al., 1997) and is considered a differential diagnostic sign of Alzheimer's disease versus frontotemporal dementia (Bonte, Harris, Roney, & Hynan, 2004).

1.4 Understanding Dementia and its Effect on Driving Skills

All the models of driving defined above accentuate the cognitive components of driving skills, with older drivers having increased risk of the presence of generalised cognitive losses, such as those seen in dementia (Vella & Lincoln, 2014). The major risk factor for dementia is age; hence, with the increased ageing population expected in the next 20 to 30 years nationally, there is expected to be a significant increase in the rate of dementia within Australia (Deloitte Access Economics, 2011).

Recognised diagnostic criteria for dementia are cited in the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV-TR (American Psychiatric Association, 2000) and indicate the impairment of long- and short-term memory and losses in at least one of the following cognitive domains: agnosia, apraxia, aphasia or executive functioning. Cognitive functions must be severe enough to interfere with occupational/social activities, and represent a decline from previous functioning. The noted losses must be sustained and not appear purely within the context of an organic brain syndrome or delirium (American Psychiatric Association, 2000). Dementia is

considered a progressive and irreversible condition (Hogan et al., 2008; Lovestone, 2009).

This thesis acknowledges that a more recent version of the DSM (American Psychiatric Association, 2013) has now been published. This major structural revision has included a significant nosological change from earlier editions, with extensive rewriting of the section in the earlier editions called 'Delirium, Dementia, Amnestic and Other Cognitive Disorders'. The DSM now uses the blanket term 'neurocognitive disorders' (for example, 'neurocognitive disorders due to Alzheimer's disease'), and the term 'dementia' is subsequently no longer mentioned (Crowe, 2015). However, because much of the data collection for this project occurred during the publication dates of the DSM-IV-TR, the term 'dementia' continues to be used throughout this thesis.

'Dementia' is a blanket term covering a variety of underlying various aetiologies. Alzheimer's disease (senile dementia Alzheimer's type) is considered to account for approximately 50% of all cases of dementia (Seeher, Withall, & Brodaty, 2011). Other frequent causes of dementia include vascular dementia (20%), dementia with Lewy bodies (15%) and frontotemporal dementia (5%), which is considered a common younger-onset dementia with the average age of onset being 50 to 60 years (Seeher et al., 2011). Dementia as Parkinson's disease is also described, accounting for 3 to 4% of all dementia cases (Seeher et al., 2011). There is a large overlap of symptoms among Alzheimer's and vascular dementias, and for that reason the diagnosis of 'mixed dementia' is often made (Knopman, Boeve, & Petersen, 2003; Seeher et al., 2011; Zekry, Hauw, & Gold, 2002).

Of the common dementias described above, **Alzheimer's disease** is a neuropathological diagnosis describing widespread macroscopic and microscopic cellular changes, especially within the cortex ('hirnrinde') (Stelzman, Schnitzlein, & Murtagh, 1995). Classically, the presentation in life is that of an insidious onset of

generalised cognitive decline. There are also significant behavioural changes, especially later in the disease (Lovestone, 2009). Alzheimer's disease usually presents with significant changes in memory function, but also with aphasias, apraxias, agnosias, and dysexecutive syndrome. By definition, there is deterioration over time, and there is always significant functional impairment (Galton, Patterson, Xuereb, & Hodges, 2000).

Vascular dementia and **vascular cognitive impairment** typically demonstrate more prominent early losses of executive function than in Alzheimer's disease (Kertesz & Clydesdale, 1994; Sachdev et al., 2004), although recent studies have suggested major overlaps between the two groups on typical neuropsychological profiles (Graham, Emery, & Hodges, 2004; Mathias & Burke, 2009; Reed et al., 2007).

Dementia with Lewy bodies classically presents with a triad of symptoms that comprise fluctuating cognitive impairment, Parkinsonism and visual hallucinations (Ferman et al., 2006; Lovestone, 2009; McKeith, 2002).

A form of **frontal lobe dementia** was described originally by the psychiatrist Arnold Pick in 1892 (Williams, 2006), while another form of frontal lobe dementia without the distinctive neuropathological Pick body has been more recently described (Cummings, 1994; Neary, Snowden, Northen, & Goulding, 1988). Frontal lobe dementia encompasses early prominent changes, including aggressive, socially disruptive and antisocial behaviour (Miller, Darby, & Benson, 1997) and early losses of insight (O'Keeffe et al., 2007). Additionally, there is a distinctive subtype of dementia called **frontotemporal dementia** (FTD) (Hodges, 2001; Kertesz & Munoz; 1998; Miller et al., 1997; Warren, Rohrer, & Rossor, 2013), which includes various common diagnostic subtypes, including those with significant expressive language deficits (primary progressive aphasia) (Mesulam, 2013; Scholten, Kneebone, Denson, Field, & Blumbergs, 1995) or impaired word comprehension and semantic memory (semantic dementia) (Mummery et al., 2000). Both of these groups maintain intact comportment

(social behaviour, insight and appropriateness). In contrast, a group referred to as a behavioural variant of FTD shows profound alterations in comportment, with loss of empathy, disinhibition and antisocial behaviours predominating (Josephs et al., 2009). Memory and visuospatial skills are relatively spared in most FTD patients (Bird & Miller, 2010).

Rarer forms of dementia have also been described, including a dementia secondary to Huntington's disease, and various prion diseases (Lovestone, 2009). Additionally, a proportion of patients with early cognitive decline chiefly affecting memory function are recognised as a prodrome to dementia, which is usually referred to as 'amnestic MCI' (aMCI), 'cognitive impairment no dementia' or 'prodromal dementia' (Lovestone, 2009). MCI is a recognised risk factor for later development of Alzheimer's disease (Campbell, Unverzagt, LaMantia, Khan, & Boustani, 2013). This group is relatively harder to diagnose in the early stages, are probably much more numerous than people with established global dementias (Petersen, 2003), and are considered to have impairments that are sufficiently mild to not interfere with daily function (Seeher et al., 2011).

The common aMCI subtype is presumed to have intact executive function (Petersen, 2003). Typically, the amnesic MCI client describes and is assessed as having losses of recent learning and memory skill, with other cognitive domains intact. However, rarely, other 'single channel' losses (such as focal losses of executive function, but with preserved memory) may also be described (Lehrner, Maly, Gliess, Auff, & Dal-Bianco, 2008). Further, a vascular subtype with more prominent losses of executive function—compared with the localised memory deficit of prodromal Alzheimer's disease—has been proposed (Nordlund et al., 2007; Zhou & Jia, 2009), as has a limbic subtype that presents with Parkinsonian symptoms and fluctuating course (Molano et al., 2010). It has now become evident that a proportion of older drivers with

MCI diagnoses may have deterioration of driving skills, even without the presence of an established dementia (Olsen, Taylor, & Thomas, 2014; Snellgrove 2006).

While, on the basis of prior published literature, it is likely that all forms of dementia may eventually lead to some decrement of driving skill (B. R. Ott & Daiello, 2010), the degree to which different forms of dementia may lead to early losses of driving skills is unclear. It has been considered (De Simone, Kaplan, Patronas, Wasserman, & Grafman, 2007; Turk & Dugan, 2014) that continuation of driving may be problematic in the presence of an FTD diagnosis, especially given that this subtype is considered to demonstrate early changes in loss of inhibition and insight, and changes in personality and self-monitoring (Rankin, 2010). Common dementias—such as Alzheimer's disease, vascular dementia and Lewy body disease—may lead to loss of inhibition (Starkstein & Kremer, 2001), executive function (Elliott, 2003) and visuospatial skills (Tiraboschi et al., 2006), with the potential of each of these elements affecting driving skills (B. R. Ott & Daiello, 2010).

1.5 Dementia and the Dysexecutive Syndrome

Executive functions are essential for normal adult activity (Goldberg, 2001). These functions contribute to individuals' ability to reason, plan, problem solve, meet goals and behave appropriately in specific situations (Hanna-Pladdy, 2007; Luria, 1980). Thus, an intact executive system with preserved modulation of inhibition function is considered crucial in high-level human activities, such as driving a motor vehicle (Lezak et al., 2012; Mathias & Lucas, 2009). Significant losses in these areas are referred to as 'dysexecutive syndrome' (Hanna-Pladdy, 2007).

Loss of executive function due to acquired brain disease has long been associated with impairment of the 'instrumental activities of daily living' (IADLs) (Martyr & Clare, 2012). These losses are common concomitants of many forms of dementia (Amieva, Phillips, Della Sala, & Henry, 2004; Kertesz & Munoz, 1998; Miller

et al., 1997). Many types of dementia featuring disease processes with focal or maximal dysexecutive changes yield prominent features of conduct disorder (Kertesz & Munoz, 1998; Neary et al., 1988). Higher rates of antisocial behaviour (including stealing, physical assault and sexual comments or advances) have been reported in patients with FTD, compared with equally cognitively impaired patients with Alzheimer's disease (Miller et al., 1997; Stip, 1995). Additionally, widespread deficits of inhibitory functioning occur during the course of Alzheimer's disease, especially in late-stage patients (Amieva et al., 2004). These can affect a wide range of everyday behaviours, with significant consequences on effective functioning in the real world (Royall et al., 2002; Starkstein & Kremer, 2001), including driving (B. R. Ott & Daiello, 2010).

A form of dysexecutive syndrome has also been repeatedly implicated as an underlying contributor to anosognosia—a deficit of self-awareness and failure to recognise a disability (Pia & Conway, 2008; Prigatano, 2010). It is well recognised that there may be loss of insight or denial of illness in dementia, and these appear to vary with dementia subtype and severity of dementia (Howorth & Saper, 2003). FTD, along with corticobasal degeneration and progressive supranuclear palsy, are noted for early loss of insight and concurrent changes in medico legal states, including testamentary capacity (O'Keeffe et al., 2007). Anosognosia has been widely reported in the dementias, including Alzheimer's disease (Kaszniak & Edmonds, 2010; Pia & Conway, 2008; Starkstein, Jorge, Mizrahi, Adrian, & Robinson, 2007; Starkstein & Power, 2010; Starkstein, Sabe, Chemerinski, Jason, & Leiguarda, 1996), FTD, corticobasal degeneration and progressive supranuclear palsy (O'Keeffe et al., 2007), Huntington's disease (Tranel, Paulsen, & Hoth, 2010) and Parkinson's disease (Prigatano, Maier, & Burns, 2010). Anosognosia is considered particularly prevalent in FTD (O'Keeffe et al., 2007).

Salmon et al. (2006) explored the neural substrates of anosognosia in a large (*n* = 209) group of Alzheimer patents, initially by measuring patient and carer self-evaluation rated on 13 cognitive domains, and then by deriving two measures of anosognosia. Impaired self-evaluation was related to a decrease in brain metabolism measured by positron emission tomography scanning of the orbital prefrontal cortex and medial temporal structures. They suggested a cognitive model of anosognosia in which medial temporal dysfunction might impair a comparison mechanism between current information on cognition and personal knowledge. They also suggested that hypoactivity in the orbitofrontal cortex may not allow Alzheimer patients to update the qualitative judgement associated with their impaired cognitive abilities. Additionally, caregivers' reports were negatively correlated to metabolic activity located in the temporoparietal junction, consistent with an impairment of self-referential processes and perspective taking in Alzheimer's disease.

Goldberg (2001) suggested that anosognosia is directly related to frontal lobe dysfunction and is associated with impaired editorial function of the frontal lobe: comparing the outcome of one's operations with one's intentions. He also suggested that awareness of a deficit is the basic prerequisite of any effort on an individual's behalf to improve his or her condition, and that an individual with anosognosia experiences no sense of loss or deficiency, and thus no urge to strive to correct it. According to Starkstein et al. (2007), there appears to be a relationship between the emergence of dangerous behaviours and anosognosia, and the loss of executive function as measured by a verbal fluency task. The implication from their study is that high-level IADL tasks, such as driving, may be early 'casualties' in the loss of executive function and anosognosia in Alzheimer's disease. Indeed, there have been a series of publications discussing the relationship between anosognosia and on-road driving skills

among dementia patients (Kay, Bundy, & Clemson, 2009; Pachana & Petriwskyj, 2006).

1.6 Driving and Dementia

Safe driving relies on the ability to perform habitual motor functions (such as operating motor vehicle controls) while simultaneously responding to changing environmental demands, including emerging threats (such as traffic, pedestrians and cyclists). The ability to perform these activities among individuals with dementia may be compromised due to the associated decline in motor responsiveness, decline in cognitive processing speed and difficulties with simultaneous processing (Angley, 2001; L. B. Brown, Ott et al., 2005; L. B. Brown, Stern et al., 2005; Cook, Sisco, & Marsiske, 2013).

The pronounced cognitive changes associated with neurodegenerative and vascular diseases prevalent among the ageing population are likely to affect the ability to drive safely, and contribute to crash rates (Australian Institute of Health and Welfare 2010; Carr, Shead, & Storandt, 2005). A range of previously published studies has demonstrated elevated crash risk among patients with Alzheimer's disease and other dementias (Breen, Breen, Moore, Breen, & O'Neill, 2007; Lees, Cosman, Lee, Rizzo, & Fricke, 2010). Of particular concern in older drivers are the cognitive deteriorations associated with dementia (Bieliauskas, Roper, Trobe, Green, & Lacy 1998; British Psychological Society, 2001) and MCI (Frittelli et al., 2009; Snellgrove, 2006). The risk of motor vehicle accidents for drivers with dementia is significantly greater than the risk for age-matched cognitively unimpaired drivers (Angley, 2001). One study reported that, in the brains of drivers aged 65 years and over who were killed in car accidents, over 50% had the neuropathological changes of Alzheimer's disease (Lipski, 1997). Additionally, Lundberg, Hakamies-Blomqvist, Almkvist, and Johansson (1998) reported that, in a series of older drivers who perished in vehicular crashes, over half

showed evidence of possible or probable Alzheimer's disease, even though none had a diagnosis of probable Alzheimer's disease in life, and a high proportion of family members were unaware of any difficulties.

In Australia, drivers with dementia are not categorically excluded from driving a private motor vehicle (Austroads, 2016), although the authors do acknowledge (Section 6.1) that a number of conditions that become more prevalent with age reduce the capacity to drive safely, and it is additionally noted that, after the age of 70, the average driver has a higher collision rate per kilometre travelled, when all factors are taken into account. Additionally, specific comment is made that the presence of dementia (of any degree of severity) means that the driver should not hold an unconditional licence. However, in Australia, the specific conditional requirements for a driver with dementia are not specified, and are left up to the clinician to decide (Austroads, 2016).

Consensus has been reached that driving with moderate to severe dementia poses significant risk to individual and public road safety, and driving should be precluded in this population (Johansson & Lundberg, 1997). However, there is debate regarding the area of competence and societal response to older drivers suffering either early dementia or MCI (prodromal dementia) (Frittelli et al., 2009; Lipski, 2001; Wadley, Okonkwo, Crowe, & Ross-Meadows, 2008). Snellgrove (2006) estimated that there may be approximately 162,500 older drivers on Australian roads with cognitive impairment associated with dementia. Moreover, at least 50% of individuals may continue to drive for up to three years following the onset of dementia—well into the moderate range of the dementing illness (Carr, Duchek, & Morris, 2000; B. M. Dobbs, Zirk, & Daly, 2009; Foley, Masaki, Ross, & White, 2000; Hopkins, Kilik, Day, Rows, & Tseng, 2004).

Lipski (2001, 2002) proposed that individuals with mild dementia be precluded from driving. The recommendations from this study included driving evaluation and

close supervision of people with MCI. Lipski argued that the definition of early dementia represents a vast, heterogeneous degree of cognitive impairments. Individuals with such impairments can steer a car, even though they may be completely disoriented in time and place. They can rely heavily on their fixed implicit memory to drive familiar routes; however, in the event of sudden changes in traffic conditions, they are unable to rapidly process new stimuli. Lipski (2002) asked if a driver with early dementia is safe to drive a motor vehicle, at what point is the driver deemed unsafe? Drivers diagnosed with early dementia have usually already been in the MCI phase for three to four years before presentation. They have continuing cognitive decline, and there is no established objective end point at which they should be re-tested or disqualified from driving before they pose a risk to public safety.

There have been a range of prospective studies investigating the actual on-road driving performance of individuals with early dementia. Hunt, Morris, Edwards, and Wilson (1993) examined the driving ability of 12 participants with prodromal Alzheimer's disease (MCI), 13 participants with mild Alzheimer's disease, and 13 healthy control participants. All prodromal Alzheimer's disease participants were judged to be safe, while 40% of drivers with mild Alzheimer's disease were unsafe. In a follow-up study (Hunt et al., 1997a), 58 controls, 36 participants with MCI and 29 participants with mild Alzheimer's disease undertook a Washington University Road Test. The authors reported that 3% of the controls, 19% of those with MCI and 41% of participants with early Alzheimer's disease failed the driving test.

Duchek et al. (2003) longitudinally assessed the on-road driving performance of healthy older adults and adults with MCI and early-stage Alzheimer's disease, as measured by the Clinical Dementia Rating (CDR) (Morris, 1993), and found that driving performance decreased in function of severity of cognitive impairment. After repeated testing, there was evidence of decline in driving skills across all three groups

of drivers, including the healthy controls; however, the greatest decline in longitudinal driving performance was in the mild Alzheimer's disease group.

A case-control study by Uc, Rizzo, Anderson, Shi, and Dawson (2004) found that, even though basic vehicle control abilities appeared normal, drivers with mild dementia (n = 32) made more frequent drive errors than did the asymptomatic controls (n = 136), and they concluded that this is because driving imposes demands on memory, attention and perception. This relationship between driving competence and cognitive deficits has also been identified in other case-control studies, including those by Clark, Hecker, Cleland, Field, and Berndt (2004); Clark et al. (2000); De Simone et al. (2007); and Whelihan, DiCarlo, and Paul (2005). These studies substantiated claims in the opinion-based literature (Breen et al., 2007; L. B. Brown & Ott, 2004; Hogan et al., 2008) that drivers with dementia may need to retire from driving as their illness progresses and, while six-monthly reassessments are recommended, the timeline between diagnosis and driving cessation is unclear (Adler, 2010; Hogan et al., 2008).

While collective opinion is that drivers should not continue in the presence of moderate to severe dementias (Johansson & Lundberg, 1997), there is additional indication that even the classification of mild (early) dementia and cognitive impairment may be a warning sign that the individual may not be competent to drive safely (Snellgrove, 2006).

1.7 Summary Comments

This chapter has introduced the issue of dementia as a significant health issue in Australia (Seeher et al., 2011). Driving is a complex and multifactorial process (Lindstrom-Forneri et al., 2010) and it is acknowledged that driving with dementia may be a complex issue because, while there is a solid body of knowledge associated with losses of driving skills in dementia (B. R. Ott & Daiello, 2010) and there are potential roles of loss of executive function (Elliott, 2003), inhibition (Starkstein & Kremer,

2001), insight (Kaszniak & Edmonds, 2010) and visuospatial function (Tiraboschi et al., 2006), there is no real consensus regarding the issue of how and when to review the driving status of older drivers with known or suspected dementia. Thus, the next chapter will consider the complex matter of identifying drivers at risk for loss of driving competence among individuals with MCI and dementia.

2. Identification of At-risk Drivers with MCI and Early Dementia, and the Potential Role of Anosognosia

2.1 Identification of At-risk Drivers

Given the risk profile of older drivers with cognitive impairment, researchers have investigated various ways to determine driving competence in this population. Four major approaches have been considered, as follows.

2.1.1 On-road tests. Previous research—including systematic reviews undertaken by Man-Son-Hing, Marshall, Molnar, and Wilson (2007) and Molnar, Patel, Marshall, Man-Son-Hing, and Wilson (2006b)—has concluded that on-road assessment of driving performance is the most accurate means of assessing fitness to drive. On-road tests provide functional assessment of driving ability in a 'live' situation and are currently considered the gold standard for assessing driving fitness (A. R. Dobbs, 1997; Fox, Bowden, Bashford, & Smith, 1997; Hunt et al., 1993; Shechtman, Awadzi, Classen, Lanford, & Joo, 2010). However, not all driving assessments are the same. Assessments are performed on different types of courses with evaluators of different qualifications and expertise in assessing older people.

Abood (2012) contrasted occupational therapy (OT)–based comprehensive driving assessments with road traffic authority (government-based) driving tests. The OT tests consider the medical context in which the assessment occurs, provide an off-road (screening) component, and consider issues of driver habit versus condition-related errors. The on-road assessment can be structured in accordance with specific physical or cognitive issues, and the assessment takes around 40 to 60 minutes as an on-road component. In contrast, the traffic authority assessments are much briefer (typically only 15 minutes), are structured and controlled by the driving tester using a set route,

and the examiner has no understanding of which errors are condition-related versus driver habit. Finally, no context, off-road interviews or screening issues are considered.

Similarly, Hunt et al. (1997b) indicated that conventional licence tests are usually highly controlled by the examiner, who is continually providing cues (such as 'turn right here'). Hunt et al. suggested that it was possible for an impaired driver to pass the brief structured test, yet still be unsafe in their usual uncontrolled setting when they must rely on their own judgement and cognitive abilities. Additionally, there are concerns regarding public and individual road safety, the liability of assessors, and the reluctance of older people to participate because of fears of licence cancellation (Abood, 2012; Barbas & Wilde, 2001; A. Dobbs et al., 2004; Snellgrove, 2006) and caregiver dependence on the continued driving of the subject driver (Adler, Rottunda, Rasmussen, & Kuskowski, 2000).

2.1.2 Driving simulators. Several studies have examined the suitability of driving simulators and on-road driving assessments for determining driving competence. Although the use of driving simulators is very appealing because they are uniformly safe, evidence indicates that performance in driving simulators is not strongly related to on-road driving performance (Barbas & Wilde, 2001; Bylsma, 1997; Gianutsos & Delibero, 1999; Harvey et al., 1995; Lundberg et al., 1997; Rizzo, McGhee, Dawson, & Anderson, 2001). Moreover, older people have been shown to perform poorly on driving simulators, irrespective of their ability to drive, simply because they lack familiarity and confidence with using computers and electronic 'games' (Balland & Ackerman, 2011; Turkington, Sircar, Allgar, & Elliot, 2001). While recent advances in technology have generally improved the standard of such simulators, there remain limitations, especially when attempting to measure driving skills (Allen, Rosenthal, & Cook, 2011).

2.1.3 Neuropsychological review. Various neuropsychological techniques have been proposed to screen for at-risk behaviour in drivers with early dementia. This approach is appealing due to the cost and complexity of on-road reviews (Mathias & Lucas, 2009; Silva, Laks, & Engelhardt, 2009). However, the results have varied widely, possibly due to variations in the definitions of dementia and/or levels of dementia, and the individual tests or suites of tests chosen. Several studies have recommended the use of the MMSE (Adler & Kuskowski, 2003; Bieliauskas et al., 1998; Fox et al., 1997).

The MMSE is a brief screening task developed for clinical detection of generalised dementia (Folstein, Folstein, & McHugh, 1975). It has been used for a wide variety of indicative tasks, although some of these have not been particularly successful. For example, Tombaugh and McIntyre (1992) reported that the MMSE is particularly insensitive to the presence of dysexecutive syndrome and constructional failure (and has minimal or no specific item content dealing with these domains). The MMSE has also been demonstrated to be relatively sensitive to premorbid ability level (Tombaugh & McIntyre, 1992) and educational attainment (O'Bryant et al., 2008a), and to have limited ability to detect the presence of an amnesic syndrome, which is central to most variants of dementia (Field, 1995). Despite this, the MMSE has been used widely as both a research and clinical tool, and a reasonably large number of studies have used this tool specifically to predict failures of on-road driving performance. While the results have been inconsistent, a general conclusion is that individuals with low MMSE scores are less likely to drive safely, which is unsurprising given that, at scores below 20/30, the individual is likely to be suffering a significant dementia, with all the losses of IADLs that accrue from this state.

Fitten et al. (1995) found that MMSE scores are closely related to driving simulators and on-road performance. Fox et al. (1997) also recommended the MMSE as

an indicator of possible emerging driving issues, with a score of 18 or below being considered a useful cut-off. Man-Son-Hing et al. (2004) suggested that the MMSE is a good predictor of on-road driving performance results, but not of crashes or traffic violations. They recommended that MMSE scores below 10 justify recommending immediate cessation of driving. However, in contrast, other studies (Clark et al., 2000; Crizzle, Classen, Bédard, Lanford, & Winter, 2012; A. R. Dobbs, 1997; Hogan, 2005; Lee, Cameron, & Lee, 2003; O'Neill, Neubauer, Boyle, Gerrard, & Surmon, 1992) indicated that MMSE scores have limited ability to discriminate individuals with diminished driving ability from those with preserved ability. Additionally, in two prospective studies, the MMSE was found not to predict future crashes or road violations (Fox et al., 1997; Trobe, Waller, Cook-Flannagan, Teshima, & Bieliauskas, 1996). A more comprehensive derivation of the MMSE (Addenbrooke's Cognitive Examination, Revised) has recently been proposed as an enhanced screener for older drivers (Ferreira, Simoes, & Maroco, 2012), as has the Montreal Cognitive Assessment (Hollis, Duncanson, Kapust, Xi, & O'Connor, 2015).

A range of published studies have attempted to predict on-road driving ability in older drivers with dementia, using more comprehensive neuropsychological tests. These include the studies by Clark et al. (2000, 2004), A. R. Dobbs (1997), Grace et al. (2005), McKenna and Bell (2007), B. R. Ott et al. (2008) and Whelihan et al. (2005). Bieliauskas (2005) suggested that testing executive function is the most fruitful way forward in terms of predicting on-road driving assessment, noting that loss of executive function in older drivers is consistent with a frontal ageing hypothesis, with the prefrontal cortex leading most other areas of the brain in the ageing process and also being particularly prone to loss of inhibition function. Daigneault et al. (2002) also suggested that individuals driving in complex situations where adaptation is required are less able to perform successfully if their executive functions are inefficient.

One study by L. B. Brown, Stern et al. (2005) using the driving scenes test from the neuropsychological battery demonstrated reasonably good classification of participants into normal older and mild dementia driver groups. McKenna and Bell (2007) also demonstrated satisfactory prediction of on-road driving performance among older drivers using the Rookwood Driving Battery, which comprises several executive function tests, visual perception tests and praxis and comprehension tests. Whelihan et al. (2005) used a wide range of neuropsychological measures on a small ($N = 23$) group of patients with questionable dementia as measured by the CDR, compared with 23 age-matched controls. They concluded that neuropsychological executive and visual attention measures may play a useful role in determining competence to drive among older individuals with early-stage cognitive decline, with the maze navigation, TMT-B (Reitan, 1958) and useful field of view (UFOV) (Edwards et al., 2006) measures being the best predictors of overall performance.

Clark et al. (2000, 2004) recruited 55 drivers with diagnoses of dementia from a hospital memory clinic and applied a standardised driving course and wide range of neuropsychological tests. The best neuropsychological predictors of on-road outcomes were the TMT-A and -B and Wechsler Adult Intelligence Scale—Third Edition (WAIS-III) Block Design (Wechsler, 1997). Dawson, Anderson, Uc, Dastrup, and Rizzo (2009) applied a composite neuropsychological battery, COGSTAT—composed of seven individual neuropsychological tasks and various visual tasks and motor accuracy tasks—to a group of drivers with dementia. COGSTAT was considered a significant predictor of safety errors for the on-road task, with a 4.1 increase in safety errors observed for a one standard deviation (SD) decrease in cognitive function.

Several other studies have offered composite predictor scores based on a series of related or unrelated cognitive tasks (Boets & Arno, 2005; DeRaedt & Ponjaert-Kristoffersen, 2001; Grace et al., 2005; Lincoln, Taylor, Vella, Bouman, & Radford,

2010). Additionally, B. R. Ott et al. (2003) and Snellgrove (2006) recommended maze-based tasks. B. R. Ott et al. used a traditional Porteus maze format (Carlozzi, 2011), whereas Snellgrove used a newly developed maze task. The TMT has been widely used in predicting driving skills among individuals with dementia (Grace et al., 2005; Hunt et al., 1997b; Rizzo et al., 2001) and older drivers (Betz & Fisher, 2009; Classen, Wang, Crizzle, Winter, & Lanford, 2013; A. R. Dobbs, Heller, & Schopflocher, 1998), although negative results have also been reported in a group of older drivers with dementia (B. M. Dobbs & Shergill, 2013) and without dementia (Vaucher et al., 2014). The American Medical Association (2010) has recommended the use of the TMT when evaluating driving competence.

In addition to individual studies that have considered the use of single or multiple neuropsychological tests and their relationship with drive outcomes, several meta-analytic reports have now been published, some of which have been critical of the methodologies of previously published studies. An early meta-analysis of attempts at neuropsychological prediction of driving assessment of older drivers with dementia (Reger et al., 2004) systematically reviewed 27 studies, although notably eight of these used caregiver reports as proxy for on-road skills. Additionally, studies used a variation of road or non-road tests (closed circuit courses), including 10 road tests, seven non-road tests, and two further studies that combined both methodologies. Further, 11 of the studies failed to provide an appropriate control group. The authors concluded that the meta-analysis revealed a significant relationship between neuropsychological functioning and driving ability, as measured by road and non-road tests. They noted that effect sizes were significant yet small for the relationship between on-road driving and all neuropsychological tests on patients with dementia. When tests were classified according to cognitive domain assessed, effect sizes were greatest for measures of

visuospatial skills. They concluded that caution must be applied when neuropsychological testing forms the basis of driving recommendations.

Molnar, Patel, Marshall, Man-Son-Hing, and Wilson (2006a, 2006b) conducted similar reviews; however, instead of aggregating tests into cognitive domains, they examined each test separately. They identified 16 studies that examined the relationship between cognitive tests and driving ability, yet only six used on-road driving as a measure of driving ability. They noted marked inconsistencies between studies, with tests showing a positive association with driving in some studies, but not others. They also identified the problem that very few studies provided cut-off scores for tests that could be used to make clinical decisions with individual patients. They considered that the purpose of cognitive screening is to identify people with borderline cognitive abilities, and refer them for specialist on-road assessment. They also suggested that cognitive tests could be used at specialist driving assessment centres as part of an overall evaluation, and used in conjunction with on-road assessment to make recommendations about safety to drive.

Vrkljan, McGrath, and Letts (2011) provided a more recent meta-analysis of office-based cognitive and sensory assessment tools in establishing fitness to drive among stroke and dementia subjects. They concluded that numerous assessment tools are available for use in clinical practice, yet they can vary substantially in administration, reliability, validity and applicability to the driving domain. They suggested that any tool used to inform clinical decision making about a person's ability to return to driving should not only have rigorous psychometric properties, but also have evidence linked to driving performance. In their analysis, a total of 42 assessment tools were identified from a literature search as having evidence potentially linked to driving assessment. Of these tools, 17 met the inclusion criteria (studies linking the tool with driving performance). Tasks were rated for predictive validity and the availability

of cut-off scores to determine pass–fail outcomes. Of these, the UFOV, TMT-A and -B, and several other motor tasks were considered to have at least adequate validity and rating. However, they noted that only the UFOV demonstrated viable cut-off scores.

A further meta-analysis (Mathias & Lucas, 2009) considered neuropsychological prediction of on-road outcomes among older drivers without dementia. They examined 21 studies involving 5,797 participants. The inclusion criteria included the use of on-road assessment, simulators or driving problems as outcome measures. They concluded that there was considerable variation in the ability of these tests to distinguish between good and bad drivers, and that it is not possible to determine the extent of overlap in the people identified as potentially unsafe and in need of more comprehensive driving evaluations. They recommended further research that assesses sensitivity (such as the ability of cognitive tests to identify unsafe drivers correctly) and specificity (such as the ability of cognitive tests to identify safe drivers correctly). They also recommended that cut-off scores with known sensitivity and specificity should be used in health settings to determine the need for additional driver assessments.

Kay, Bundy, Clemson, Cheal, and Glendenning's (2012) critical review of neuropsychological predictors suggested that a screening battery as a replacement for a road test should achieve both sensitivity and specificity of at least 90%; however, to date, none of the batteries tested has reached that goal for a binary classification of safe versus at-risk drivers. They suggested that, for published studies to be considered suitable for predicting on-road performance, they should provide specificity, sensitivity and an area under the curve (AUC) statistic for receiver operating characteristic (ROC) curves (Mason & Graham, 2002).

2.1.4 Driver and/or informant questionnaires. Several authorities (e.g., Canadian Medical Association, 2006; Hogan et al., 2007; Molnar, Byszewski, Rapoport, & Dalziel, 2009) have recommended using driver self-scoring questionnaires

and/or informant (carer/spouse) questionnaires to alert older drivers, their families and their medical professionals to possible issues of declining driving skills in older drivers with and without dementia. However, these appear to have been recommended by expert panels and/or consensus, rather than by application of formal statistical predictive accuracy. These will be considered further in Section 2.3 below.

2.2 Anosognosia (Deficit of Self-awareness) in Driving and Dementia

Among individuals suffering from dementia, there may be issues of anosognosia (deficit of self-awareness), especially when associated with dysexecutive changes secondary to the dementia (see Section 1.5). Thus, it is recognised that anosognosia and loss of insight may be significant in the decision to retire from driving among older drivers (Kay et al., 2009) and drivers with dementia (Pachana & Petriwskyj, 2006). It has been noted that older drivers without dementia tend to overestimate their own performance (Freund, Colgrove, Burke, & McLeod, 2005; Pachana & Petriwskyj, 2006; Sullivan, Smith, Horswill, & Lurie-Beck, 2011). Lack of awareness of deficits is also a common feature of the early stages of Alzheimer's disease, and this lack of insight to the decline of driving abilities may increase the risk for drivers with dementia (Fox et al., 1997; Pachana & Petriwskyj, 2006; Wild & Cottrell, 2003). Most measures of awareness of deficits have involved comparisons of the driver's estimation of his or her abilities with those of other informants (relatives or health professionals), or objective measures of individuals' abilities (Pachana & Petriwskyj, 2006).

Wild and Cottrell (2003) reported on a small sample of drivers with early Alzheimer's disease who were compared with unimpaired drivers on a deficit awareness questionnaire (Green, Goldstein, Sirockman, & Green, 1993), a driving safety self-rating questionnaire, a driving safety evaluation completed by a trained driving evaluator, and an on-road evaluation. All participants were currently still driving. The results indicated that the informants were significantly more likely to rate their relative

or friend with Alzheimer's disease as an average or below-average driver than were the informants rating the healthy controls. The healthy controls were more likely to rate themselves as more impaired than their informants, while the opposite was true for drivers with Alzheimer's disease. Finally, while the drivers with Alzheimer's disease performed significantly worse during the driving tests, they tended to rate their level of driving ability as similar to the unimpaired controls.

Considering the issue of reduced insight among older drivers, Kay et al. (2009) described the use of a standardised driving awareness questionnaire ('DriveAware') derived from an awareness questionnaire developed by S. W. Anderson and Tranel (1989). They noted that lack of awareness is commonly measured as the difference between a driver's self score and a carer's independent score on the same measure, and highlighted that a limitation of this is the subjective opinions of the different parties' understanding, interpretation and experience. They referred to only one previous study specifically examining loss of awareness in older drivers, and this measure relied on comparing drivers' and informants' ratings (Wild & Cottrell, 2003). Kay et al. (2009) suggested that there may be issues with the subjective nature of the informant and that the ratings may be dependent on the informant's relationship with the driver. In addition, some drivers may not have an informant available. For that reason, Kay et al. developed their driving awareness questionnaire to measure awareness as part of an off-road assessment by comparing drivers' answers to specific questions reflecting driving awareness with clinicians' ratings. They used a prospective cohort design to determine the agreement between clinicians' ratings of awareness of driving ability using DriveAware, with the on-road assessment and a second clinician's rating of awareness after an on-road assessment. They recruited 60 participants with various neurological conditions, including MCI, dementia, Parkinson's disease and a small number of other medical conditions. They used the DriveAware questionnaire, which asked specific

questions regarding opinion of performance on the visual recognition slide test previously presented. They also completed an on-road assessment using a standardised route. The results of the study indicated substantial agreement between raising awareness of driving ability using DriveAware for the on-road assessment, and rating awareness after on-road assessment. They also noted that awareness of driving ability has previously been identified as an important factor for safe driving performance among older drivers (Anstey et al., 2005).

A later study (Allan, Coxon, Bundy, Peattie, & Keay, 2015) used DriveAware and associated DriveSafe instruments, and found that self-reported driving restriction in a large sample (n = 380) of community living older drivers was associated with poorer DriveSafe scores, and that better performance on the TMT was associated with better DriveAware performance. An iPad version of the DriveSafe DriveAware format has also recently been published (Kay & Bundy, 2015).

2.3 Legislative and Clinical Consensus Approaches to Identify At-risk Drivers

Various authorities have made recommendations about managing the cessation of driving with dementia, and particularly about the recognition of at-risk individuals. A wide variety of these programs of recommendations have been published, many covering much of the same ground. Molnar et al. (2009) recommended a serial trichotomisation decision tree. They indicated that, without any definitive research on the issue of establishing at-risk driving individuals with dementia, consensus guidelines tended to be used, and these are often based on individual expert opinion or consensus of a small groups of experts—such as the Canadian Medical Association's (2006) Driver's Guide, seventh edition, and the American Medical Association (2010). Such guidelines tend to recommend tests such as the MMSE (Bieliauskas et al., 1998; Fox et al.,1997), clock drawing testing, and TMT-A and TMT-B (Fox et al., 1997; Hunt et al.,

1993). Molnar et al. (2009) made the point that none of these screens have well-validated cut-off scores predicting fitness to drive, and that some conflicting data have been published (Molnar et al., 2006b).

Molnar et al. (2009) recommended that, for moderate to severe dementia, driving cessation should be immediate because the patient is clearly unsafe to continue driving. They pointed out that the more complex issue is the presence of mild to moderate dementia, which does not automatically mean that the person cannot drive. They noted that some people with mild dementia may still be able to drive safely for a limited period, yet require individualised assessment and periodic follow-up. They suggested that attempts to mandate that all people with dementia should be forced to cease driving, regardless of whether they are still safe or not, is not legally supportable and could inadvertently increase the risk to the general public. They also suggested that such draconian measures could result in more people with dementia avoiding a diagnostic assessment, which might result in more people with undiagnosed dementia continuing to drive.

Molnar et al. (2009) suggested that, with less severe cases, clinicians need to decide if they have sufficient information to make a clinical decision regarding fitness to drive. They referred to the Canadian Medical Association's (2006) driving guidelines and Canadian Consensus Conference on Dementia guidelines (Hogan et al., 2007). These publications recommend that people with moderate to severe dementia should not drive, and employ an opinion-based definition of moderate to severe dementia as demonstrating new impairments due to cognition in one or more personal activities of daily living. Molnar et al. (2009) suggested that assessment of fitness to drive in people with mild dementia is a complex issue and should consider not only cognitive issues, but also other medical and physical issues. They highlighted that driving cessation is often more acceptable or palatable to individuals if the decision is also based on

physical (non-cognitive) findings. They proposed two different methods to organise the complex array of factors affecting driving:

- a 'CanDRIVE' mnemonic: **c**ognition, **a**cute or fluctuating illness, **n**euromusculoskeletal disease or neurological effects, **d**rugs, **r**ecord (driving record of accidents or moving violations), **i**n-**c**ar experiences (reports of recent changes in driving skills and/or confidence), **v**ision and **e**thanol use
- the 'Ten Minute Office Based Dementia and Driving Check List for Use by Physicians and Healthcare Professionals', previously published in the third edition of the *Driving and Dementia Toolkit* (Byszewski, 2009), which Molnar et al. (2009) stressed is 'based on clinical opinion and experience, not evidence' (p. 87).

Molnar et al. (2009) indicated that both these approaches are heavily based on history and physical examination, yet also incorporate cognitive tests, such as the MMSE, clock drawing and/or TMT-A and -B. They made the point that the trichotomisation process asks 'which patients are obviously unfit to drive, which are clearly safe, and which require further evaluation?' If fitness to drive remains unclear after performing assessments such as those described in the serial trichotomisation approach, physicians should refer the individuals for further evaluation. They suggested that referral to a centre specialising in the diagnosis and treatment of dementia should be considered if there are dementia-related issues other than driving to consider; however, if fitness to drive is the only issue, referral to a centre providing specialised on-road testing would be more appropriate. However, they did note some caveats. For example, in some provinces in Canada, the Ministry of Transportation does not accept its own on-road tests as sufficient to assess people with cognitive impairment. Rather, it requires a more comprehensive on-road evaluation to be performed at specialised ministry-certified centres that are often operated by occupational therapists. Molnar et al. (2009) stated

that, if a person with mild dementia is found to be able to continue to drive safely, a physician should still broach the subject of eventual driving cessation when the dementia progresses. Fitness to drive should be re-evaluated every six to 12 months, according to the Canadian Medical Association's (2006) driver's guide and Molnar et al. (2006a).

Molnar et al. (2006a) stated that once fitness to drive has been assessed, if the findings suggest an unacceptable risk, they must be acted on. Many clinicians find the disclosure of unfitness to drive to be a difficult and sometimes painful task that fundamentally alters the physician–patient relationship. They understandably express a desire to avoid this potentially confrontational situation because they fear it will emotionally harm their patients and may result in the patient and their families leaving the practice (Jang et al., 2007; Marshall & Gilbert 1999).

Lipski (1997) recommended that a recognised form of cognitive screening should be used to assess all patients over 70 years who drive. He raised the possibility that future research may involve interactive computer-based simulations to evaluate on-road driving skills, but made no specific recommendations regarding which screening should be used. In Canada, Byszewski, Aminzadeh, Robinson, Molnar, and Dalziel (2001) published a *Driving and Dementia Toolkit*, which made specific recommendations that questionnaires be used for both drivers and family members/caregivers to alert them to possible risky driving behaviours. Other studies have also considered the self-report of on-road behaviour in older drivers with and without dementia (Norris, Matthews, & Riad, 2000; Reason, Manstead, Stradling, Baxter, & Campbell, 1990) and reports from third parties (typically spouses and/or carers) of driver behaviour (Parker, McDonald, Rabbitt, & Sutcliffe, 2000).

Later versions of the *Driving and Dementia Toolkit* (Third Edition; Byszewski, 2009) de-emphasised the role of the self-questionnaire to alert drivers with early

dementia to the possibility that they have deteriorated driving skills. Instead, the toolkit recommended forming a clinical opinion using the Dalziel 'Ten Minute Office Based Dementia and Driving Check List', with an attached algorithm that once again suggested a trichotomous decision tree. Byszewski's (2009) trichotomous outcome is: (i) still safe to drive, yet requires follow-up; (ii) uncertain risk (requires comprehensive on-road driving evaluation); and (iii) unsafe to drive and requires a disclosure meeting and meeting with patient caregivers, as well as discussions about transportation options (see Figure 2.1 below).

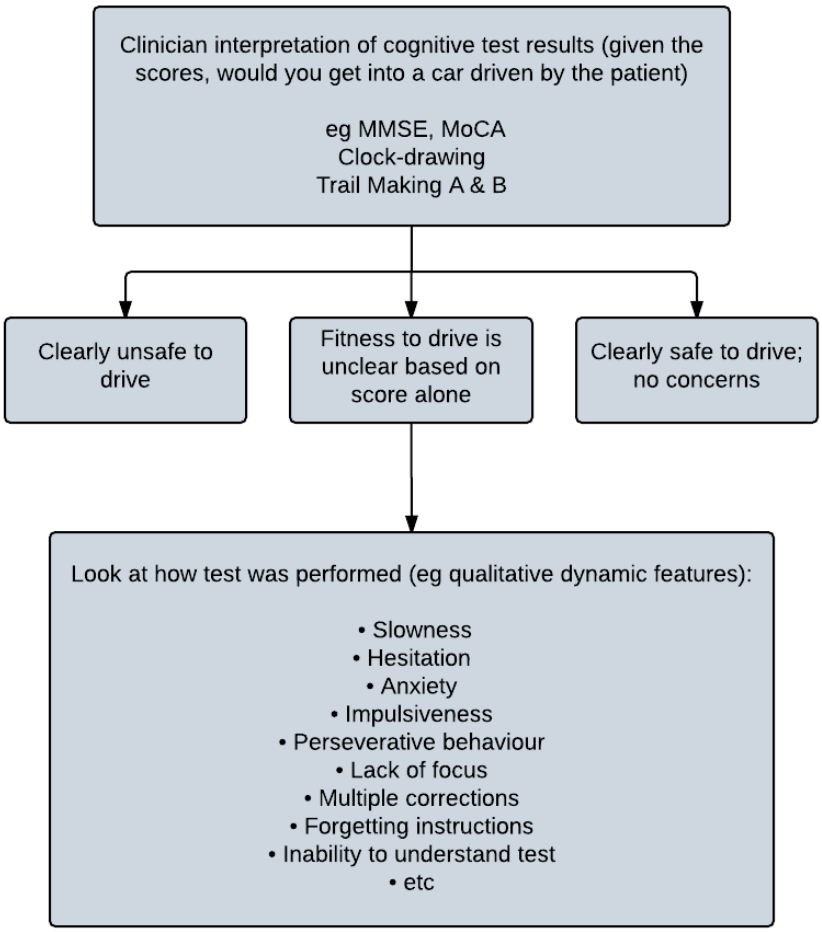

Figure 2.1. Trichotomous decision tree for review of the driver with dementia. Source: Based on Molnar et al. (2009), reproduced by kind permission of Dr F. Molnar and Healthplexus.net).

The Canadian Medical Association's (2006) guidelines suggest a dichotomous two-step process yielding a decision as to whether a diagnosis of dementia accrues. If moderate or severe dementia is present, the patient is considered unsafe to drive. If a diagnosis of mild dementia accrues, a second dichotomy suggests either reassessment in six to 12 months in order to check deterioration. If there are concerns regarding current safety, an on-road test should occur.

The American Medical Association (2010) published a physicians' guide to assessing and counselling older drivers. This again suggests a two-step decision tree, initially dividing into 'at-risk' and 'not at-risk', and then further dividing. They recommended assessment of 'red-flag' events, which B. M. Dobbs (2005) suggested should include acute medical events; expressions of concern from the family or patient; the presence of various chronic medical conditions; and, particularly, unpredictable/episodic events, such as angina and seizure, and also a review of medication. The American Medical Association (2010) recommends a functional assessment (Chapter 3) using an 'Assessment of Driving Related Skills', which includes a series of motor and sensory checks, together with the TMT-B (without first presenting TMT-A, which is against the guidelines of the original paper by Reitan, 1958). TMT-B scores with completion times > 180 seconds are considered abnormal, yet no rationale for this selection is given. The American Medical Association also recommends using the clock drawing test, which exists in various versions and with various scoring systems (Peters & Pinto, 2008).

A program referred to as the 'DriveAble' program has been developed based on a long series of research papers, including those by A. R. Dobbs (1997), A. R. Dobbs et al. (1998), A. Dobbs et al. (2004) and P. McCracken (2007). DriveAble (P. McCracken, 2007) suggests checking on driving competency in the presence of cognitive impairment, checking on insight, and maintaining these in the context of protecting the safety of others on the road. As per the *Driving and Dementia Toolkit*, P. McCracken (2007) suggested a series of questions for both the driver and family members to determine the presence of any declines of function. He referred to several warning signs, including a lack of awareness of driving errors, a tendency to become lost or confused while driving, an apparent lack of awareness of other vehicles, a tendency to miss traffic signs, an inability to keep up with the speed of traffic, close calls (especially

if unnoticed) and frequent honking from other drivers. Typical driver errors were considered to include errors at intersections and left turns (right turns in Australia), as well as driving too slowly, difficulty merging with traffic, and accidents close to home. He also noted that, in his series, drivers with dementia consistently overrated their competence. He recommended that an on-road driver assessment was the gold standard. In a series of on-road evaluations, the identified discriminating errors included positional or observational errors during left-hand turns or when changing lanes, and catastrophic (red-flag) errors that included a requirement for traffic to adjust to a programmed vehicle's progress, or the examiner having to take control to avoid a crash or dangerous situation. These could include driving the wrong way on a freeway or stopping at a green light. The DriveAble evaluation consisted of a two-phase evaluation using a computer-based in-office assessment (95% accuracy), followed by a road test for indeterminate outcomes (P. McCracken, 2007).

The DriveAble screening task has now been codified as a three-step process (B. M. Dobbs & Schopflocher, 2010) that includes a DriveAble Cognitive Assessment Tool, a touchscreen online task, and a pencil-and-paper task called 'Screen for the Identification of Cognitively Impaired Medically at Risk Drivers' (SIMARD)—an MMSE-type task that is claimed to be a five-minute pen-and-paper test shown to have a high degree of sensitivity and specificity for establishing at-risk drivers. The third level is an actual on-road standardised assessment called 'Driveable On-Road Evaluation'. It is noted that these assessments were originally developed in the United States (US) and are now available in Australia, but currently only in Western Australia (see www.driveable.com.au).

A program referred to as Roadwise Review (Porter & Tuokko, 2011) is an online screening tool developed by the American Automobile Association to help older drivers measure certain mental and physical abilities that are important for safe driving

(http://www.aaafoundation.org/resources/index.cfm?button=RoadwiseOnline). However, this has been criticised in terms of its ability to predict on-road driver behaviour (Bédard, Riendeau, Weaver, & Clarkson, 2011).

The American Academy of Neurology (Iverson et al., 2010) recommended primary use of the CDR scale to establish the presence of a level of dementia suggestive of inability to continue to maintain safe management of a motor vehicle. They added various other recommendations, including caregivers' rating of drivers' driving ability, a history of traffic citations, a history of crashes, reduced driving mileage, self-reported situation avoidance, an MMSE score of 24 or below, and aggressive or impulsive personality characteristics.

A Canadian program called 'CanDRIVE' (Man-Son-Hing et al., 2004) also red-flagged various on-road behaviours, including failure to follow give-way signals, incorrect lane changes, improper turning and turning from the wrong lane. On review of their data, Man-Son-Hing et al., (2004) suggested that drivers with Alzheimer's disease are generally safe during the first two years of cognitive decline, but not after three years. They suggested that an increase in crash risk develops towards the end of the third year, and more than doubles in the fourth year. They reported that people with Alzheimer's disease are seven times more likely to be involved in a road traffic accident than are their healthy aged-matched controls. They recommended that individuals with mild dementia (CDR of 1.0 or above) should cease driving, and suggested that this equates to an MMSE score of 19 to 24.

A number of authorities have established and published policies with regard to driving and its restriction in the presence of dementia. Alzheimer's Australia (2004, 2016) published formal driving policy statements that partly indicate that, while a diagnosis of dementia should not automatically preclude a person from driving, all people with dementia will reach a point where it is unsafe for them to drive. They stated

that each person has individual driving capabilities and will experience different patterns and timing of impairment as their particular condition progresses. They warned that any automatic link between a diagnosis of dementia and the removal of a driver's licence could provide a disincentive to a person presenting for early diagnosis and treatment. They stated that there is a requirement for the ability to determine capacity to drive, and that there is a need to regularly review functional performance. They stated that driver assessments combining medical off-road and on-road assessments currently appear to give the best indicator of driving ability. They suggested that improved access to comprehensive driving assessments for drivers with dementia is essential in all regions, including rural areas, to encourage drivers with dementia to seek testing and to minimise the waiting incurred.

The Hartford Financial Services Group—a large US-based insurance company—has published an advisory document (Hartford/MIT AgeLab, 2013) with recommendations based on a series of research projects operated in conjunction with the MIT AgeLab. Once again, they recommended that driving will need to cease at some point following the onset of dementia, but also made the point that, for early dementia, driving need not be restricted. They included a self-administered 'warning signs for drivers with dementia'—a checklist that includes two 'red-flag' items: (i) confusing the accelerator and brake pedals and (ii) stopping in traffic for no apparent reason. They also recommended that an on-road assessment should be the 'gold standard' for measuring driving competence in the presence of dementia.

The Monash University Accident Research Centre and Austroads (Pronk et al., 2004) recommended a model licence assessment procedure for older and disabled drivers, requiring older driver testing based on functional ability, rather than chronological age. This was also targeted at identifying older drivers suspected of having increased risk of crashing, by using a community referral mechanism. They also

recommended the introduction of an older drivers' screening test to reduce the need for all drivers to undergo on-road driving.

In New South Wales, the National Roads and Motorists' Association (2008) argued against the newly introduced New South Wales legislation requiring annual medical check-ups from age 75 to 80, and practical driving assessments for drivers aged 85+, and every two years from then on. The argument against this system was essentially similar to that previously noted—that ageing *per se* should not be considered a limitation for driving, although this argument ignores the greatly increased risk of dementia in those aged 85+ in the general population (Deloitte Access Economics, 2011). It is noted that the New South Wales legislation was discussed extensively prior to being introduced (for further details, see Griffith, 2007). Griffith (2007) noted that, in Australia, age-based driving tests are only mandated in two jurisdictions: New South Wales and (at the time) Western Australia. In the US, only two states require older drivers to undertake on-road tests at a given age, regardless of personal driving record. He also noted that mandatory on-road tests are not a feature of licensing requirements for older drivers in Canada; however, restricted testing standards and a more comprehensive evaluation program are found in Ontario, where driving licences must be renewed at 80 years of age and every two years thereafter. Griffith noted that New Zealand removed a previously mandated on-road driving test for 80 year olds in 2006. He also indicated that licensing procedures in Europe confirm that very few jurisdictions use driving tests for older drivers.

The Royal Automobile Club of Queensland (2012) published an older drivers' self-assessment questionnaire that included questions relating to medical conditions and mobility. They also recommended an on-road assessment for older drivers, although they made no comment about the recommended age for reassessment. Further, the Australian Automobile Association—a peak body representing all of the eight states'

and territories' motoring organisations—published a policy framework paper that also argues that age *per se* is not a sufficient reason for cessation of driving, although they also recognised a requirement for older drivers to transition to non-driving status in due course (Australian Automobile Association, 2010).

The Australian Society for Geriatric Medicine (now the Australian and New Zealand Society for Geriatric Medicine) published a position statement on driving and dementia (Snellgrove & Hecker, 2003, with later revision by Cameron, 2009), and noted that evidence supports an increased accident rate for older drivers, including those with dementia. They noted that it is accepted that drivers with moderate to severe dementia are unsafe to drive; however, some drivers in the mild stages of dementia may drive safely, at least for a limited time after the disease onset. Snellgrove and Hecker (2003) noted that some forms of dementia are associated with prominent executive dysfunction, including primary FTD (the frontal variant of Alzheimer's disease) and some forms of vascular dementia—especially extensive small vessel cerebrovascular disease. They recommended that, for this reason, these presentations should serve as early warning signs for the requirement to provide an on-road assessment. Snellgrove and Hecker (2003) and Cameron (2009) also noted that other forms of dementia—including Lewy body disease—are associated with significant fluctuations in attention, alertness and cognition, and are subsequently likely to yield early declines in the ability to drive safely. They recommended: (i) education and training programs for general practitioners (GPs) to encourage early and accurate dementia assessment and diagnosis; (ii) the development of driving assessment tools for use by GPs, including brief psychometric screening tests; (iii) increased availability and subsidy of on-road assessments; and (iv) provision of an independent arbitration panel to remove the difficult and punitive task of licence cancellation from a general specialist medical practitioner, whose primary role is patient support.

The British Psychological Society (2001) noted that different neuropsychological impairments may result in different cognitive deficits. Moreover, two individuals with the same diagnosis may differ markedly in their clinical presentation and fitness to drive. The primary carer is the first point of contact for the majority of patients, yet GPs' workload, training and clinical relationship with their patients leave them ill equipped to assess the cognitive factors relevant to driving. The British Psychological Society (2001) suggested that, within specialist clinical services—particularly clinical psychology, OT and psychiatry—a body of clinical knowledge and research evidence is available to contribute to this assessment.

2.4 Rationale for Current Study

Currently, there is no universally accepted criterion to establish driving competence in older drivers, apart from completing an on-road assessment. It is not feasible to conduct on-road assessments of all older drivers in Australia, yet there appears to be real need to be able to provide medical practitioners with a credible and valid screening instrument for drivers with dementia. These screening instruments could then be provided to much larger numbers of candidate older drivers than could be assessed for on-road reviews. Drivers who 'fail' the screen could then be referred for an on-road review in much smaller numbers as needed, as recommended by Pronk et al. (2004) and Molnar et al. (2009).

This project seeks to evaluate a series of currently available screening instruments (essentially self-scored questionnaires for older drivers and their carers/close relatives) to determine which of these may be fruitful for screening 'at-risk' older drivers. In line with previous published research, this study also seeks to determine the relationship between neuropsychological test results and actual on-road driver outcomes in older drivers with known or suspected dementia. Further, this project seeks to tabulate dementia subtypes by on-road pass/fail criteria, as this is considered

important by some previous authors who suggested that some dementia subtypes may be more closely associated with early loss of driving skill than others (Breen et al., 2007; Cameron, 2009; Snellgrove & Hecker, 2003).

These considerations raised interest in the issue of driving and dementia at the author's former workplace at the Division of Rehabilitation and Aged Care, Repatriation General Hospital, Daw Park, South Australia, and the author was co-author of a funded and published study (Clark et al., 2000, 2004) that considered the issue of the neuropsychological prediction of on-road performance in drivers with confirmed dementia. One of the recommendations of that study was the establishment of a brief screening examination to replace the comprehensive neuropsychological examination previously used. One of the co-authors of the original study, Carol Snellgrove, proposed and performed a follow-up study to examine a new brief screening instrument, which later became the core of her PhD dissertation (Snellgrove, 2006). The scope of the project was extended to include individuals with putative MCI (prodromal dementia), which was beyond the scope of the original study. At the completion of Snellgrove's data collection (115 drives, 2000 to 2004), it was recognised that there was an important role for a standalone dementia driving clinic to provide on-road assessment on an ongoing basis. For that reason and following Snellgrove's departure from the division, it was decided that a new dementia driving clinic should be established and operated by the author (who, as senior clinical neuropsychologist for the division, had completed all neuropsychological reviews for the original published study). This was considered a standalone clinical service, although there was also obvious opportunity to pose additional research questions and collect additional data regarding potential screening instruments for on-road driving performance for drivers with dementia.

Additionally, it should be noted that, although this clinic operated initially within the auspices of the Repatriation General Hospital, emerging issues with office

space and carpark availability mitigated against continuation of the clinic in its original form. For that reason, the clinic was subsequently transferred to the author's private dementia clinic, where it has continued from 2004 to the present. Progressively, more sets of potential screening data were collected, especially involving the matter of driver self-evaluation and informant evaluation of driving performance. A subject that arose from these issues was an emerging interest in the presence of anosognosia (denial of illness) and its potential effects on driver self-evaluation among a larger group of drivers with known or suspected dementia. This was the basis for the data collected for the current study. The tools selected for this study included the following:

- two cognitive assessment instruments: the MMSE (as suggested by Fox et al., 1997) and the TMT (as suggested by Mathias & Lucas, 2009)
- a driver self-report scale (Byszewski et al., 2001)
- informant (carer/spouse) ratings of driver behaviour (Snellgrove, 2006, based on earlier driver rating scales suggested by Ball et al., 1998; Byszewski et al., 2001; Dobson, Brown, Ball, Powers, & McFadden, 1999; French, West, Elander, & Wilding, 1993; Marottoli et al, 1998; Norris et al., 2000; Parker et al., 2000)
- two instruments designed to measure anosognosia in individuals with known or suspected dementia
- one clinician-rated scale (Mendez & Shapira, 2005) developed as part of the CERAD program (Fillenbaum et al., 2008) and derived from the awareness questionnaire developed by S. W. Anderson and Tranel (1989)
- a scale measuring differential responses between the test subject and informant-carer (Starkstein et al., 1996).

The latter two instruments were not specifically designed to measure anosognosia in drivers, yet seek responses relating to general clinical state.

The objectives of the study include attempting to establish optimal in-office psychological testing and questionnaires to screen for actual on-road driving outcomes in a group of drivers with known or suspected dementias, using an on-road review as a 'gold standard'. Depending on the outcome of the data analysis, the author proposes that recommendations be made regarding the selection of optimal in-office screening of drivers with known or suspected dementia. These recommendations could then be presented for consideration to stakeholders with concerns regarding the issue of driving in elderly populations, such as the Australian Medical Association; South Australian Departments of Health and Transport; and pressure groups, such as the Royal Automobile Association, GP divisions, and the Australian and New Zealand College of Geriatric Medicine. A secondary aim is to determine whether individuals with some putative dementia subtypes (such as frontotemporal dementia) are at higher risk for on-road failure than individuals with more common putative dementia diagnoses (such as probable Alzheimer's disease).

2.5 Experimental Hypotheses

This research hypothesises that:

- Individuals with some putative dementia subtypes (such as FTD) will be more likely to fail on-road assessment than individuals with putative Alzheimer's disease. Other forms of cognitive decline—such as MCI (prodromal dementia)—will also have a lower on-road fail rate than more generalised dementias (see Chapter 4).
- Neuropsychological measures, such as the MMSE and TMT, are able to screen for on-road pass–fail (see Chapter 5).
- Older drivers with known or suspected dementia will complete a self-rating scale that is able to screen for on-road outcomes (see Chapter 6).

- Informant carers (spouses and adult children) will complete a series of rating scales that are able to screen for on-road outcomes. If sufficient respondent numbers are available, it is hypothesised that the informant adult children of participants will be better screeners for outcomes than will the informant spouses, and that informants with drivers' licences will be better screeners for of outcomes than will non-drivers (see Chapter 7).
- An anosognosia-based driver versus informant rating scale will be able to screen for on-road outcomes (see Chapter 8).
- An anosognosia-based clinician rating scale will be able to screen for on-road outcomes (see Chapter 8).

3. Method: 'I'll take you for a drive *now*!'[1]

3.1 Study Design

This study was designed as a cross-sectional, observational study of a cohort of drivers referred to a dementia driving clinic.

3.2 Referral Sources

The participants were licensed drivers referred for on-road review by their treating medical practitioner (typically a geriatrician or GP), following a diagnosis of dementia or some suspicion of early dementia (or MCI), where the referring doctor felt there was some reason to suppose that the individual's driving skill may have declined to concerning levels. See Table 3.1 for a summary of referral sources.

Table 3.1

Referral Sources (N = 215)

Referral source	Number of referrals
Geriatrician/physician	127
GP	50
Neurologist	34
Psychiatrist	4

3.3 Participants

Participation in this project was optional, and drivers were free to discontinue the process at any time. This was a retrospective study. Data have been continually collected since 2004, and there is ongoing collection. There were 215 completed drives at 27 October 2015. Although the driving clinic has continued beyond this date, the data lock for this study remains at this date.

All 215 participants who attended an on-road assessment were included in the data analysis of on-road outcomes (Chapter 4). As will be detailed in Section 3.12

[1] The chapter headings used in this thesis are quotations from the participant drivers.

below, not all 215 completed drive participants were attended by carer-relatives, which prevented collection of carer opinion in some cases. Additionally, for operational reasons, not all drive subjects completed self-evaluation forms or were available for neuropsychological review. As a result, the numbers vary in each dataset in Chapters 4 to 8.

3.4 Inclusion and Exclusion Criteria

3.4.1 Inclusion criteria. To be included in the study, the participant was required to:

- be a currently licensed driver, without medical or law suspension or cancellation
- be suffering from a known or suspected dementia or generalised cognitive decline, as diagnosed by licensed medical practitioner (usually geriatrician or GP), with putative dementia subtype defined where possible
- be passed as medically fit to participate in the drive by their referring doctor (in terms of vision, mobility and so forth). The referring doctors were typically querying the driver's ability to continue to hold a drivers' licence on the basis of their cognitive status. This was the major role of this clinic as a service to referring practitioners and their patients.

3.4.2 Exclusion criteria. Although this clinic was established to provide on-road reviews for drivers with known or suspected dementia, clinical need dictated that small numbers of clients without known or suspected dementia, but with other generalised cognitive declines (such as non-acute post stroke, epilepsy, hypoxia and post-encephalitis patients), also attended for assessment. Data for these individuals were included for analysis. All referrals proceeded from registered medical practitioners, and while a proportion of participants had histories of comorbid medical conditions, the specific exclusion criteria included:

- residing in a care facility (such as a hostel or nursing home)
- having no active licence to drive a private motor vehicle
- an inability to exhibit sufficient visual, hearing or communication capabilities to complete an on-road driving assessment
- cognitive impairment resulting from acute cerebral trauma or injuries
- secondary to chronic trauma, vitamin deficiency states (such as folate, vitamin B12 and other B complex deficiencies), active infection (such as cerebral abscess, neurosyphilis or encephalitis), significant endocrine or metabolic disease, intellectual disability or oligophrenia
- coexisting medical conditions known negatively to influence on-road driving performance, including uncontrolled epilepsy or convulsions, current clinically significant psychiatric disease, current clinically significant acute cardiovascular disease, acute cerebrovascular disease (such as stroke or transient ischemic attack) or a history of drug or alcohol abuse within the last year.

3.5 Withdrawal Procedure

The drive was a single session review. The participant was free to withdraw from the drive at any time, and had read the information form and completed a consent form prior to commencing the drive (Appendices 1 and 2). Some participants (n = 42) who were booked to attend did not attend for the following reasons: relinquished licence prior to scheduled appointment (n = 23), cancelled appointment with no follow-up (n = 8), licence cancelled by medical officer prior to appointment (n = 4), failed to attend (n = 3), refused appointment (n = 3), or Section 80 permit (permission to attend on-road assessment) was not granted by the Department of Transport (n = 1).

3.6 Standardised On-road Driving Assessment

The driving assessment comprised a 50-minute in-traffic road test along a predetermined route, using a current licensing authority (Transport South Australia) vehicle on-road test (VORT) assessment in a standard manual or automatic 2002 (later 2007) Toyota Corolla (depending on participant preferences) with power steering, electronically operated windows, an engine cut-off switch, and dual braking and accelerator systems. All tests were conducted at approximately the same time of day, in light road and clear weather conditions in order to ensure consistency and maximise safety. An assessor was seated in the front next to the participant. This assessor was authorised and accredited to conduct driving assessments for Transport South Australia, with specific expertise in assessing the fitness to drive of people with a range of medical conditions and physical disabilities, including dementia.

The on-road driving assessment was conducted in traffic around both business and residential areas, and assessed typical driving skills, including maintaining speed, obeying traffic signs, signalling, turning, managing right of way, changing lanes, anticipating and reacting to traffic conditions, negotiating intersections, and carpark parking. During the drive, the assessor scored errors in these skills and manoeuvers using a standardised Transport South Australia VORT scoring sheet (TASK 30) (Government of South Australia, Department for Transport, Energy and Infrastructure, 2006), yielding quantitative scores for left-turn errors (%), right-turn errors (%) and general drive errors (%), from which an overall accuracy result (%) was calculated (see Appendix 3). Additionally, in order to describe the on-road driving performance of the participants, a total number of law breaks were recorded (such as failure to adhere to speed limits or failure to stop at stop signs).

The total number of physical interventions provided by the assessor was also recorded, and was counted as part of the law break total. Physical interventions included

taking control of the steering wheel or applying the brakes or accelerator, and were used to ensure the safety of participants and other road users by avoiding imminent collisions. The driving assessment was intended to reveal the driving errors that are associated with cognitive decline, excluding those errors shown to be the 'bad habits' of experienced competent drivers, such as failing to indicate for five seconds before changing lanes or entering traffic. For this reason, a lowered overall result of 70% or above was selected to entitle the participant to a 'pass', while 69% or below was a 'fail'. For learner drivers, Transport South Australia requires an overall result of 85% or above for a 'pass'. The advantage of this pass–fail criterion is that it has obvious practical relevance. Failure genuinely carries the implication of 'not safe to drive'.

A single assessor was used for this study, although inter-rater reliability for two independent assessors (including the current assessor) was previously established for 32 drives (Snellgrove, 2006), which indicated a $p < .001$ intra-class coefficient for the general drive results, overall results as a percentage, number of law breaks, and number of interventions—see Table 3.2. The on-road assessor was blinded to the results of any neuropsychological test results and/or questionnaire responses.

Table 3.2

Inter-rater Reliability for On-road Driving Assessments (after Snellgrove, 2006)

Criterion	Intra-class coefficient value	95% CI	F (31)
Left-turn faults	.64	.25–.82	2.74*
Right-turn faults	.64	.25–.82	2.74*
General drive faults	.81	.61–.91	5.22**
Overall result as %	.84	.67–.92	6.28**
Number of law breaks	.92	.85–.96	13.7**
Number of interventions	.98	.92–1.00	17.76**
Overall result as pass–fail	1.00	1.00–1.00	

*$p < .01$, ** $p < .001$

3.7 Differential Diagnosis of Drive Participants with Known or Suspected Dementias

As described in Chapter 1, it was considered possible that some forms of dementia might be associated with higher drive failure rates than other forms of dementia. For this reason, data associated with differential diagnosis of dementia subtype criteria were also tabulated (Chapter 4). The major diagnostic categories and diagnostic criteria for each dementia subtype were as follows:

- Alzheimer's disease (McKhann et al., 2011)
- vascular dementia (van Straaten et al., 2003)
- aMCI (Albert et al., 2011)
- frontotemporal dementia (Warren et al., 2013)
- primary progressive aphasia (Warren et al., 2013)
- Lewy body and Parkinson's disease dementia (Donaghy & McKeith, 2014).

3.8 Neuropsychological Assessment

As part of this clinic and project, many (though not all) referrals had previously completed a neuropsychological review with the author as part of the author's usual clinical role. All neuropsychological reviews were completed by the author—an experienced clinical neuropsychologist and Australian Psychological Society College of

Clinical Neuropsychologist (APS, CCN) member (foundation member, 1984), and Australian Health Practitioner Regulation Agency–registered clinical neuropsychologist and principal placement supervisor. Not all clinical test results for neuropsychological review were considered for analysis in this project. All dementia-related clinical neuropsychological reviews include a variety of assessment tools to measure various cognitive domains. Two measurement tools were included for this study: TMT-A and TMT-B (Reitan, 1958). The TMT was selected as a measure of executive function widely used in past studies of neuropsychological screening for driver competence (see Chapter 2). The TMT consists of two conditions:

- Part A—a number sequencing task requiring the correct sequencing of numbers 1 to 25
- Part B—a number-letter sequencing task that requires the participant to track a series of numbers and letters (such as 1-A-2-B-3-C up to L-13) in a pencil-and-paper format (see Appendices 4a and 4b).

The results from the TMT were collected (where available) and analysed. Conventional outcome score data (time to completion) were collected. For coding purposes, a score of 600 seconds (10 minutes) was recorded for individuals who could not spontaneously complete the more complex TMT-B (procedure as detailed in M. R. Clark et al., 2000). Additionally, a simple error score (number of errors to completion) was tabulated for both TMT-A and -B. Test–retest reliability (Dikman, Heaton, Grant, & Temkin, 1999) and construct validity (Sanchez-Cubillo et al., 2009) for the TMT have been reported as satisfactory.

The author did not personally collect data for the MMSE; however, it should be noted that most (though not all) referring medical officers included recent MMSE scores in their referral letters. These were also tabulated for analysis, as it has been noted (Chapter 2) that the MMSE has been widely used as a screening tool for driving

among individuals with known or suspected dementia. These records are considered in the neuropsychological assessment chapter (Chapter 5). The MMSE consists of a variety of items, and administration is considered to take 10 minutes for an experienced interviewer (Lezak et al., 2012). A perfect score is 30 points. Item analysis has reported five distinct cognitive domains: concentration/working memory (serial 7s or spelling 'world' backwards), language and praxis (naming, following commands and construction), orientation, memory (delayed recall of three orally presented items) and attention span (immediate recall of the same three items) (Banos & Franklin, 2002). For the MMSE, test–retest reliability and inter-rater reliability have been reported as moderately high, and construct validity to be excellent (Bossers, van der Woude, Boersma, Scherder, & van Heuvelen, 2012).

Premorbid intelligence quotient (IQ) assessments were included as part of the neuropsychological reviews using the National Adult Reading Test—Revised (NART-R) (Crawford, 1992). This is a development of the earlier NART (Nelson, 1982). The NART and NART-R (using an identical test format, but employing several different words) use 50 irregular words (words whose correct pronunciation cannot be guessed) to estimate crystallised knowledge and thus premorbid intelligence level. The examinee reads the words aloud, and the number of pronunciation errors is recorded, enabling transformation into a figure that has been shown to predict premorbid ability level using more comprehensive and time-consuming tasks such as the WAIS-III (Wechsler, 1997). This version has been reported as having high internal consistency, test–retest reliability and inter-rater reliability (Crawford, 2003), and to provide a close approximation of WAIS-derived Full Scale IQ (Bright, Jaldow, & Kopelman, 2002). This task was used in the current study to determine whether the two experimental groups for the study (pass versus fail drives) differed with respect to premorbid ability level.

3.9 Participant and Informant Questionnaires

On the basis of experience gained from progressive debriefing sessions for completed drives, it became evident that many of the participants who failed their drives appeared to have limited insight to their current driving skills. Sometimes they denied that they had made any errors, even those that were significant, such as near misses and failure to give way. For that reason, the author decided to introduce progressively a series of questionnaires to be presented to the drive participants (later to informant-carer/spouses as well) to determine their ability to recognise any deficits in driving skill. As a result, for later drives, when the driver participants attended the clinic, they were additionally asked to complete a series of questionnaires designed to measure their perception of their own driving competence. In addition, where possible, informant carers (typically spouses or adult children) were asked to complete a series of questionnaires designed to measure their impression of the driver's competence. These are detailed below.

3.9.1 DDQ. The initial questionnaire introduced was the DDQ (Byszewski et al., 2001) (see Appendix 5). This had previously been recommended by the Dementia Network of Ottawa-Carlton as a way of alerting older drives with dementia to the possibility that they might be losing some of their driving skills. The questionnaire is a 10-item 'yes/no' format instrument designed to act as an alert device for drivers and their families. When the 'yes' questions are endorsed, this should alert drivers and their carers to the need of further evaluation (coded 0 = yes, 1 = no, with higher scores suggesting no recognition of any errors). The questionnaire presupposes that the drivers have the ability to recognise any of the error types described by these questions.

3.9.2 Informant-caregiver questionnaires. To measure informant opinion regarding driver skills and recent driving record, a comprehensive informant-based questionnaire was also introduced, based on the questionnaire used in the project

described by Snellgrove (2006), and incorporating into a single large questionnaire content derived from previously published studies, as listed below. The resultant Caregiver Questionnaire (see Appendix 6) included:

- Caregiver Confidence (CC) (Marottoli et al., 1998)
- Driving Style (DS) (French et al., 1993)
- Driver Behaviour (DB) (after Norris et al., 2000 and Dobson et al., 1999)
- Accident History (Ac) (Parker et al., 2000)
- Patient Driving Modifications (PDM) (after Ball et al., 1998; Marottoli et al., 1998)
- Families Questionnaire (FQ)—the informant questionnaire derived from the *Driving and Dementia Toolkit* (Byszewski et al., 2001).

The CC presents 10 questions in a 10-point Likert scale (1 = not at all confident, 10 = completely confident), with questions in the format: 'How confident do you feel as a passenger with <x> driving at night?'

The DS presents 15 questions in a six-point Likert scale (1 = never or very infrequently, 6 = very frequently or always), with questions in the format: 'Does <x> find it easy to ignore distractions?'

The DB presents 23 questions in a six-point Likert scale (1 = never, 6 = nearly all the time), with questions in the format: 'How often, if at all, does <x> misread signs and take the wrong turn off a roundabout?'

The Ac asks a series of four 'yes/no' questions regarding recent accidents and near misses, with responses coded into 'serious', 'minor' and 'nil' accident categories, with questions in the format: 'In the last three years, was <x> the driver in an accident serious enough to cause injury to himself/herself or others?'

The PDM presents nine questions in a five-point Likert scale (1 = never, 5 = always), with questions in the format: 'On how many days during an average week does <x> avoid making right turns across oncoming traffic?'

The FQ is a questionnaire with a 10-item 'yes/no' format instrument identical in format to the DDQ noted above. When the 'yes' questions are endorsed, this should alert carers to the need of further evaluation. An example question is: 'Do you feel uncomfortable in any way when driving with <x>?'

3.10 Anosognosia (Insight) Scales

3.10.1 CERAD insight scale. The CERAD anosognosia (insight) scale (Mendez & Shapira, 2005; see Appendix 7) is a clinician-scored scale based on an earlier version by S. W. Anderson and Tranel (1989), although the original was written for patients with brain injury and stroke in addition to dementia. The original version contained items such as: 'How is your speech?', 'Has it been affected at all?' and 'Do you understand what other people say?' Notably, the Mendez and Shapira (2005) version of this scale contains items designed to detect individuals' recognition of changes and/or limitations in their ability to conduct their lives—the items do not relate to specific driving limitation. This scale consists of four items measured on a four-point Likert scale, and includes items such as: 'Do you have an illness or a problem that requires medical attention?' Lower scores suggest limited recognition of any difficulties. This scale was completed at the time of the initial neuropsychological review with the client—prior to the date of the on-road review.

3.10.2 Anosognosia Questionnaire—Dementia (AQ-D). This questionnaire was introduced at the driving clinic more recently than the other measures (from 2011); thus, the final sample number was smaller than for several other measures. Starkstein et al. (1996) introduced the AQ-D scale (see Appendices 8a AQ-D-D and 8b AQ-D-C), which consists of 30 questions that assess impairments in basic and IADLs, as well as

behavioural changes. Starkstein et al. (1996) considered a cut-off score of 14 points for anosognosia, based on findings from an age-comparable healthy sample. The first section assesses intellectual functioning (such as: 'Do you have problems remembering dates?' and 'Do you have problems remembering telephone calls?'). The second section examines changes in interests and personality (such as 'Do you get easily irritated?' and 'Have you lost interest in things?'). Each answer is rated as 'never' (zero points), 'sometimes' (one point), 'usually' (two points) and 'always' (three points). Thus, higher scores indicate more severe impairments.

Form A is answered by the participant alone, while Form B (a similar questionnaire written in the third person) is answered by the informant, who is blind to the participant's answers in Form A. The difference score is the subtraction between the scores in Forms B and A. Thus, positive scores indicate that the informant rated the participant as more impaired than the participant's own evaluation (the participant was less aware of his or her cognitive or emotional changes). The reliability and validity of this scale has been demonstrated for use with Alzheimer's disease (Starkstein et al., 1996).

3.11 Referral Flow

The participants involved in this study were referred to the clinic according to the following referral process:

1. All drivers included in this study presented following a referral from their treating medical practitioner, after a diagnosis of dementia or some suspicion of early dementia MCI or other generalised cognitive decline.

2. Inclusion and exclusion criteria were applied, including confirmation of putative diagnosis (in the case of known dementia, details of dementia aetiology). Typically, referred drivers had already received comprehensive clinical review (including brain imaging confirmation) from their referring doctors, and these criteria

were used to tabulate the dementia subtypes discussed in Chapter 4. Additionally, individuals referred by GPs had typically also been previously reviewed by geriatricians or neurologists.

3. Neuropsychological review: Typically, the referred drivers had completed neuropsychological assessment prior to the date of the scheduled drive. Drives and neuropsychological assessments never occurred on the same date due to the presumed high workload that would have ensued from completing two comprehensive assessments on the same day. However, the neuropsychological assessment typically occurred within two weeks prior to the date of the on-road assessment. The CERAD clinician scale was completed at the same time as the neuropsychological review, as part of the clinical interview. However, some drivers did not receive a neuropsychological review, as the clinic operates as a standalone on-road review clinic. However, all participant drivers and (where available) informants did complete at least some questionnaires requesting their opinion of the participant's on-road driving skills.

4. The questionnaires were completed by the participants and informants on the day of the scheduled drive, immediately prior to commencement of the drive.

5. The drivers received an on-road assessment in a dual control car on a standardised road route, and were examined by a licensed and experienced driver instructor. This was followed by a post-drive debriefing attended by the participant, assessor, investigator and (where available) informant.

6. The outcome of the drive formed the basis of a recommendation to the referring doctor regarding the continuation or otherwise of the driver's licence status.

3.12 Estimated Sample Size

Prior to commencing the study, it was assumed that a medium effect size would be achieved (Cohen's *d*). An effect size of one indicates that one group differs from another by the value of one SD, while an effect size of zero means that the two groups

are identical. Setting the effect size at .50 (*medium* as defined by Cohen, 1992), with a power (1-ß error probability) of 0.95 and significance level of 5% (two-tailed), indicates a requirement for 42 participants (Mayr, Erdfelder, Buchner, & Faul, 2007). With a completed set of 215 drives, these criteria were clearly met for the overall drive sample, as well as for the neuropsychological tools (n = range 93–100), the driver questionnaire (n = 73) and the insight scales (n = range 45–81). The Caregiver Questionnaire (a sequence of briefer questionnaires used by Snellgrove, 2006) achieved a lower return rate than did the other scales (n = range 25–41); thus, some sections of this questionnaire did not achieve the required numbers.

3.13 Statistical Analysis

All data were analysed using SPSS for Mac v.22.0 (SPSS, 2013). Preliminary analysis was completed using analysis of variance (ANOVA) (Bennett, 1990) to determine any group differences (pass versus fail) in the on-road review (as the dependent variable) versus the various measures used as the independent variables, as presented in Chapters 4 to 8.

Logistic regression was used to examine the relationship between the dependent variable (pass/fail) and a range of independent variables, as defined in Chapters 4 to 8. Logistic regression is useful in determining which variables affect the probability of an outcome when the dependent variable (global rating) has only two levels (pass/fail) (Munro, 2001) and is typically used to examine whether a condition is absent or present (Portney & Watkins, 2000). The likelihood of the predicted outcome is based on the odds of being classified into one of two groups (maximum likelihood). The method of enter logistic regression was used, as the contribution of each of the independent variables was unknown. The Wald statistic was used to indicate whether the coefficient was significantly different from zero, which would indicate that the independent variable was contributing to the model (Thomas & Rao, 1987).

ROC curves were used to plot the rate of true positives (sensitivity) to false positives (1-specificity), and to identify cut-off scores on the assessment measures found accurately to predict failing the on-road test. The ROC curve is a way of graphically describing the relationship between a test's sensitivity and specificity (Spitalnic, 2004a, 2004b). Additionally, the AUC of the ROC represents the degree of accuracy of the clinical test. If this area is equal to 1.0, the test is 100% accurate because both the sensitivity and specificity are 1.0, so there are no false positives and no false negatives. In contrast, a test that cannot discriminate between normal and abnormal corresponds to an ROC curve the same as the reference line—that is, a diagonal line from 0.0 to 1.1. The ROC area for such a line is 0.5. An AUC of 0.5 indicates that the screening measure's predictive ability is equivalent to chance (Crizzle et al., 2012). Sensitivity, specificity and Youden's index (*J*) (Schisterman, Perkins, Liu, & Bondell, 2005) were calculated for cut-off scores on each assessment to maximise utility in clinical settings.

'Sensitivity' is described as the proportion of individuals with a particular condition (in this case, unsafe driving ability) who test positive via a screening test, such as the MMSE. Sensitivity is calculated by dividing the number of true positives by the number of true positives plus the number of false negatives (Streiner & Norman, 2003). The real-world implication of a significant number of false negatives is that the screening tool does not identify some individuals who would fail a road test and are unsafe drivers. Thus, it is important to choose a sensitive test if there are serious consequences to missing the disease. Specificity refers to the proportion of individuals who do not have a particular condition (unsafe driving), yet test negative for that condition with a given screening tool. Specificity is calculated by dividing the number of true negatives by the number of true negatives plus the number of false positives (Streiner & Norman, 2003). The implications of a significant number of false positives

in a screening context are that a given screening tool refers individuals without the condition to a costly and complex on-road driver evaluation, and could lead to some individuals being recommended for driving cessation (possibly prematurely) without ever undergoing a driving assessment.

The selection of optimal cut-off points may be either data driven or decision analytically based (Steyerberg, Van Calster, & Pencina, 2011). In this study, the determination of optimal data-driven cut-off scores was based on Youden's index—a statistical representation of the maximal vertical distance between the ROC curve and the chance performance of the measure (Schisterman et al., 2005). The highest numerical value of Youden's index for each measure identifies the point at which sensitivity and specificity are the highest. Youden's *J* is defined as *J* = sensitivity + specificity – 1. The selection of a cut-off point is part of a clinical decision that will depend on context and be a trade-off between optimal sensitivity and specificity (Grimes & Schulz, 2002). Selecting the optimal balance of sensitivity and specificity depends on the purpose for which the test will be used. A screening test should be highly sensitive and a confirmatory test should be highly specific; however, practically, there will be a balance between the two (Steyerberg et al., 2011).

3.14 Ethics Approval

This retrospective study has received approval from the Southern Adelaide Clinical Human Research Ethics Committee (see Appendix 9).

4. Drive Outcomes: 'I didn't fail, did I?'

4.1 Summary of Drive Outcomes

Table 4.1 summarises the drive outcomes for the 2004 to 2015 period, representing 215 completed drives. A further 42 prospective participants who were booked to attend did not attend for various reasons, as previously noted in Section 3.5. These are also summarised in Table 4.1.

Table 4.1

Drive Outcomes, 2004–2015

Drive outcomes	Numbers
Completed drives	215
• Pass	39 (18%)
• Fail	176 (82%)
Drive outcomes by gender:	
Male	131 (60.9% of total)
• Pass	28 (21.4%)
• Fail	103 (78.6%)
Female	84 (39.1% of total)
• Pass	11 (13%)
• Fail	73 (87%)
Referred, but did not complete drive:	
• Relinquished licence	23
• Cancelled appointment, no follow-up	8
• Referred, licence then cancelled by medical officer	4
• Failed to attend	3
• Refused appointment	3
• Section 80 permit not granted	1
Total non-drives	42

With regard to the total population, of the 215 completed drivers, 131 were male and the remaining 84 were female. For pass–fail outcomes, 28 males passed and 11 females passed, while the remainder failed. It is acknowledged there is a high overall fail rate for all drives, so any logistic regression analysis will be very biased towards the fail group.

Table 4.2 summarises the demographic and NART-R IQ estimates by on-road drive outcomes. On average, the participants who failed the on-road test were older: $F(2,215) = 4.75$, $p = .030$. There was no significant association between gender and on-road outcomes, $\chi^2 (2,215)=2.362$ $p =.124$, or IQ, as estimated by the NART-R results $F(2,80) = .486$, $p = .488$).

Table 4.2

Demographics and IQ Measure Results, by Road Test Outcomes

Characteristic % of total	Total sample	Passed road test 18.3	Failed road test 81.86	Statistic (*p)*
Age	*n* = 215	*n* = 39	*n* = 176	
Av ± SD	75.5 ± 9.69	72.46 ± 10.39	76.17 ± 9.43	*F* = 4.75
Range	43–92	45–90	43–92	(.030)
Gender (% male)	*n* = 215 (60.9%)	*n* = 39 (20.5%)	*n* = 176 (58.5%)	
m/f	131/84	8/31	103/73	χ^2 = 2.362 (.124)
NART-R IQ est.	*n* = 80	*n* = 18	*n* = 62	
Av ± SD	102.15 ± 10	103.67 ± 9.2	101.7 ± 10.8	*F* = .486
Range	73–120	87–120	73–120	(.488)

4.2 Driver Outcome by Primary Diagnosis.

Pursuant to s.2.5, it is hypothesised that individuals with some putative dementia subtypes (such as FTD) will be more likely to fail on-road assessment than individuals with putative Alzheimer's disease. Other forms of cognitive decline—such as MCI (prodromal dementia)—will also have a lower on-road fail rate than more generalised dementias.

Table 4.3 and Figure 4.1 summarise the driver outcome (% fail rate) by primary diagnosis.

Table 4.3

Driver Outcome by Primary Diagnosis

	Pass	Fail	Total
All	*39 (18%)*	*176 (81%)*	*215*
Alzheimer's disease [1]	11 (10%)	80 (90%)	101
Vascular dementia	4 (9%)	24 (91%)	28
aMCI	8 (54%)	9 (46%)	17
FTD	0 (0%)	17 (100%)	17
Primary progressive aphasia	1 (25%)	3 (75%)	4
Lewy body/Parkinson's disease	1 (11%)	8 (88%)	9
Other dementias*	1 (25%)	3 (75%)	4
Cerebrovascular accident	3 (21%)	11 (79%)	14
No diagnosis #	3 (60%)	2 (40%)	4
Other**	8 (50%)	8 (50%)	16

No formal diagnosis at time of referral

* One each of multiple sclerosis, Huntington's disease, corticobasal degeneration. One multiple sclerosis client passed, all others failed.

** Wernicke-Korsakoff (alcohol), anoxia, epilepsy, post-encephalitic, post-traumatic stress disorder (12), schizophrenia:

- Wernicke-Korsakoff (alcohol): 7 drives, 1 pass
- Anoxia: 2 drives, 2 passes
- Epilepsy: 2 drives, 2 passes
- Encephalitis: 1 drive, 1 pass
- Post-traumatic stress disorder: 2 drives, 2 passes
- Schizophrenia: 2 drives, 0 passes

[1] Alzheimer's disease is a neuropathological diagnosis. The presence of clinically suspected Alzheimer's disease is referred to as 'probable Alzheimer's disease' (McKhann et al., 2011).

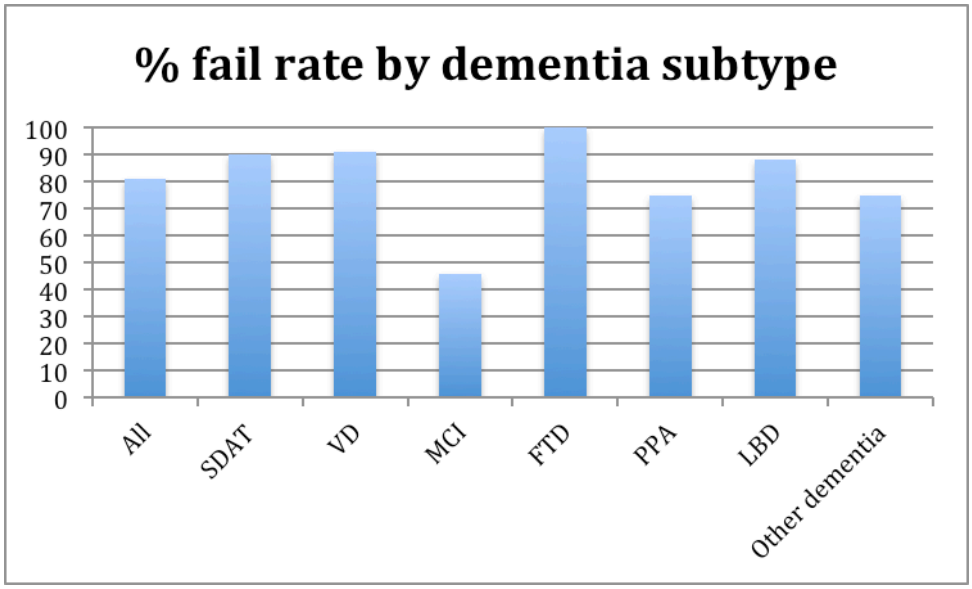

Figure 4.1. Percentage fail rate by dementia subtype.

Perusal of the above-tabulated data indicated a high fail rate of all dementia subtypes—with the exception of MCI (46% fail rate)—with common dementia subtypes

(such as Alzheimer's disease and vascular dementia) within the 90% fail range. Notably, the FTD diagnosis was associated with a 100% fail rate.

A chi-square test was used to examine the passing rate between FTD (n = 17) and all other primary diagnoses (n = 198). The relationship between these two variables was significant: χ^2 (1, N = 215) = 4.0905, p < .05. However, some caution must be taken in consideration of this outcome, as it is possible that the two groups (FTD versus all other primary diagnoses) differed with respect to dementia severity. While it was not possible with the available data to determine the length of time since the dementia was diagnosed, a clinical measure of dementia severity (Swanwick et al., 1999), it was noted that, on a screening measure of dementia severity (MMSE results), the two groups did not differ significantly in scores: t (91) = 1.852, p = .067.

5. Neuropsychology Screening for On-road Outcomes: 'Sharp as a noodle'

For each of the following results chapters, the results will be presented in three sections. The first section presents a one-way ANOVA for preliminary analysis. The second presents a regression analysis to predict outcomes (pass versus fail drivers). The third section presents a series of ROC curves (where feasible) to demonstrate the optimum sensitivity and specificity of predictor measures.

Pursuant to 2.2.5, it is hypothesised that neuropsychological measures, such as the MMSE and TMT, are able to screen for on-road pass–fail.

5.1 ANOVA Results

Table 5.1 describes the cognitive test results by on-road outcome. On average, the participants who failed the on-road test were older: $F(2,215) = 4.75$, $p = .030$. There was no significant association between gender and on-road outcomes: χ^2 (2, N = 215) = 2.362, $p = .124$. A number ($n = 93$) of referred drivers had previously received MMSE screening as part of their referral process. There was no significant difference in MMSE scores between the participants who passed and failed the on-road test: $F(2,93) = 2.19$, $p = .142$.

Additionally as seen in Figure 5.1—a bar chart that plots all MMSE scores as drive pass versus fail—it is evident that the overlap between the two groups was so great that it was unlikely that a useful cut-off score for drive pass–fail using the MMSE score could be derived. This is further investigated in Section 5.2.

Table 5.1

Cognitive Test Results, by Road Test Outcome

Characteristic % of total	Total sample	Pass road test 18.3	Fail road test 81.86	Statistic (*p*)
MMSE score/30	*n* = 93	*n* = 19	*n* = 74	
Av ± SD	24.95 ± 3.15	25.89 ± 3.18	24.70 ± 3.18	*F* = 2.19
Range	13–30	21–30	13–30	(.142)
TMT-A (time, sec)	*n* = 100	*n* = 21	*n* = 79	
Av ± SD	71.72 ± 38.83	59.48 ± 22.27	75.10 ± 41.65	*F* = 2.73
Range	22–253	32–126	22–253	(.102)
TMT-B (time, sec)	*n* = 100	*n* = 21	*n* = 79	
Av ± SD	282.89 ± 184.1	218.43 ± 143.7	300.03 ± 190.51	*F* = 3.33
Range	72–600	76–600	72–600	(.071)
TMT-A (errors)	*n* = 100	*n* = 21	*n* = 79	
Av ± SD	.34 ± .65	.238 ± .539	.367 ± .682	*F* = .642
Range	0–2	0–2	0–2	(.475)
TMT-B (errors)	*n* = 100	*n* = 21	*n* = 79	
Av ± SD	2.50 ± 2.33	1.29 ± 1.52	2.82 ± 2.42	*F* = 7.65
Range	0–10	0–5	0–10	(.007)

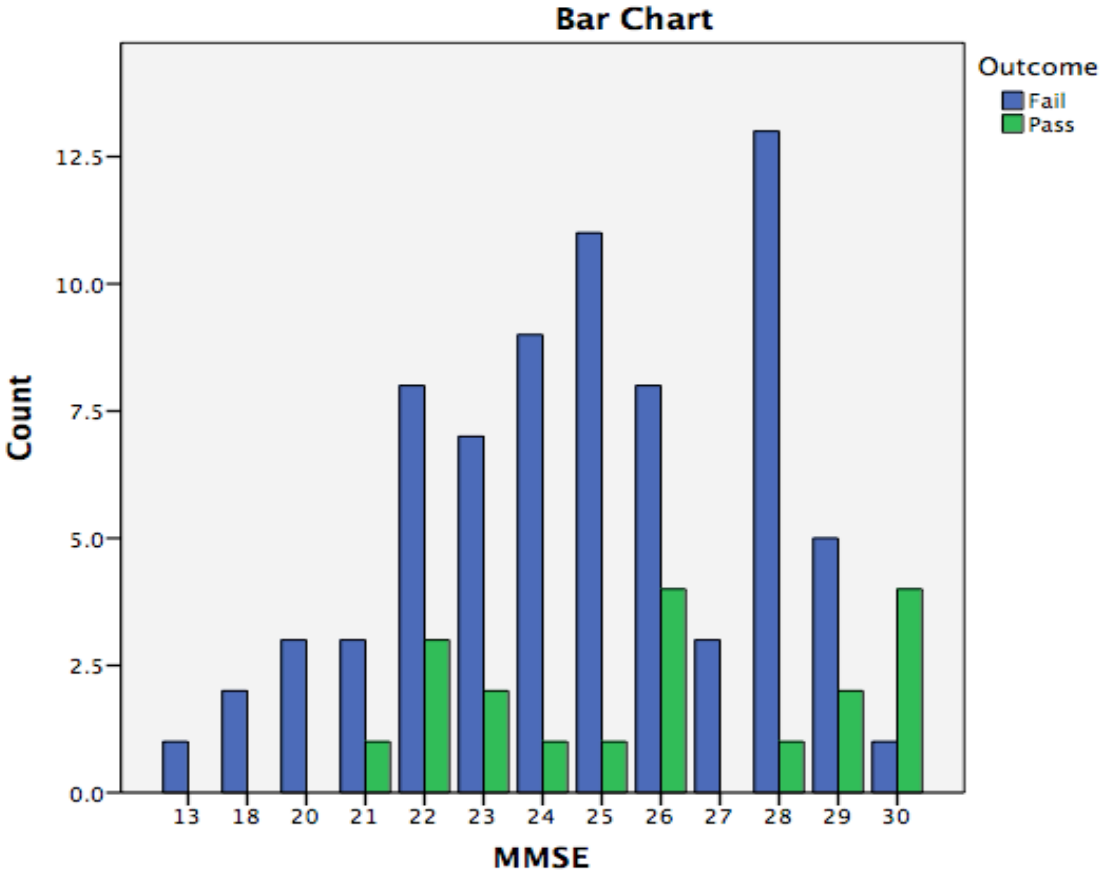

Figure 5.1. Bar chart representing on-road outcomes (fail/pass) for MMSE scores (score out of 30), *n* = 93.

There was no significant difference between the participants who passed and failed the on-road review for TMT-A *time to completion* ($F[2,100] = 2.73$, $p = .102$) or TMT-A *errors* ($F[2,100] = .642$, $p = .475$). For TMT-B (number-letter sequencing) *time to completion*, the results approached but did not reach significance at the .05 level of confidence: $F(2,100) = 3.33$, $p = .071$. However, there was a significant difference for the TMT-B *error* rate between the participants who passed and failed the on-road test: $F(2,93) = 7.65$, $p = .007$. This result suggests that this measure may be useful as a screener of on-road outcomes for drivers with dementia.

5.2 Logistic Regression Analysis Results

Logistic regression analyses were performed to assess the effect of measures of cognitive status on the likelihood that the individual would fail a road test. As shown in Table 5.2 below, a model containing the MMSE and age as predictors was marginally statistically significant ($\chi^2[2, N = 93] = 6.454$, $p = .04$), indicating that the model was able to distinguish between individuals who passed and failed the road test. The model as a whole explained 10.5% (Nagelkerke R^2) of the variance in pass–fail status and correctly classified 79.6% of the cases. Table 5.2 displays the unstandardised regression coefficients (Beta), standard error (SE), Exp B (odds ratios) and statistical significance levels. The SPSS logistic regression output sets an arbitrary cut value of .5. At this level for the MMSE results, the specificity level is .973 and the sensitivity level is .105.

Table 5.2

Logistic Regression Analysis of MMSE Predictors of On-road Drive Outcomes

Predictor	Beta	SE	Wald χ^2	df	Sig(p)	Exp(B)*OR*
Age	-.056	.028	3.977	1	.046	.945
MMSE	.107	.091	1.378	1	.240	1.113
Constant	.092	3.295	.001	1	.978	1.097
Test			χ^2	df	Sig(p)	
Goodness-of-fit test (Hosmer & Lemeshow)			11.050	8	.199	
Method: Enter						
Omnibus tests of model coefficients			6.454	2	.040	
(-2 Log likelihood) Nagelkerke R^2			.105			

The regression equation was *OUTCOME* = .092 − .056 * age + .107 * MMSE (Table 5.2). However, as indicated in Table 5.2, age could account for a significant proportion of unique variance outcome (Sig .046). An equation using MMSE score alone was not statistically significant ($\chi^2[1, n = 93] = 2.326, p = .127$), indicating that now the model was unable to distinguish between individuals who passed and failed the road test. The model with MMSE score alone as a whole explained 3.9% (Nagelkerke R^2) of the variance in pass–fail status and correctly classified 79.6% of the cases.

As seen in Table 5.3, the full model containing the TMT-A and -B completion time, errors, and age and sex as predictors was statistically significant ($\chi^2[6, n = 100] = 13.523, p = .019$), indicating that the model was able to distinguish between individuals who passed and failed the road test. The model as a whole explained 19.7% (Nagelkerke R^2) of the variance in pass–fail status and correctly classified 81.0% of the cases. Recalculation of the TMT results without the age component (as was done with the MMSE results) still yielded a model able to distinguish pass–fail status ($\chi^2[4, n = 100) = 9.843, p = .043$), explained 14.6% of the variance in pass–fail status, and correctly classified 79.9%. The TMT results show a specificity level of .987 and the sensitivity level of .143 at the SPSS arbitrary cut value of .5

Table 5.3 displays the unstandardised regression coefficients (Beta), SE, Exp B (odds ratios) and statistical significance levels.

Table 5.3

Logistic Regression Analysis of Trails-based Predictors of On-road Drive Outcomes

Predictor	Beta	SE	Wald χ^2	df	Sig(p)	Exp(B)*OR*
Age	-.054	.029	3.504	1	.061	.948
TMT-A time	-.004	.012	.127	1	.721	.996
TMT-B time	.002	.002	.466	1	.495	1.002
TMT-A errors	.394	.519	.577	1	.448	1.484
TMT-B errors	-.496	.231	4.592	1	.032	.609
Constant	3.203	1.868	2.941	1	.086	24.598

Test	χ^2	df	Sig(p)
Goodness-of-fit test (Hosmer & Lemeshow)	10.453	8	.235
Method: Enter			
Omnibus tests of model coefficients	13.523	6	.019
(-2 Log likelihood) Nagelkerke R^2	.197		

The regression equation was *OUTCOME* = 3.203 − .054 * age − .004 * TMT-A time + .002 * TMT-B time + .394 * TMT-A error − .496 * TMT-B error (Table 5.3). It will be seen that TMT-B error could account for a significant proportion of unique variance outcome (Sig .032), and that age also approached significance (Sig .061).

5.3 Use of ROC Curves to Describe Optimum Ability of Each Scale to Predict Actual On-road Outcomes

ROC curves were created by plotting the sensitivity and specificity rate for each of the cognitive measures indicated above. Figures 5.2 to 5.4 present the ROCs for MMSE, TMT-A (*time to completion* and *errors*) and TMT-B (*time to completion* and *errors*). The MMSE AUC was .60 (95% CI = .444, .756, *p* = .182). TMT-A produced a slightly more discriminating set of ROC curves for *time to completion* (AUC = .624 [95% CI = .502, .747, *p* = .081]), but not for *errors* (AUC = .536 [95% CI = .402, .671, *p* = .612]). TMT-B *time to completion* produced an AUC of .624 (95% CI = .496, .752, *p* = .081) and *errors* produced an AUC of .692 (95% CI = .576, .808, *p* = .007).

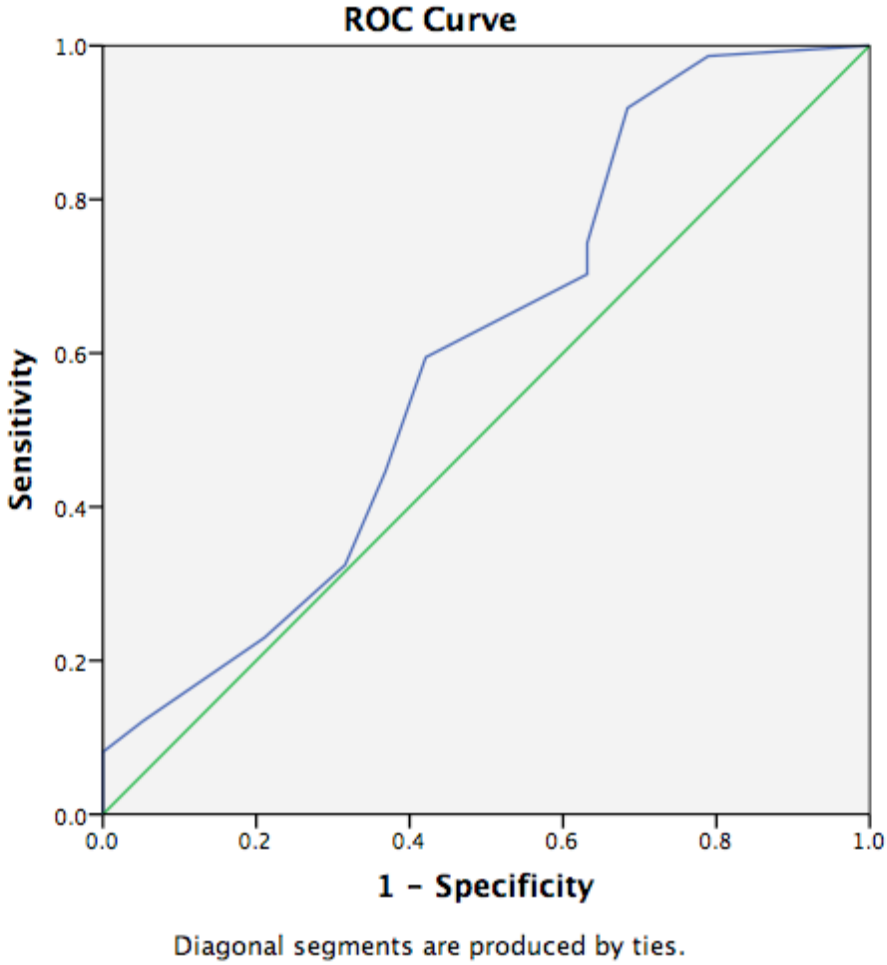

Figure 5.2. ROC curve for MMSE scores: AUC = .60 (95% CI = .444, .756, p = .182).

Table 5.4 displays the diagnostic test performance of different cut-off scores for MMSE. This table suggests that the best cut-off score for MMSE prediction of on-road drive performance is 25.5 points, with an optimal J (Youden) index of -.174, although the sensitivity of this cut-off point of .405 and 1-specificity of .579 are very modest, suggesting that the utility of the MMSE as an on-road screener is relatively limited.

Table 5.4

MMSE Coordinates of the Curve (J = Sensitivity + Specificity − 1)

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
12.0	1.00	1.00	0	0
15.5	.986	1.00	0	-.014
19.0	.959	1.00	0	-.041
20.5	.919	1.00	0	-.081
21.5	.878	.947	.053	-.069
22.5	.770	.789	.211	-.019
23.5	.676	.684	.316	-.008
24.5	.554	.632	.386	-.06
25.5	.405	.579	.421	-.174
26.5	.297	.368	.632	-.071
27.5	.257	.368	.632	-.111
28.5	.081	.316	.984	-.235
29.5	.014	.211	.789	-.197
31	0	0	0	0

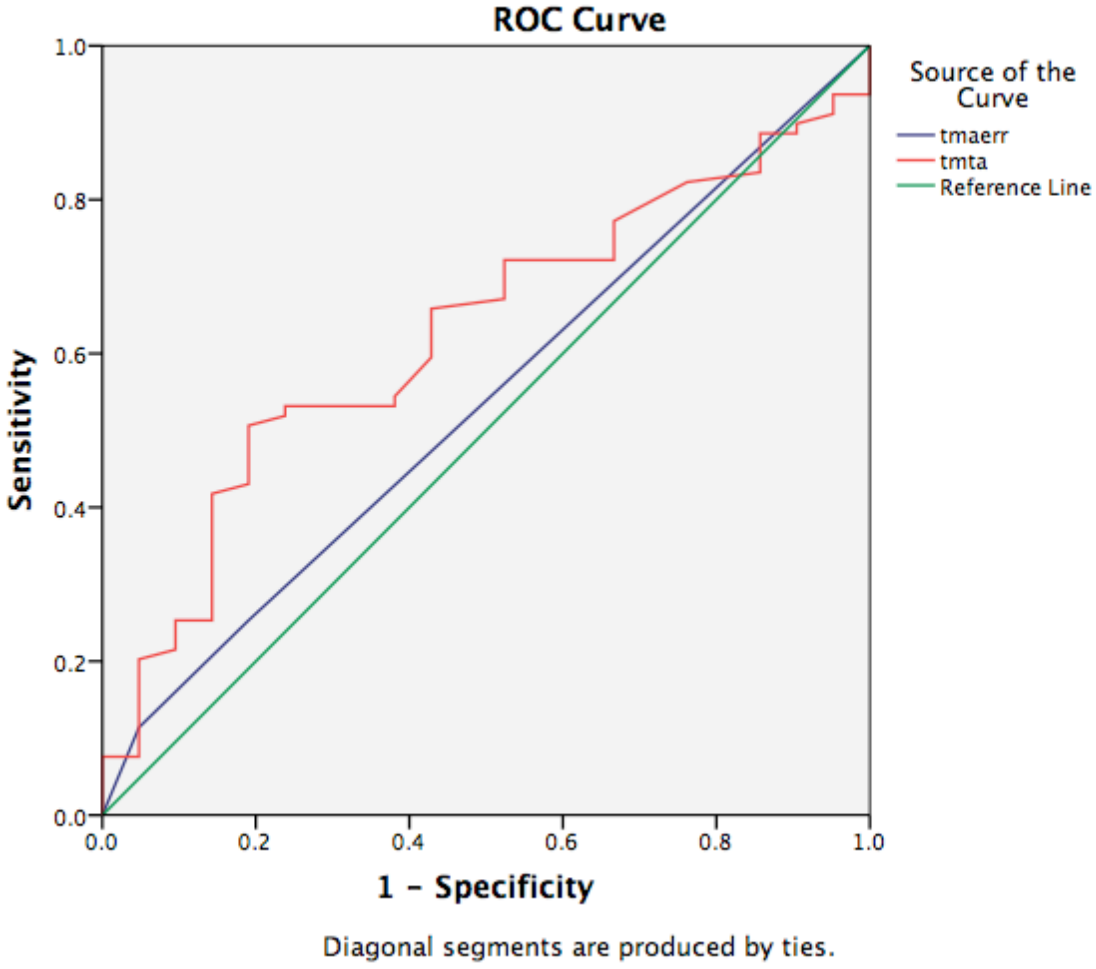

Figure 5.3. ROC curve for TMT-A *time to completion* (AUC = .624 [95% CI = .502, .747, p = .081]) and *errors* (AUC = .536 [95% CI = .402, .671, p = .612]).

Table 5.5 displays the diagnostic test performance of different cut-off scores for TMT-A *time to completion*. This table suggests that the best cut-off score for TMT-A *time to completion* is 31.5", although with a *J* (Youden) index of only .063, with a high sensitivity of .937, but a 1-specificity of 1.00 yielding a specificity of 0. These results were not considered helpful for prediction of pass versus fail group performance.

Table 5.5

TMT-A Time to Completion *Coordinates of the Curve (J = Sensitivity + Specificity − 1)*

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
21.0	1.00	1.00	0	0
31.5	.937	1.00	0	-.063
34.0	.924	.952	.048	-.028
38.0	.886	.905	.095	-.019
41.5	.848	.857	.143	-.009

Table 5.6 displays the diagnostic test performance of different cut-off scores for TMT-A *errors*. This table suggests that the best cut-off score for TMT-A *errors* is => 1.5, although once again with a *J* (Youden) index of .066 and a low sensitivity of .114, but a 1-specificity of .048 relating to a high specificity of 0.952. Once again, these results were not considered helpful for screening of pass versus fail group performance.

Table 5.6

TMT-A Errors *Coordinates of the Curve (J = Sensitivity + Specificity − 1)*

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
-1.0	1.00	1.00	0	0
.5	.253	.190	.81	.063
1.5	.114	.048	.952	.066
3.0	0	0	1	0

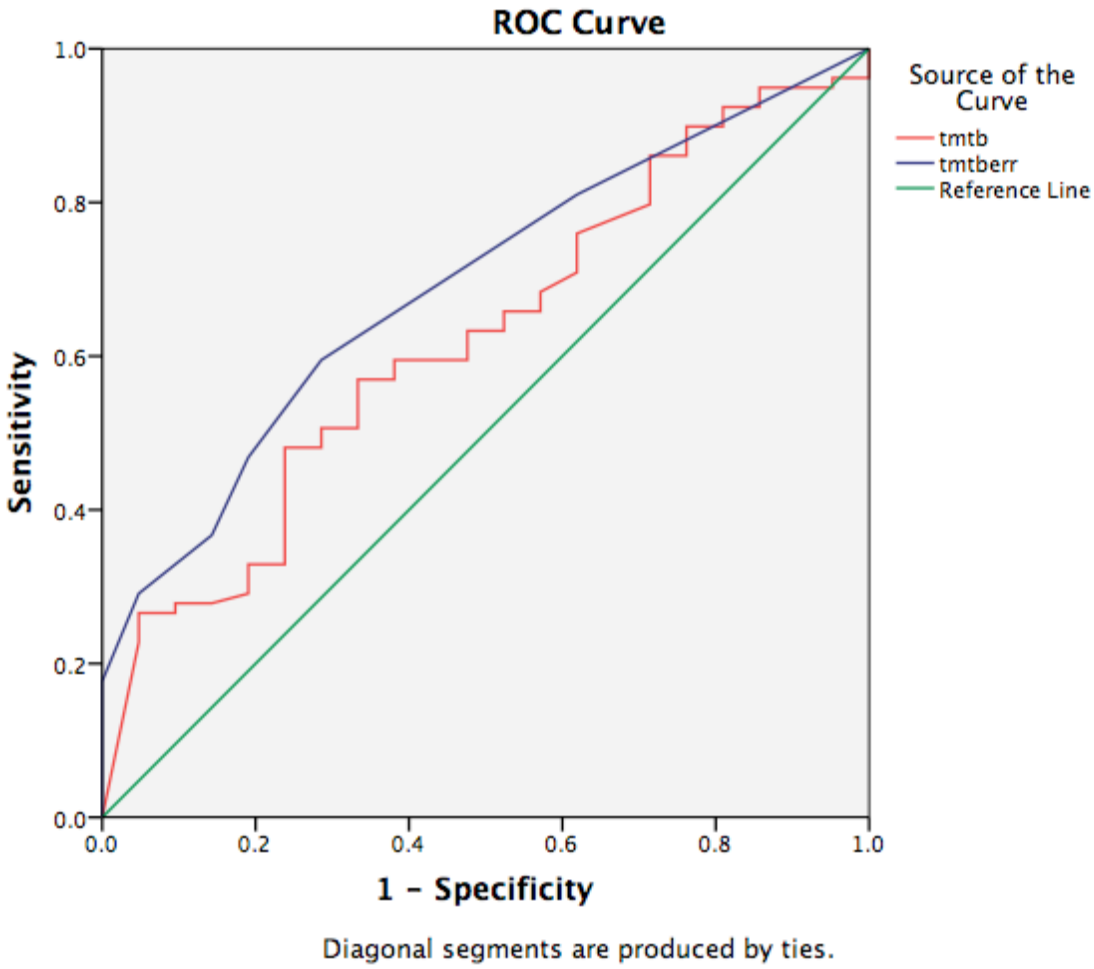

Figure 5.4. ROC curve for TMT-B *time to completion* (AUC of .624 [95% CI = .496, .752, *p* = .081]) and *errors* (AUC of .692 [95% CI = .576, .808, *p* = .007]).

Table 5.7 displays the diagnostic test performance of different cut-off scores for TMT-B *time to completion*. For TMT-B *time to completion*, a cut-off score of => 187.5" yielded the largest *J* (Youden) index of .237, with a sensitivity of .570 and specificity of .667.

Table 5.7

TMT-B Time to Completion *Coordinates of the Curve (J = Sensitivity + Specificity − 1)*

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
94.0	.949	.857	.143	.092
96.5	.937	.857	.143	.08
98.5	.924	.857	.143	.067
101.5	.924	.810	.19	.114
104.0	.911	.810	.19	.101
106.0	.899	.810	.19	.089
109.5	.899	.762	.238	.137
112.5	.873	.762	.238	.111
115.5	.861	.762	.238	.099
120.5	.861	.714	.286	.147
127.0	.848	.714	.286	.134
131.5	.835	.714	.286	.121
134.5	.823	.714	.286	.109
143.0	.797	.714	.286	.083
150.0	.759	.619	.381	.14
152.0	.747	.619	.381	.128
153.5	.709	.619	.381	.09
154.5	.684	.571	.429	.113
156.0	.671	.571	.429	.1
157.5	.658	.571	.429	.087
158.5	.658	.524	.476	.134
163.0	.646	.524	.476	.122
170.0	.633	.524	.476	.109
173.5	.633	.476	.524	.157
174.5	.620	.476	.524	.144
176.0	.608	.476	.524	.132
177.5	.595	.476	.524	.119
179.0	.595	.381	.619	.214
183.5	.570	.381	.619	.189
187.5	.570	.333	.667	.237
188.5	.544	.333	.667	.211
191.5	.532	.333	.667	.199
200.0	.519	.333	.667	.186
211.0	.506	.333	.667	.173
217.0	.506	.286	.714	.22
219.5	.494	.286	.714	.208
222.5	.481	.286	.714	.195
225.0	.481	.238	.762	.148
229.5	.468	.238	.762	.243
236.5	.456	.238	.762	.218

Table 5.8 displays the diagnostic test performance of different cut-off scores for TMT-B *errors*. For TMT-B *errors*, a cut-off score of => 1.5 yielded the largest *J* (Youden) index of .309, with a sensitivity of .595 and specificity of .714.

Table 5.8

TMT-B Errors *Coordinates of the Curve (J = Sensitivity + Specificity − 1)*

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
-1.0	1.00	1.00	0	0
.5	.810	.619	.381	.191
1.5	.595	.286	.714	.309
2.5	.468	.19	.81	.278
3.5	.367	.143	.857	.224
4.5	.291	.048	.952	.243
5.5	.177	0	1	.177

6. Driver Participant Self-report: 'That was terrific'

6.1 ANOVA Results

Pursuant to s.2.5, it is hypothesised that a driver self-rating scale is able to screen for on-road outcomes (see Chapter 6).

There was no significant difference in the DDQ scores between participants who passed and failed the on-road test: $F(2,73) = 1.43$, $p = .234$ (see Table 6.1).

Table 6.1

Results of DDQ Driver Participant Self-rating Scale (Raw Scores, Pass v. Fail)

Characteristic % of total	Total sample	Passed road test 17.8	Failed road test 82.2	F *p*
DDQ* (range 0–10)	*n* = 73	*n* = 13	*n* = 60	1.43 (.234)
Av ± SD	.93 ± 1.25	1.31 ± 1.49	.85 ± 1.90	
Range	0–6	0–4	0–6	

* Raw scores, 10 yes (1) – no (2) answers, with high scores representing more problem behaviours (Byszewski et al., 2001).

6.2 Logistic Regression Analysis Results

A logistic regression analysis was performed to assess the effect of the DDQ questionnaire on the likelihood that the individual would fail a road test. As seen in Table 6.2 below, the full model containing the DDQ as predictor was not statistically significant, χ^2 (1, $N = 73$) = 1.315, $p = .252$, indicating that the model was unable to distinguish between individuals who passed and failed the road test. The model as a whole explained only 2.9% (Nagelkerke R^2) of the variance in pass–fail status. Table 6.2 displays the unstandardised regression coefficients (Beta), SE, Exp B (odds ratios) and statistical significance levels.

Table 6.2

Logistic Regression Analysis of DDQ Predictors of On-road Drive Outcomes

Predictor	Beta	SE	Wald χ^2	df	Sig(p)	Exp(B)*OR*
DDQ score	.259	.221	1.381	1	.240	1.296
Constant	-1.80	.404		1	.00001	.165
Test			χ^2	df	Sig(p)	
Goodness-of-fit test (Hosmer & Lemeshow)			2.723	2	.256	
Method: Enter						
Omnibus tests of model coefficients			1.315	1	.252	
(-2 Log likelihood) Nagelkerke R^2			.029			

The regression equation is *OUTCOME* = -1.80 + .259 * DDQ score (Table 6.2).

6.3 ROC Curve Results

Given the non-significant ANOVA and logistic regression results, it was deemed unnecessary to plot ROC curves for this variable.

7. Informant (Spouse/Child) Opinions of On-road Performance: 'She is my Co-pilot'

7.1 ANOVA Results

Pursuant to s.2.5, it is hypothesised that rating scales completed by informant carers are able to screen for on-road outcomes

Table 7.1 summarises the ANOVA results from the various carer questionnaires presented to informants in a single document entitled 'Caregiver Questionnaire'. This indicated that none of the component questionnaires demonstrated significant differences in scores between the informants of participants (Caregiver Confidence: $F[2,41] = .475$, $p = .495$; Driving Style: $F[2,40] = .862$, $p = .359$; Driver Behaviour: $F[2,34] = .547$, $p = .465$; Accident Rate: $F[2,39] = .531$, $p = .471$; Patient Driving Modifications: $F[2,38] = .009$, $p = .925$; Families Questionnaire: $F[2,25] = .774$, $p = .388$).

The initial intention was further to divide the results by different generations of carers (spouse versus children); however, it appeared unnecessary to do so because the results were so clearly non-significant. It was initially hypothesised that adult children respondents may be more reliable than spouse respondents; however, the current data did not support this. There was a further intention to tabulate the results of the informants by their own driving status, with the working hypothesis that informants with drivers' licences would be more reliable witnesses than non-driver informants. However, it was noted that for the entire population, only one respondent (a spouse) was a non-driver; hence, this analysis could not be performed.

It is acknowledged that the sample size for this section of this study is less than ideal, and that several driver participants were not accompanied by an informant on the day of the assessment. It is also noted that a high proportion of respondents declined to

complete some sections of the questionnaire, and it is acknowledged that several negative comments regarding the questionnaire format were received. There were a number of missing values, with a total of 41 questionnaires distributed, but many sections skipped by informants.

Table 7.1

Informant-carer Questionnaire Results, by Road Test Outcome

Component	Total	Pass road test	Fail road test	F (*p*)
CC (possible score range 1–10)	*n* = 41 5.47 ± 2.91 1–10	*n* = 6 6.23 ± 2.93 1–10	*n* = 35 5.34 ± 2.94 4–10	.475 (.495)
DS (possible score range 13–72)	*n* = 40 26.6 ± 8.38 13–52	*n* = 6 23.67 ± 9.29 13–35	*n* = 34 27.12 ± 8.25 13–52	.862 (.359)
DB (possible score range 23–276)	*n* = 34 36.38 ± 10.39 24–65	*n* = 4 32.75 ± 10.84 28–49	*n* = 30 36.87 ± 10.42 24–65	.547 (.465)
Ac (possible score range 0–3)	*n* = 39 1.51 ± .75 0–3	*n* = 4 1.25 ± .96 0–2	*n* = 35 1.54 ± .74 1–3	.531 (.471)
PDM (possible score range 9–45)	*n* = 38 18.74 ± 7.266 9–38	*n* = 6 19.00 ± 6.23 9–25	*n* = 32 18.69 ± 7.53 9–38	.009 (.925)
FQ (possible score range 1–10)	*N* = 25 7.12 ± 2.49 2–10	*N* = 5 8.00 ± 2.00 5–10	*N* = 20 6.9 ± 2.59 2–10	.774 (.388)

CC = Caregiver Confidence (mean of 10 items each scored on 10-point Likert scale, where high scores represent higher confidence) (Marottoli et al., 1998)
DS = Driving Style (total score, 15 items each scored on a six-point Likert scale, where high scores represent negative comments—'nearly all the time') (French et al., 1993)
DB = Driver Behaviour (total score, 23 items, each scored on a six-point Likert scale, where high scores represent negative comments—'nearly all the time') (after Dobson et al., 1999; Norris et al., 2000)
Ac = Accident Rate (total score, four 'yes/no' questions coded 0–3, where high scores represent higher accident/near miss rate) (Parker et al., 2000)
PDM = Patient Driving Modifications (total score, nine items each scored on a five-point Likert scale, where high scores represent comments on avoiding types of traffic situations—'always') (after Ball et al., 1998; Marottoli et al., 1998)
FQ = Families Questionnaire (raw scores, 10 'yes/no' answers, where high scores represent more problem behaviours) (Byszewski et al., 2001)

7.2 Logistic Regression Analysis Results

A logistic regression analysis was performed to assess the effect of informant responses on the likelihood that the individual would fail a road test. As seen in Table 7.2, the full model containing the Caregiver Confidence, Driving Style, Driver

Behaviour, Accident Rate, Patient (Participant) Driving Modifications and Families Questionnaire was not statistically significant, χ^2 (6, N = 25–41) = 4.864, p = .561, indicating that the model was unable to distinguish between individuals who passed and failed the road test. The model as a whole explained 41.0% (Nagelkerke R^2) of the variance. Table 7.2 displays the unstandardised regression coefficients (Beta), SE, Exp B (odds ratios) and statistical significance levels.

Table 7.2

Logistic Regression Analysis of Informant-Caregiver Questionnaire

Component	Beta	SE	Wald χ^2	df	Sig(p)	Exp(B)*OR*
CC	.140	.642	.047	1	.828	1.150
DS	.626	.452	1.920	1	.166	1.870
DB	-.136	.118	1.337	1	.248	.873
Ac	-2.476	2.346	1.114	1	.291	.084
PDM	-.215	.185	1.356	1	.244	.807
FQ	-.591	.538	1.206	1	.272	.554
Constant	-3.597	9.040	.158	1	.691	.027

Test	χ^2	df	Sig(p)
Goodness-of-fit test (Hosmer & Lemeshow)	7.730	7	.357
Method: Enter			
Omnibus tests of model coefficients	4.864	6	.561
(-2 Log likelihood) Nagelkerke R^2	.410		

The regression equation is *OUTCOME* = -3.597 + .140 * CC + .626 * DS-.136 * DB-2.476 * Ac-.215 * PDM-.591 * FQ (Table 7.2). No component of the Caregiver Questionnaire was able to account for a significant proportion of unique variance outcome.

7.3 ROC Curve Results

Given the non-significant ANOVA and logistic regression results, it was deemed unnecessary to plot the ROC curves for this variable.

8. Anosognosia in Drivers with Dementia: 'What red light?'

8.1 ANOVA Results

Pursuant to s.2.5, it is hypothesised that an anosognosia-based driver versus informant rating scale and also a clinician-based rating scale will be able to screen for on-road outcomes.

The data presented include both the CERAD clinician-rated insight scale and the AQ-D, where similar questions are asked of both the driver and informant-carer, and the difference between the two scores is then compared. Table 8.1 presents the ANOVA results for these scales, with the Anosognosia Questionnaire results including AQ-D-C (carer-informant response), AQ-D-D (driver response) and AQ-D diff (a subtraction between the two scores). This demonstrated that there was a highly significant difference in CERAD scores between the participants who passed and failed the on-road test: $F(2,81) = 23.64$, $p = .000$. Additionally, the Anosognosia Questionnaire carer-informant (AQ-D-C) scores demonstrated significant differences between participants who passed and failed the on-road test: $F(2,45) = 6.153$, $p = .017$. However, there were no significant differences for AQ-D driver scores AQ-D-D ($F[2,45] = 1.726$, $p = .196$) or AQ-D difference scores ($F[2,45] = 2.152$, $p = .15$) between participants who passed and failed the on-road test.

Table 8.1

Results of Insight Scales, by Road Test Outcome

Scale	Total	Pass road test	Fail road test	F (*p*)
CERAD	*n* = 81	*n* = 17	*n* = 64	23.64 (.000)
Av ± SD	3.59 ± 3.62	6.94 ± 4.53	2.70 ± 2.53	
Range	0–12	0–12	0–12	
AQ-D-C carer-informant	*n* = 45	*n* = 10	*n* = 35	6.153 (.017)
Av ± SD	14.4 ± 7.82	9.30 ± 5.313	15.88 ± 7.86	
Range	3–32	4–22	3–32	
AQ-D-D driver	*n* = 45	*n* = 10	*n* = 35	1.726 (.196)
Av ± SD	8.07 ± 5.41	6.10 ± 3.54	8.63 ± 5.75	
Range	0–22	2–10	0–22	
AQ diff (carer − driver)	*n* = 45	*n* = 10	*n* = 35	2.152 (.15)
Av ± SD	7.00 ± 9.41	3.20 ± 6.49	8.08 ± 9.89	
Range	(-12)–31	(-3)–20	(-12)–31	

8.2 Logistic Regression Analysis Results

A logistic regression analysis was performed to assess the effect of measures of insight on the likelihood that the individual would fail a road test. Two separate analyses were considered—one for the CERAD clinician scale, and one combining the scores on the AQ-D carer-informant (C), driver participant (D) and driver minus informant differences. As seen in Table 8.2 below, the model containing the CERAD questionnaire was statistically significant ($\chi^2[1, n = 81] = 4.807, p = .000$), indicating that the model was able to distinguish between individuals who passed and failed the road test. The model as a whole explained 29.7% (Nagelkerke R^2) of the variance in pass–fail status and correctly classified 84.0% of the cases. Table 8.2 displays the unstandardised regression coefficients (Beta), SE, Exp B (odds ratios) and statistical significance levels. The SPSS logistic regression output sets an arbitrary cut value of .5. At this level, the CERAD questionnaire demonstrates a specificity level of .938 and a sensitivity level of .471.

Table 8.2

Logistic Regression Analysis of CERAD-based Insight Scale Predictor of On-road Drive Outcomes

Predictor	Beta	SE	Wald χ^2	df	Sig(p)	Exp(B)*OR*
CERAD	.309	.082	12.269	1	.000	1.362
Constant	-2.736	.531	26.550	1	.000	.065

Test	χ^2	df	Sig(p)
Goodness-of-fit test (Hosmer & Lemeshow)	4.807	6	.569
Method: Enter			
Omnibus tests of model coefficients	17.123	1	.000
(-2 Log likelihood) Nagelkerke R^2	.297		

The regression equation is *OUTCOME* = -2.736 + .309 * CERAD (Table 8.2). It can be seen that the CERAD could account for a significant proportion of unique variance outcome (Sig .000). As seen in Table 8.3 below, a model containing the AQ-D carer-informant, AQ-D driver participant and AQ-D differences (AQ-D driver minus AQ-D carer-informant) was also statistically significant ($\chi^2[3, n = 45] = 9.252, p = .026$), indicating that the model was able to distinguish between individuals who passed and failed the road test. The model as a whole explained 28.4% (Nagelkerke R^2) of the variance in pass–fail status and correctly classified 80.0% of the cases. Table 8.3 displays the unstandardised regression coefficients (Beta), SE, Exp B (odds ratios) and statistical significance levels. For the SPSS logistic regression arbitrary cut value of .5, the specificity level is .914 and the sensitivity level is .400.

Table 8.3

Logistic Regression Analysis of AQ-D-based Predictors of On-road Drive Outcomes

Predictor	Beta	SE	Wald χ^2	df	Sig(p)	Exp(B)*OR*
AQ-D-C*	5.178	2799.302	.000	1	.999	177.276
AQ-D-D**	-5.423	2799.302	.000	1	.998	.004
AQ-Ddiff ***	-5.220	2799.302	.000	1	.998	.005
Constant	1.346	1.024	1.726	1	.189	3.842
Test			χ^2	df	Sig(p)	
Goodness-of-fit test (Hosmer & Lemeshow)			2.017	7	.959	
Method: Enter						
Omnibus tests of model coefficients			9.252	3	.026	
(-2 Log likelihood) Nagelkerke R^2			.284			

* Anosognosia Questionnaire—carer-informant
** Anosognosia Questionnaire—driver
*** Anosognosia Questionnaire—carer minus driver score.

The regression equation is *OUTCOME* = 1.346 + 5.178 * AQ-D-C-5.423 * AQ-D-D-5.220 * AQ-Ddiff (Table 8.3).

8.3 ROC Results

ROC curves were created by plotting the sensitivity and specificity rate for each of the insight measures indicated above. Figures 8.1 and 8.2 present the ROCs for the CERAD and Anosognosia Questionnaire scores. The CERAD AUC was .763 (95% CI = .621, .906, p = .001). The AQ-D-C (carer) was AUC = .773 (95% CI = .616, .930, p = .009); however, the AQ-D-D (driver) was AUC = .610 (95% CI = .431, .789, p = .293), while the AQ-D diff (difference score) produced an AUC of .670 (95% CI = .496, .844, p = .104).

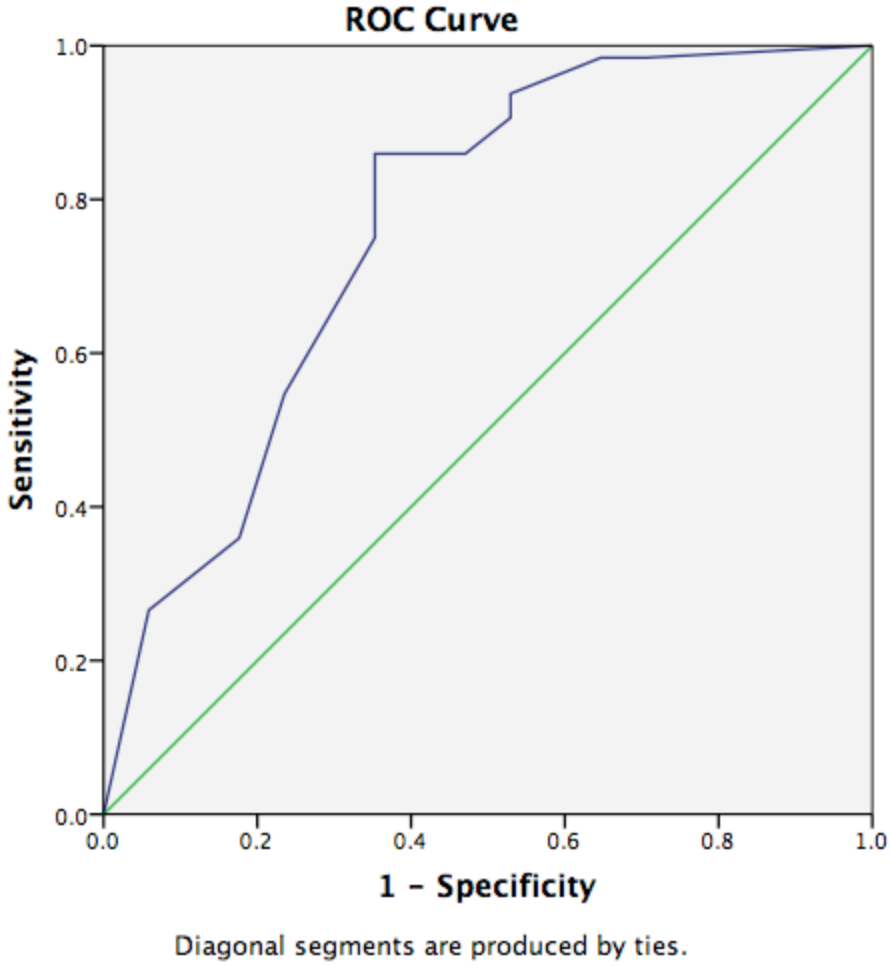

Figure 8.1. ROC curve for CERAD score: AUC = .763 (95% CI = .621, .906, p = .001).

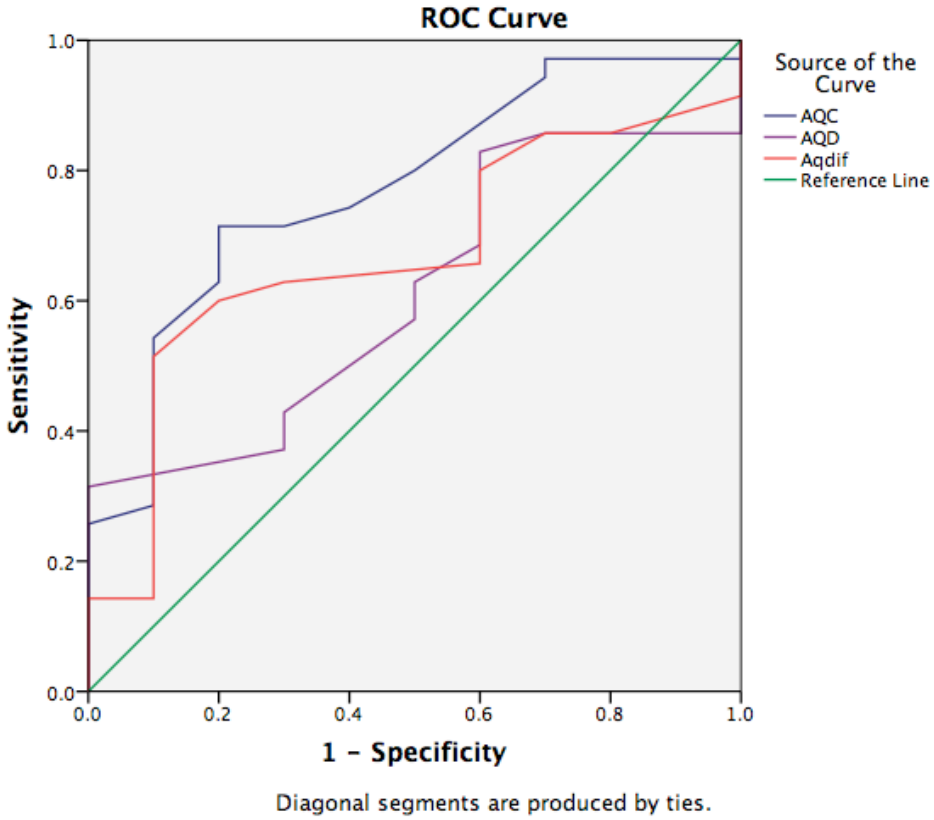

Figure 8.2. ROC curves for Anosognosia Questionnaire scores: AQC (carer): AUC = .773 (95% CI = .616, .930, p = .009); AQ-D (driver): AUC = .610 (95% CI = .431, .789, p = .293); AQdiff: AUC = .670 (95% CI = .496, .844, p = .104).

Table 8.4 displays the diagnostic test performance of different cut-off scores for the CERAD questionnaire. Here, a cut-off score of => 5.0 yielded the largest J (Youden) index of .506, with a sensitivity of .859 and specificity of .647.

Table 8.4

CERAD Coordinates of the Curve (J = Sensitivity + Specificity − 1)

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
-1.00	.000	.000	1.000	0
.5	.266	.059	.941	.207
1.5	.359	.176	.824	.183
2.5	.547	.235	.765	.312
3.5	.750	.353	.647	.397
5.0	.859	.353	.647	.506
6.5	.859	.471	.529	.388
7.5	.906	.529	.471	.377
8.5	.938	.529	.471	.409
10.0	.984	.647	.353	.337
11.5	.984	.706	.294	.278
13.5	1.00	1.00	0	0

Table 8.5 displays the diagnostic test performance of different cut-off scores for the AQ-D carer-informant questionnaire. Here, a cut-off score of => 11.5 yielded the largest *J* (Youden) index of .514, with a sensitivity of .714 and specificity of .8.

Table 8.5

AQ-D Carer-informant Coordinates of the Curve (J = Sensitivity + Specificity − 1)

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
2.0	1.00	1.00	0	0
3.5	.971	1.00	0	-.029
4.5	.971	.900	.1	.071
5.5	.971	.700	.3	.271
6.5	.943	.700	.3	.243
8.0	.800	.500	.5	.3
9.5	.473	.400	.6	.343
10.5	.714	.300	.7	.414
11.5	.714	.200	.8	.514
12.5	.629	.200	.8	.429
13.5	.543	.100	.9	.443
15.0	.457	.100	.9	.357
16.5	.371	.100	.9	.271
17.5	.343	.100	.9	.243
18.5	.341	.100	.9	.214
20.5	.286	.100	.9	.186
23.5	.257	.000	1	.257

Table 8.6 displays the diagnostic test performance of different cut-off scores for the AQ-D driver questionnaire. Here, a cut-off score of => 10.5 yielded the largest *J* (Youden) index of .514, with a sensitivity of .314 and specificity of 1.

Table 8.6

AQ-D Driver Coordinates of the Curve (J = Sensitivity + Specificity − 1)

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
-1.00	1.00	1.00	0	0
.5	.914	1.00	0	-.086
1.5	.857	1.00	0	-.143
2.5	.857	.700	.3	.157
3.5	.829	.600	.4	.229
4.5	.771	.600	.4	.171
5.5	.686	.600	.4	.086
6.5	.629	.500	.5	.129
7.5	.571	.500	.5	.071
8.5	.429	.300	.7	.129
9.5	.371	.300	.7	.071
10.5	.314	.00	1	.314
11.5	.286	.00	1	.286
13.0	.229	.00	1	.229
14.5	.171	.00	1	.171
15.5	.143	.00	1	.143
19.0	.057	.00	1	.057
23.0	.00	.00	1	0

Table 8.7 displays the diagnostic test performance of different cut-off scores for the AQ-D questionnaire *differences*. Here, a cut-off score of => 6.0 yielded the largest *J* (Youden) index of .414, with a sensitivity of .514 and specificity of .9.

Table 8.7

Anosognosia Questionnaire Difference Scores Coordinates of the Curve (J = Sensitivity + Specificity − 1)

+ve if greater than or equal to	Sens	1-Spec	Spec	*J*
-13.0	1.00	1.00	0	0
-11.0	.971	1.00	0	-.029
-7.0	.943	1.00	0	-.057
-3.5	.914	1.00	0	-.086
-2.5	.886	.900	.1	1.014
-1.5	.857	.800	.2	.057
-0.5	.857	.700	.3	.157
0.5	.800	.600	.4	.2
1.5	.771	.600	.4	.171
2.5	.657	.600	.4	.057
3.5	.629	.300	.7	.329
4.5	.600	.200	.8	.4
6.0	.514	.100	.9	.414
8.0	.457	.100	.9	.357
9.5	.429	.100	.9	.329
10.5	.400	.100	.9	.3
11.0	.371	.100	.9	.271
12.5	.314	.100	.9	.214
13.5	.257	.100	.9	.157
16.5	.200	.100	.9	.1
18.5	.171	.100	.9	.071

9. Discussion: 'What am I going to do now?'

9.1 General Discussion: The Role for a Dementia Driving Clinic

While there is wide acceptance that a driver with moderate to severe dementia should cease driving forthwith (Johansson & Lundberg, 1997) and it is widely accepted that those with mild dementia and MCI can continue to drive for the time being (Molnar et al., 2009), there is at least some emerging evidence that even those with mild dementia and MCI may be affected (Olsen et al, 2014; Snellgrove, 2006). It is also widely accepted that a comprehensive on-road review (A. R. Dobbs, 1997; Fox et al., 1997; Hunt et al., 1993; Shechtman et al., 2010) represents the gold standard for establishing driving competency. Given the cost and complexity of on-road examinations for older drivers or drivers with dementia, it would appear desirable for clinicians to be able to screen for consideration of a more comprehensive on-road examination.

Unfortunately, there is no accepted trigger point for this, and no universally accepted way of detecting or screening for drivers with dementia who may be losing their driving competence. Widely, this has been by way of voluntary retirement from driving when the driver recognises that there has been deterioration in driving skill. This was the underlying assumption for early older driver questionnaires, such as that derived from the Dementia Network of Ottawa-Carleton (Byszewski et al., 2001). It has been suggested that healthy older drivers are able to self-regulate their driving behaviours and make adjustments to increase their safety, while older drivers with impaired cognitive functioning fail to recognise the potential effects of their deficits and do not modify their driving habits to accommodate these (Pachana & Petriwskj, 2006). As part of the dementia process, especially for some subtypes of dementia, anosognosia (a deficit of self-awareness and failure to recognise a disability) (Pia & Conway, 2008;

Prigatano, 2010) may prevent the prudent decision to retire from driving (Craig, 2010). For this reason, recognition of the possible loss of driving ability often has to be made by a concerned family member or health professional. Unfortunately, this is far from a systematic process.

Previous legislation has required an older driver to have a medical in-office assessment when he or she reaches a certain age (Austroads, 2003). However, age-related triggers have become unfashionable (Palmore, 1999) and, notably, legislation associated with a requirement for on-road assessment based purely on the age of the driver has been withdrawn in two states of Australia—Western Australia and Tasmania (Department for Infrastructure, Energy and Resources, Tasmania, 2011; Department of Transport WA, 2013)—leaving only one state with an on-road review required every two years from age 85: New South Wales (Department of Transport, Roads and Maritime Services NSW, 2013). Most states (NSW; Tas; WA; Qld, Department of Transport & Main Roads, 2015) do require renewal of medical clearance every year once the driver reaches a certain age range, require reporting of significant medical conditions, and can include specific limitations (such as driving within daylight hours only or within a given radius from home) (Department of Transport and Main Roads Qld, 2015). No territories require specific age-based medical reviews (Australian Capital Territory Government, 2003; Department of Transport NT, 2014). One state (South Australia) has never established on-road assessment for a given age group, and abandoned the requirement for age-based annual medical review in 2013—although, once again, there is a specific requirement for reporting of significant medical conditions (Department of Planning, Transport and Infrastructure SA, 2013). The remaining state-based annual reviews are in-office medical reviews and not practical examinations. Additionally, one state government study suggested that, even though the state's older driver licensing requirements were the least restrictive of all states, there

was evidence that older drivers were experiencing discrimination and unfair treatment on the basis of their age, and made recommendations that professionals should be made more aware of their obligations regarding age discrimination and the positive duty to eliminate discrimination (Victorian Equal Opportunity and Human Rights Commission, 2012).

Even though age-specific on-road assessments are now only performed in one state (New South Wales), it should be noted that, at the 85+ year of age drive assessment, it is likely that at least one-third of all drivers of this age group—as with the general population of this age range—are likely to be suffering from dementia at some level (Gao, Hendrie, Hall, & Hui, 1998; A. Ott, Breteler, van Harskamp, Stijnen, & Hofman, 1998). Additionally, the population studies for this age group typically use the MMSE, and are subsequently likely to underestimate the degree of dementia in the general population (Ashford, 2008; O'Bryant et al., 2008a; Tombaugh & McIntyre, 1992). Given that the MMSE has significant limitations in its ability to detect amnesia (Field, 1995), it is particularly unsuitable for detecting the presence of MCI, which is likely to be even more common than dementia among ageing groups (Busse, Bischkopf, Riedel-Heller, & Angermeyer, 2003; Chaves, Camozzato, Godinho, Piazenski, & Kaye, 2009). It has been suggested that it is possible that up to two-thirds of drivers in the 85+ age group are suffering from a degenerative brain condition that would be presumed to affect their driving capabilities (Snellgrove, 2006).

For these reasons, it seems desirable to have available an accepted (and acceptable) on-road driving assessment with an appropriately certified and experienced driving assessor. It was for this reason that the current clinic was established. As noted in Chapter 2, this represents a standalone clinic where individuals with known or suspected dementia and known or suspected deterioration of driving skills can receive an on-road assessment. The existence of a dementia driving clinic in its current form

was an obvious opportunity to measure the ability of candidate screening devices to screen for the outcomes of an on-road driving review, which is considered to be the gold standard.

It appears desirable to be able to flag any early losses of cognitive and driving skill in older drivers, and particularly to determine the type and severity of dementia (see further comments below). Unfortunately, federal road regulations (Austroads, 2012, 2016) are reasonably non-specific regarding the need to review the driving skills of older drivers and people at risk for the development of dementia, and much decision making is placed in the hands of local medical officers and other concerned health professionals. Further, as noted above, state-based legislation regarding the older driver is varied, and does not take into account the risk of dementia among older drivers.

The current Austroads (2012, 2016) requirements for drivers suffering from dementia are considerably more detailed than those of an earlier edition (Austroads, 2003). Part 6 of the 2016 version now requires that, for both commercial and private licensing, a person is not fit to hold an unconditional licence if they have a diagnosis of dementia. However, a conditional licence may be granted by a driver licensing authority subject to at least annual review, taking account of the nature of the driving task and information provided by the treating doctor regarding levels of impairment of any of the following: visual perception, insight, judgement, attention, reaction time, or memory, and likely to impact on driving ability, as well as the results of a practical driver assessment, if required. Part A in Section 4.9 of this document covers conditional licences, which provides a mechanism for optimising driver and public safety, while maintaining driver independence, when a driver has a long-term or progressive health condition or injury that may affect his or her ability to drive safely. It identifies the need for medical treatments, vehicle modifications and/or driving restrictions that enable a person to drive safely. Examples of such restrictions include power brakes required for

a driver with reduced lower limb strength; hearing aids to be worn in the case of hearing deficiency; periodic review by a driver assessor for degenerative diseases; and limitations to driving only during off-peak, only driving within 20 km of the radius of the place of residence, driving in daylight hours only, or no freeway driving for drivers with deterioration of attention. These are only examples and not an exhaustive list. Part A in Section 4.9 mentions the use of practical driver assessments, but does not make any specific recommendations regarding the type of driver assessment to be performed, and simply provides a list of local driver licensing authority telephone numbers to contact for further information.

Ideally, legislative requirements should be tidied up. As often appears the case, specific recommendations and guidelines are suggested not by government authorities, but by learned societies, such as the Australian and New Zealand College of Geriatric Medicine (Cameron, 2009; Snellgrove & Hecker, 2003) and Alzheimer's Australia (2004, 2016). Unfortunately, once again, these societies do not provide particularly detailed documents and make only general comments regarding driving and dementia; thus, these bodies could potentially be approached to suggest that more detailed recommendations be disseminated. Additionally, local GP divisions in South Australia have been identified and ideally should be made aware of these recommendations by a comprehensive education campaign (see Appendix 10 for an exhaustive list). Specific additional recommendations arising from this study, as well as more recently published studies, are included below.

9.2 Matters Arising from this Study

9.2.1 The need for early diagnosis. It is now widely accepted that driving skills can be affected in the presence of dementia (Angley, 2001; Austroads, 2016; Johansson & Lundberg, 1997). Clearly, early detection of dementia is essential in this context, as the presence of an unrecognised dementia will hamper early recognition of

the possibility of deteriorated driving skills. The issue is of particular concern because it has been indicated that: (i) a high rate of dementia may be missed in community living older patients presenting to casualty departments for medical issues (Timmons et al., 2015); (ii) community screening for dementia has low sensitivity, especially for the presence of mild dementia (Bradford, Kunik, Schultz, Williams, & Singh, 2009); and (iii) up to 50% of dementia cases in the community may go undiagnosed (Phillips, Pond, & Goode, 2011; Rees, 2011).

Further, there is no universally accepted method for measuring or staging dementia severity. While the CDR[2] (Morris, 1993) has been widely adopted (e.g., Morris et al., 1997; O'Bryant et al., 2008b), other scoring schemas exist, including the Functional Assessment Staging (FAST)[3] (Reisberg, 1988), Global Deterioration Scale (GDS)[4] (Reisberg, Ferris, de Leon, & Cook, 1982), DSM-IV[5] (American Psychiatric Association, 2000), DSM-5[6] (American Psychiatric Association, 2013), International Classification of Diseases 10th Edition (ICD-10)[7] (Riedel-Heller, Busse, Aurich,

[2] The CDR requires estimation of function in six domains—including memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care—and then calculation of a sum of boxes that summarise four stages: 0 = no impairment, 0.5 = questionable impairment (also referred to as MCI) (Chang et al., 2011), 1.0 = mild impairment, 2.0 = moderate impairment and 3.0 = severe impairment.

2. CDR requires estimation of function in 6 domains including memory, orientation, judgment & problem solving, community affairs, home & hobbies, and personal care, and then calculation of a sum of boxes which summarise into 4 stages: 0 no impairment, 0.5 questionable impairment (also referred to as MCI, Chang et al., 2011), 1.0 mild impairment, 2.0 moderate impairment, and 3.0 severe impairment.

[3] The FAST's seven levels include: 1 = normal adult, 2 = normal older adult, 3 = early dementia, 4 = mild dementia, 5 = moderate dementia, 6 = moderately severe dementia and 7 = severe dementia.

[4] The GDS's six levels include: 1 = no cognitive decline, 2 = very mild cognitive decline, 3 = mild cognitive decline, 4 = moderate cognitive decline, 5 = moderately severe cognitive decline, 6 = severe cognitive decline (middle dementia) and 7 = very severe cognitive decline (late dementia).

[5] The DSM-IV has five criteria with 12 aetiological modifier codes. Further, it has a fully operationalised diagnostic algorithm for these criteria (Prince et al., 2008) requiring a 1.5 SD departure from appropriate normative values for each of the following domains: (i) memory and at least one of (ii) language, (iii) apraxia, (iv) agnosia and (v) executive impairment.

[6] The DSM-5 has two levels of severity—mild and major neurocognitive disorders—with 13 aetiological modifier codes.

[7] Requires memory decline and a decline in other cognitive abilities sufficient to impair personal activities of daily living, with preserved awareness of the environment, a decline in emotional control or motivation or a change in social behaviour has to be established, and to have been present for at least six months. The ICD-10 encompasses a severity rating of mild, moderate or severe.

Matschinger, & Angermeyer, 2001) and Allen Cognitive Levels (ACL) test[8] (Velligan et al, 1998).

In their review of dementia staging systems, Reisberg et al. (2011) suggested notional staged equivalency levels between the CDR, GDS, FAST, MMSE and 'normal, questionable impairment, and impaired' ranges on psychometric tests, without specific rationale. While it was beyond the scope of the current study to investigate the base rate of older drivers without dementia diagnoses, the current figures relating to drivers with diagnoses of MCI suggest that, even though drivers with this diagnosis have hitherto been considered of low risk for failing on-road drives, their driving status should still be considered carefully. The possibility of early decline of driving skill should be considered during initial diagnosis, and on a regular basis from that time on.

While MCI is presumed to be associated with intact IADLs, including driving (Petersen, 2003), there is emerging evidence (Duchek et al., 2003; Hunt et al, 1997a; Olsen et al., 2014; Snellgrove, 2006) that at least some drivers with diagnosed MCI will fail a practical driving assessment. The data from the current series (Chapter 4) support this proposition, with participants with this diagnosis demonstrating a fail rate of 46%—a figure close to that previously described with a similar diagnosis (48% reported by Snellgrove, 2006). It is acknowledged that both studies may have recorded inflated rates of failure in MCI participants, as both received referrals for MCI drivers where there was suspicion from the referring medical officer of reduced driving skills. Thus, this may represent a biased sample and it cannot be assumed that all MCI drivers are likely to demonstrate this level of loss of driving skill. Even so, the implication of these data is that a CDR of 0.5 (which nominally represents the presence of intact IADLs) is not necessarily indicative of preserved driving competency. It has also been noted (Chang et

[8] The ACL's six levels include: 6 = planned actions (no disability), 5 = exploratory actions, 4 = goal directed actions, 3 = manual actions, 2 = postural actions and 1 = automatic actions (severe cognitive dysfunction resulting in the need for custodial care).

al., 2011) that, for the CDR range of 0.5, there is marked functional variability, and various subtypes and aetiological bases have been identified (Lehrner et al., 2008; Molano et al., 2010). This again reinforces the possibility that a driver with a CDR score of 0.5 may still be demonstrating early losses of IADLs, including driving competency.

Wadley et al. (2009) emphasised the need for increased vigilance among clinicians, family members and individuals with MCI for initially benign changes in driving, which may become increasingly problematic over time. Vogel et al. (2004) raised the possibility that individuals with MCI may show reduced insight, while Kowalski, Love, Tuokko, Macdonald, and Hultsch (2012) reported that few MCI participants in their driving study recognised any deterioration in their driving skills, and were not considering the need to retire from driving in the future, despite the presence of cognitive decline. Additionally, Stein and Dubinsky (2011) indicated, using a simulator-based methodology, that driving impairment can occur in the presence of MCI, and that loss of driving competency may occur in the earliest stages of the disease. The current results reinforce these findings, and suggest the need to at least consider the possibility that the patient with MCI may in fact already be losing driving competency.

A further complication is that, in MCI, there is a presumption of preserved general functional level, with intact civil competencies, including financial capacity (Triebel et al., 2009), Will making (Peisah & Shulman, 2012), the ability to form marriage or other contracts (Moye & Marson, 2007), and the ability to give informed consent to proceed with or forego medical procedures (Okonkwo et al., 2008). These matters are complicated by the fact that MCI has been shown to yield functional impairments in IADLs (Perneczky et al., 2006), and that MCI is heterogeneous for aetiology, manifestations and outcomes (Werner & Korczyn, 2008).

It should also be noted that MCI is a recognised risk factor for later development of dementia (Campbell et al., 2013) and that, once a driver is diagnosed with MCI, even if he or she passes an on-road drive or screening procedure, there will be a need for later serial checking for the possibility of an emerging generalised dementia and its associated losses in driver competency (Frittelli et al., 2009). Additionally, as the rate of progression from MCI to dementia is some 9.6% per annum, according to a meta-analysis (Mitchell & Shiri-Feshki, 2009), with a lifetime conversion rate from MCI to Alzheimer's disease of up to 65% (Busse, Angermeyer, & Riedel-Heller, 2006; Tuokko et al., 2003), it follows that the driver with MCI will also require repeated follow-ups after an initial successful drive, unless other medical conditions supervene.

9.2.2 The need for differential diagnosis. While it is likely that all forms of dementia will, at some point in the disease process, prevent the individual from driving safely, some forms of dementia are recognised as having an early effect on driving competence (Rapoport, Sarracini, Molnar, & Hermann, 2008). Major subtypes of dementia—such as Alzheimer's disease and vascular dementia—are likely to have a widespread effect on driving skills beyond the mild dementia stage (Molnar et al., 2009), and the effects on each of these are commonly bracketed together (Carmody, Traynor, & Iverson, 2012; Fitten et al., 1995; Groves et al., 2000), even though the clinical presentation, management and trajectory of decline of the two subtypes are considerably different (Smits et al., 2014).

It has been long recognised that some forms of dementia, such as FTD, lead to very early loss of executive function and that this aetiology of dementia should subsequently be recognised as being incompatible with continued licensed driving, even in the early stage of the disease (Hodges, 2001; Mendez & Shapira, 2005). While several authorities describe driving in individuals with FTD as being problematic due to issues of judgement, distractibility, impulsivity and aggression (e.g., Doty, 2006;

Frontotemporal Dementia Caregiver Support Center, 2003; University of California, 2016), few peer-reviewed studies have directly addressed the issue. A recent review by Dugan, Turk, and Wang (2013) surveyed 367 abstracts published between 1992 and 2013, and found only four that fulfilled their survey criteria. Of these, three were case-control studies and only one (de Simone et al., 2007) specifically dealt with FTD drivers. Here, 15 cases matched with controls demonstrated behavioural changes, including aggressive and agitated driving style. The second study from Zuin, Ortiz, Boromei, and Lopez (2002) (56 dementia cases, including two FTD) found no on-road differences between the two groups. The third (Frisoni et al., 1995) compared 19 FTD with 16 Alzheimer's disease drivers, and reported that the FTD drivers exhibited poor impulse control and distractibility. The fourth study (Miller et al., 1997) was a case study–based design that investigated 22 FTD and 14 Alzheimer's disease drivers, with the former drivers demonstrating socially disrupted and antisocial behaviour both on- and off-road.

One more recent study (Fujito et al., 2016) considered the differences between 28 FTD and 67 Alzheimer's disease drivers, with the former group showing a higher rate of changes in driver behaviour (89% versus 76%), alongside a high rate of causing on-road accidents (odds ratio of 10.4). However, this study used a semi-structured interview of drivers and informants, rather than an on-road assessment.

The 100% fail rate for FTD patients in the current series stands as additional support for the hypothesis that FTD drivers should be considered for early examination of driving skills. Although the Lewy body/Parkinson's disease group in the current series demonstrated a similar fail rate to that of Alzheimer's disease (88% versus 90%), the finding that Lewy body disease appears to have a more rapid progression than Alzheimer's disease (Ballard, Patel, Oyebode, & Wilcock, 1996; Olichney et al., 1998) suggests that this group should also be considered for close re-examination.

Further forms of dementia, such as primary progressive aphasia, are theoretically considered to have a lesser effect on high-level function, including driving skills, with a presumption of intact comportment in this group (Mesulam, 2013; Scholten et al., 1995; Wolfe & Clark, 2012). Given this, it was of interest that the current series demonstrated a 75% fail rate for primary progressive aphasia drivers—lower than that of Alzheimer's disease, but higher than that of MCI. This finding suggests that no form of dementia may be considered low risk for association with deterioration of driving skills. Due to the heterogeneity of dementia trajectories, it would appear crucial in the first instance to determine the dementia subtype present. Differential diagnosis is also crucial in order to rule out reversible (Dwolatzky & Clarfield, 2003) and/or psychiatric conditions, including depression, which may mimic dementia under certain conditions (Fischer, 1996).

9.2.3 Neuropsychological screening. There has been considerable debate as to whether the MMSE is a useful driving screener (Fitten et al., 1995; Fox et al., 1997; Hollis et al., 2015; Reger et al., 2004). The current data suggest that the MMSE is particularly unsuited as a screener, noting that no less than 26/93 drivers who failed their on-road test scored 28 or above on the 30 point MMSE—a score conventionally considered consistent with intact cognition (Tombaugh & McIntyre, 1992).

Additionally, the MMSE has been shown to have limited ability to detect dementia in a population of older individuals with higher educational attainment (O'Bryant et al., 2008a). Here, the authors reported that the traditional cut-off score for dementia (24) yielded a sensitivity of .66 and specificity of .99, whereas a higher cut-off score of 27 yielded sensitivity of .89 and specificity of .91. O'Bryant et al. (2008a) recommended this higher cut-off point when screening for dementia in higher educated individuals; however, even this cut-off point was considered inadequate for screening in a mixed group of dementia and MCI individuals (sensitivity of .69 and specificity of

.91), which underlines the inadequacy of the MMSE in detecting individuals with amnesic MCI, as previously suggested (Field, 1995). Frittelli et al. (2009) indicated a high rate of failure on a simulated driving task of individuals with MCI (mean MMSE score for this group of 26.5 +/- 3.5), an additional indication that the MMSE cannot detect deterioration of driving skill in older drivers, especially those with MCI, but without generalised dementia. In the current series, Frittelli et al.'s (2009) recommended cut-off score of 27 for MCI would have yielded a sensitivity of .257 and specificity of .632. Further, all passed drivers scored 21 or above; thus, using this cut-off score would have yielded a sensitivity of .878, but a specificity of .05.

The TMT has long been considered a valid measure of on-road driving skills, as it is believed that it measures many of the underlying cognitive building blocks of driving skills, including speed of information processing, visual scanning, problem solving and divided attention (Carr et al., 2011; Crowe, 1998; Mathias & Lucas, 2009). It has also been considered a valid measure of motor impulsivity and/or inhibitory deficit, secondary to underlying executive dysfunction (Alvarez-Moya et al., 2011), especially in Alzheimer's disease (Amieva et al., 1998).

The current series demonstrated an AUC of .692 for the optimum Trail Making screener (TMT-B *errors*), followed by TMT-B *time to completion* (AUC .624), TMT-A *time to completion* (.624) and TMT-A *errors* (.536). TMT-A appears to be a non-contributory candidate screener. While practicality would suggest that TMT-A should be discontinued for screening purposes, a procedure of this type is against that specified by the author (Reitan, 1958), who made firm pronouncements regarding adherence to the published test presentation format. While the TMT has repeatedly been referred to as a useful screener (Dawson et al., 2009; Mathias & Lucas, 2009; Silva et al., 2009), there are some caveats. The TMT is not conventionally considered a screening device, but is more usually given as part of comprehensive neuropsychological review (Lezak

et al., 2012). As such, it is important that these results are not considered in isolation, but within the context of a more comprehensive review. Any widespread use of the TMT as a screener could preclude its use in a more comprehensive examination. There is a longstanding assumption (Lezak et al., 2012) that the individual presenting for neuropsychological review is test naïve—that is, they have had no prior exposure to the task presented. Thus, any widespread use of this task as a screener may render the long-term use of the TMT less useful. For this reason, there is some objection to providing widespread exposure to the TMT in screening clinics, especially for serial use. Additionally, as this is a public domain task, there is already only marginal control over its dissemination and use.

The TMT is usually presented as part of a comprehensive neuropsychological review; thus, any such review would always take into account variables, such as patient premorbid ability level and age. Like the MMSE (O'Bryant et al., 2008a; Tombaugh & McIntyre, 1992), performance is determined not only by the presence of cognitive decline, but also by age, educational background and premorbid ability level (Ashendorf et al., 2008; Bornstein, Paniak, & O'Brien, 1987; Mitrushina, Boone, & D'Elia, 1999). Any use of a single cut-off score for either time to completion or number of errors committed will fail to take into account these important variables.

Instead of using the standard TMT, there may be some opportunity to use a parallel form of TMT for widespread dissemination as a screener. Parallel forms have already been developed (Galletly & Field, 1987; L. M. McCracken & Franzen, 1992) and could represent an opportunity to disseminate an alternative yet equivalent task specifically for screening—although, once again, this should ideally form part of a comprehensive neuropsychological review. Additionally, there is now a commercially available version (Delis, Kaplan, & Kramer, 2001) of the TMT, which is a greatly elaborated version of the original. It is conceivable that tasks of this type could be

reserved for full neuropsychological review, while leaving the current TMT public domain task available for widespread screening. Other cognate tracking-type tasks could also potentially be used (Barncord & Wanlass, 2001; Dugbartey, Townes, & Mahurin, 2000; Mrazic, Millis, & Drane, 2010).

9.2.4 Driver self-rating. As previously mentioned, several authorities have recommended the use of driver self-report or self-reflection procedures as a way of alerting oneself, one's family and one's caregivers to the possibility of any emerging driving decrements (Canadian Medical Association, 2006; Hogan et al., 2007; Molnar et al., 2009). Other bodies (e.g., Australian Automobile Association, 2010; National Roads and Motorists' Association, 2008) have adopted the view that older drivers are well placed to make their own decisions about when to retire from driving. There is now however emerging evidence that even older drivers without cognitive deficits show no relationship between self-evaluation of driving skills and actual on-road test outcome (Classen, Wang, Winter, Velozo, Lanford, & Bédard, 2013; Riendeau, Maxwell, Patterson, Weaver, & Bédard, 2016). Dalchow, Niewoehner, Henderson, and Carr (2010) noted that in a series of older drivers who were referred for fitness to drive assessments, participants rated their confidence on a Likert scale both pre and post drive, and those who failed the on-road assessment did not report any reduction in confidence following being informed of their on-road result. In one further large series (n=270) the vast majority of older participants (98%) rated themselves as average or above average drivers (Wood, Lacherez, & Anstey, 2013). Additionally, this study not only indicated no relationship between driving outcome and driver opinion, but also noted that older drivers who had reported a crash in the last 5 years were more confident than those who did not report a crash, the authors referring to these outcomes as indicative that some older drivers have reduced insight into their driving abilities. The current series, which investigated participants with putative cognitive decline, also

failed to demonstrate any relationship between participant opinion and on-road outcome.

9.2.5 Informant (caregiver-spouse) rating. The current research had some initial consideration that an informant (carer-spouse) evaluation could be a fruitful way of screening for loss of driving competency. An initial hypothesis was that informants who are children of the participant may be better estimators of driving performance than informant spouses. It was also hypothesised that non-driving informants would be less accurate in evaluating participant driving skills than informants with licences. However, in the current series, only one informant was a non-driver, which precluded any opportunity for analysis of these results. Additionally, the informant-spouse and informant-adult children appeared to be equally accurate (or inaccurate) in evaluating participant driver skills as a group, although it was noted in the current series that, in many cases, individual informants had developed the strong view that the participant's driving skills had significantly deteriorated.

Past studies have also noted that informant spouses are not necessarily accurate evaluators of participant driving skill (Brown et al., 2005; Croston, Meuser, Berg-Weger, Grant, & Carr, 2009). While the reason for this is unclear, one possibility is that, given that both members of the couple are likely of a similar age and may have similar risk factors for the development of dementia (Norton et al., 2010), in some cases, the informant-spouse may be developing parallel losses of cognition and insight. A further possibility is that the informant-spouse is dependent on the driver with dementia, and has a vested interest in having the driver maintain a licence for convenience and/or self-esteem, and is therefore not answering the questionnaire items consistently (Adler et al., 2000; Carmody et al., 2012; Croston et al., 2009).

The data from the current study suggested that, as a group, adult children informants were also not accurate evaluators of their parents' driving skills and, in at

least some cases, may have had little or no direct knowledge of this skill. There were a few notable exceptions in which the informant children were aware of limitations of driver skill and were keen for a formal on-road evaluation and recommendation of driving cessation as soon as possible. Thus, it appears to be important that family members should avail themselves of as much direct evidence of the driver's skill as practicable. Some formal alerting mechanism or educational package could be valuable in this regard. This could possibly be achieved either by a structured interview or handouts (an example is included in Appendix 11, based on Doty, 2007, and reproduced with permission).

9.2.6 Use of anosognosia (insight) scales. The results from the current study suggest that the use of a clinician-rated insight scale (CERAD) (Mendez & Shapira, 2005) may be a fruitful method of identifying changed behaviour and attitude in drivers who may be showing signs of loss of ability to self-reflect. The CERAD scale proved to be an effective screener for on-road outcomes, which is of particular interest because the format of the questionnaire was not specific to driving, but was designed to be a general measure of the participant's insight to his or her condition. Notably, this questionnaire was not given within the context of the driving assessment *per se*, but as part of the previous neuropsychological review. The fact that this is associated with on-road performance suggests immediately that this would represent a worthwhile screener for clinicians to at least consider the possibility that there may be issues of driving competency.

Likewise, the AQ-D (Starkstein et al., 1996) demonstrated reasonable utility in raising the issue of reduced insight among drivers with dementia, by measuring differential responding on cognitive and behavioural changes between the participant and an informant, although the sample size for this measure was still rather limited. The issue of anosognosia in dementia is so significant that it appears to be important for

both health professionals and carers to receive specific briefing about the possible effect of an anosognosia on the presentation of the proband. As previously suggested, using an educational package could be considered (see Appendix 11, based on Doty, 2007). The presence of reduced insight regarding driving outcomes (and, by implication, other aspects of IADLs) across all dementia populations in the current study implies that the consideration and evaluation of anosognosia should ideally be included in any comprehensive clinical review in dementia populations (Agnew & Morris, 1998; Salmon et al., 2006), including those with MCI (Ries et al., 2007)—not only within the driving and dementia context, but also more generally.

The results from the current series have demonstrated limited recognition of compromised driving skill in many participants with diagnoses of dementia or MCI. As previously mentioned (section 9.2(iv)), cognitively intact older drivers were also noted to overestimate their actual on-road driving skills (Sullivan et al., 2011), and a non-stratified (by dementia status) population of older drivers referred for driving evaluations rated themselves highly, with their self-ratings demonstrating no relationship between either drive outcomes or cognitive status (Freund et al., 2005; Riendeau et al., 2016; Wood, Lacharez, & Anstey, 2013). Thus, the fact that older drivers with dementia also tend to overestimate their driving skill should be no surprise.

9.2.7 Proposed application of triggers for on-road review. It appears that there is no single trigger that might prompt the need for an on-road review in an older driver with a putative dementia diagnosis. Candidate triggers could include clinician concern or informant-carer concern, despite this study's somewhat negative results regarding informant opinion. The presence of an increased accident rate might also serve as a trigger, although self-reported crash rates may be less than accurate, and—as noted in Chapter 7—in the current series, the reported recent accident rate from informants also proved to be non-contributory.

Croston et al. (2009) considered a large (n = 119) series of retired drivers with dementia, and highlighted the importance of family and physician input in the final decision to retire from driving, which implies that any such triggers should involve observations from those parties in particular. Ideally, an education program should be established for local medical officers with specific indicators of potential dangerous driving behaviours in older people (such as crash rates) (Dalziel, 2009; Molnar et al., 2009). This is particularly important given that previously published studies (Jang et al., 2007; Shanahan, Sladek, & Phillips, 2007) have indicated that both public and private doctors have poor knowledge of legislation regarding cessation of driving, and are under-confident in their ability to assess driving fitness.

Various studies have suggested that warning signs (triggers) should be sought among at-risk individuals. P. McCracken (2007) referred to driving errors (noted by informants), including an apparent lack of awareness of driving errors, a tendency to become lost or confused while driving, an apparent lack of awareness of other vehicles, a tendency to miss traffic signs, an inability to manage traffic speed, close calls (especially when unnoticed) and frequent honking from other drivers. Further, the Hartford Financial Services Group (Hartford/MIT AgeLab, 2013) suggested that warning signs might include difficulty maintaining lane position, near misses, confusing the accelerator and brake pedals, and stopping in the traffic stream for no apparent reason—with the latter two being considered ‘red-flag’ items.

As noted in Chapter 2, Molnar et al. (2009) suggested using the CanDRIVE mnemonic to alert clinicians to possible warning signs (cognition, acute/fluctuating illness, neuromuscular disease/neurological effects, drugs, record, in-car experiences, vision and ethanol use). O’Connor, Kapust, Lin, Hollis, and Jones (2010) recommended that physicians use a ‘4Cs’ mnemonic (crash history, family concerns, clinical

evaluation and cognitive functions) to help alert them to the possibility of reduced driving competency among older drivers.

Iverson et al. (2010) suggested that examining medical practitioners should consider the following matters, which are considered risk factors on the basis of their meta-analysis: caregiver report of marginal or unsafe skills, a history of citations (traffic tickets), a history of crashes, driving < 60 miles (100 km) per week, situational avoidance, aggression or impulsivity, an MMSE <= 24, and various other factors (including alcohol, medications, sleep disorders, visual impairment and motor impairment).

Carmody et al. (2012) suggested the following management strategy for GPs:

- Raise the issue of driving with all patients with cognitive impairment.
- Avoid an over-reliance on MMSE scores.
- Acknowledge that some spouses are unreliable judges of driving skills—they may be afraid to raise their concerns because of the potential consequences.
- Aim to provide an early diagnosis of dementia (if possible), as this enables individuals and their families to plan for the transition to not driving.
- Remind the individual of his or her obligation to report their diagnosis to the driver licensing authority.
- Direct individuals and their families to reliable sources of additional information, such as Alzheimer's Australia.
- Discuss alternative forms of transport, such as public transport and driving with family members.
- Consider discussing the potential effect an accident would have on others.
- Inform individuals that, should an accident occur, they may face civil or criminal prosecution.

- Explain that car or life insurance policies will be void if driving when deemed medically unfit to do so.
- Document all discussions.
- Reassess dementia severity and fitness to drive every six months for drivers with mild dementia who are deemed safe to continue driving.
- Consider an occupational therapist driver assessment referral (limited by availability and cost), which can be repeated.
- If unsure how to proceed, refer the individual to a geriatrician or neurologist.

While there is no single 'warning sign' checklist that is entirely suitable, it is evident that many of the suggestions listed above contain similar content. For that reason, a quasi-formal listing of warning signs is suggested below, divided into three broad domains for convenience:

1. *Cognitive changes*: Clear signs of cognitive change, not necessarily limited purely to recent forgetfulness. These can include losses in language output, organisational or visuospatial skills. If this leads to suspicion of the presence of dementia, this should include consideration of the dementia subtype and severity (Fujito et al., 2016; Lipski, 2001; Snellgrove, 2006; current study).
2. *Behavioural changes*: Clear indication of behavioural changes from premorbid levels, including aggressiveness, impulsivity, episodic confusion and/or reduced insight (Carmody et al., 2012; Molnar et al., 2009; Pachana & Petriwskyj, 2006).
3. *Operational changes*: Obvious changes in driving style, including self-limitation of driving conditions, distance travelled, a history of near misses, unexplained accidents, and changes in on-road behaviour (Hartford/MIT AgeLab, 2013; P. McCracken; 2007). Use of the Hartford checklist is suggested (Appendix 12; reproduced with permission).

9.2.8 Selection of cut-off points for screening tools. It will be recalled (Chapter 3), that this study used ROC curves to plot the rate of true positives (sensitivity) to false positives (1-specificity) and identify cut-off scores on the assessment measures found accurately to predict failing the on-road test, and that the AUC of the ROC represents the degree of accuracy of the clinical test (Crizzle et al., 2012). This enables selection of an optimum cut-off score for each of the selected predictor measures, by trading-off between sensitivity and specificity for each candidate's cut-off score. Youden's index (*J*) (Schisterman et al., 2005) also represents a data-driven means of selecting optimum sensitivity and specificity. However, it has also been suggested that there should be a balance between the two (which may vary depending on the context) and that a screening test should ideally be highly sensitive, and a confirmatory test should be highly specific. In such a case, the choice of cut-off score is considered decision analytically based (Steyerberg et al., 2011).

For the purposes of this study, sensitivity represents the ability of an assessment to accurately identify individuals with unsafe driving abilities who would fail the on-road test, while specificity represents the ability of an assessment to accurately identify individuals who would pass the on-road test. The Youden index scores described in Chapters 5 to 8 indicate the operation of a data-driven trade-off between sensitivity and specificity. However, there may be some danger that a rigid selection of the score indicated by the Youden index may not represent best clinical practice, and that a context-driven selection may be more appropriate. Choosing a different cut-off score would result in a decrease in either sensitivity or specificity because of the trade-offs between them (as sensitivity increases, specificity decreases, and vice versa). These trade-offs depend on the stringency of the criterion.

Using a smaller cut-off value (a less stringent criterion) would decrease sensitivity (a type-I error), thereby increasing a clinician's chance of wrongly

classifying an unsafe driver as fit to drive. Conversely, using a higher cut-off value (a more stringent criterion) would decrease specificity (a type-II error), thereby increasing the chance of incorrectly identifying a safe driver as unfit to drive (Shechtman et al., 2010). Low sensitivity (type-I error) entails mistakenly identifying unsafe drivers as fit to drive. The clinical consequences of this type of error involve risking the life, safety and property of the driver and others. Conversely, a low specificity (type-II error) entails mistakenly classifying safe drivers as unfit to drive. This clinical error may result in revoking a driver's licence when he or she is still fit to drive. The consequences of this type of error involve negative effects on the driver's (and sometimes his or her family's) independence and quality of life.

This balance is referred to using the mnemonic 'SpPIn/SnNOut'. If a highly **sp**ecific test is used, a **p**ositive result rules **in** the diagnosis. In contrast, if a highly **se**nsitive test is used, a **n**egative result rules **out** the diagnosis (Gilbert, Logan, Moyer, & Elliott, 2001). A screening test should be highly sensitive and a confirmatory test should be highly specific; however, practically, there will be a balance between the two (Steyerberg et al., 2011). On this basis and in the context of the current study, where neuropsychological and questionnaire tools are being considered for inclusion in a screening package associated with a GP or other medical clinics, selecting a cut-off score for maximal appropriate sensitivity (without sacrificing all levels of specificity) would appear to be appropriate. In contrast, when using these or other tools in a more specialist clinic (such as the current dementia driving clinic), it would appear to be appropriate to select cut-off scores that allow a greater level of specificity to rule *in* the diagnosis of deteriorated driving skills.

9.2.9 Other considerations. From the knowledge gained in the current series, it would appear that post-drive debriefings might represent a fruitful forum to raise the issue of loss of driving skill and dementia. Given the author's experience from the 215

completed drives, there are essentially two possible post-drive debrief scenarios for non-passing drive outcomes. The first scenario involves the informant hearing the result and indicating that he or she already had suspicions that this outcome would occur. This represents a way of reinforcing a pre-existing opinion using objective data to reinforce the message to the participant that driving competency has now declined. The second scenario is more difficult to manage. This involves both the informant and participant believing that driving competency is preserved. However, this scenario represents the opportunity to educate both parties about the possible effect of dementia on driving performance, with specific reference to errors that were committed by the participant during the drive.

In either case, there is the opportunity to educate and counsel the participant regarding future transport issues, as detailed in Chapter 6 ('Counselling the Patient Who is No Longer Safe to Drive') of the *Physician's Guide to Assessing and Counseling Older Drivers* (American Medical Association, 2010). This includes:

- stressing why it is important to stop driving, including mentioning the potential risk of continued driving; a reminder of the risks to oneself, loved ones and other road users; and asking how the driver would feel if they were involved in a crash that injured someone else
- using economic arguments (such as the standing and running costs of vehicles)
- acknowledging that driving cessation may be associated with a decrease in social integration (Mezuk & Rebok, 2008)
- encouraging family/caregiver assistance where appropriate, including establishing a roster of available drivers/carers
- canvassing transport alternatives, including taxis, public transport and community buses or cars

- considering additional reinforcement and/or counselling at a later date, if required.

The use of post-drive educative debriefing sessions utilizing results from on-road drive and carer-informant questionnaire results has also been suggested (Classen, Wang, Winter, Velozo, Lanford, & Bédard, 2013; Riendeau et al., 2016). The latter study also recommended use of educational interventions to increase knowledge and self-awareness of changes in driving skill related to ageing. A recent group education and support programme to assist with driving cessation in older drivers has also been advocated (Liddle et al., 2014).

9.3 Recommendation of a Decision Tree

As discussed in Chapter 2, Molnar et al. (2009) recommended using a trichotomous decision tree to assist clinicians to make decisions about the driver suffering from dementia. On the basis of the current study, Figure 9.1 presents an elaborated trichotomous decision tree, with rationales.

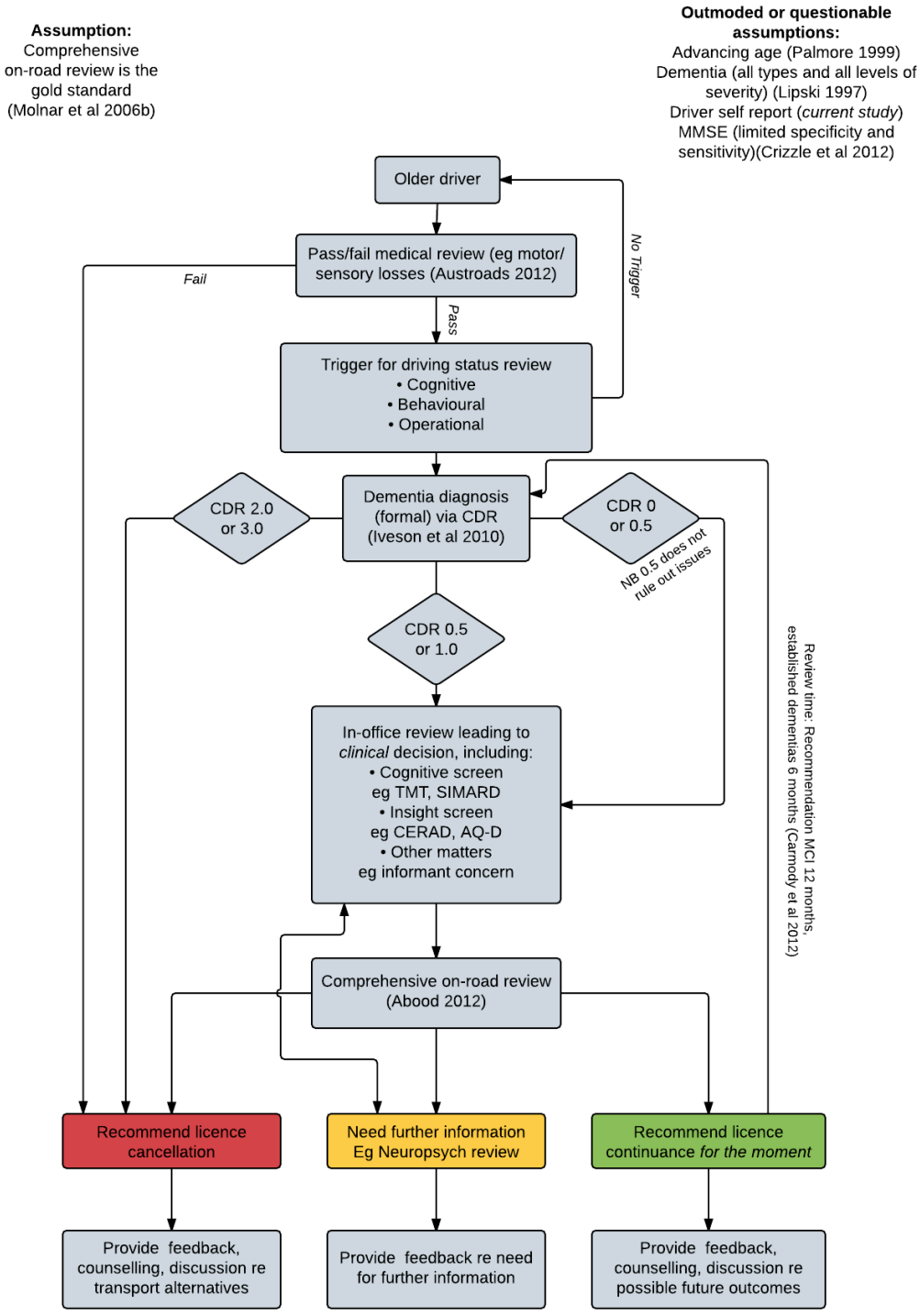

Figure 9.1. Proposed trichotomous decision tree for evaluating drivers with known or suspected dementia.

The current chart preserves the trichotomous pattern suggested by Molnar et al. (2009; see Figure 2.1), but now divides decisions into 'licence continuance *for the moment*', 'more information needed' and 'recommend licence cancellation' (while Molnar et al.'s terminology was 'clearly safe to drive; no concerns', 'fitness to drive is unclear based on score alone' and 'clearly unsafe to drive'). It is acknowledged that the current terminology is considerably altered. The flowchart includes additional detail regarding suggestions for applications of trigger mechanisms and screening procedures.

Commencing at the top of the chart is an underlying assumption that a comprehensive on-road review is the gold standard for review of driving status. As noted in the body of this thesis, there are various outmoded assumptions that are likely of questionable value. For example, these include the concept that advancing age leads to loss of driving skills (Palmore, 1999), that dementia of all types and levels of severity should lead to immediate cessation of driving rights (Lipski, 1997), and that some previously widely used screening tools (such as the MMSE) may have limited value due to specificity and sensitivity issues (Crizzle et al., 2012).

In the flowchart, the initial decision box indicates the presentation of the older driver to the clinician. The first step in the process is a general medical review pursuant to Austroads (2012, 2016). If the individual fails this due to an underlying medical condition, the licence may need to be cancelled or suspended in due course. If there is a pass in the medical review, there may be a series of trigger mechanisms that have raised questions in the clinician's mind regarding the possibility of compromised driving skill. If there is no trigger, the process ceases, but may be reconsidered at a later date.

For convenience, these triggers have been divided into three major areas: cognitive, behavioural and operational. Cognitive changes can include alterations in cognitive status of a significant degree, and may (for example) have arisen as a result of a comment from informants or a prior neuropsychological review. Behavioural changes

can include reports or observations of aggressiveness or impulsivity, or concern regarding driver insight. Operational changes can include self-report or informant report of changes in driver behaviour, including accidents and/or near misses.

Following identification of a trigger, a formal dementia diagnosis—consistent with the recommendation of Iverson et al. (2010) and using the CDR—should ideally be completed. The CDR is a semi-structured interview performed by an experienced clinician and involves an in-office cognitive assessment, interviews with both the driver and informant, and then a comparison of the two sets of respondents' information. Scores are then assigned for six domains (memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care), and these are combined into a summary score of 0 (normal), 0.5 (MCI), 1.0 (mild dementia), 2.0 (moderate dementia) or 3.0 (severe dementia). Pursuant to the recommendation of Iverson et al. (2010), scores of 2.0 or above should lead to a recommendation for licence cancellation. In contrast, a CDR of 0 or 0.5 would lead to a recommendation for licence continuance *for the moment*. Reconsideration of drive status can then be made at a later time.

As previously mentioned, all forms of dementia are considered progressive (Hogan et al., 2008; Lovestone, 2009) and, in the presence of a diagnosis of MCI, a conversion rate to dementia of 9.6% per annum might be expected (Mitchell & Shiri-Feshki, 2009). Assuming the presence of one of these two states, these reviews should ideally occur on a regular basis—a suggestion is a 12-monthly review for MCI, and six-monthly review for all other diagnoses. This would then lead to a reassessment via CDR and the need for further screening, as required.

It should be noted that, pursuant to findings from Snellgrove (2006) and the current study, a CDR score of 0.5 does not necessarily eliminate the possibility of declines in driving ability; thus, a CDR score of 0.5 should lead to a more formal in-

office review, as should a CDR score of 1.0 (mild dementia). The in-office review should involve formal screening, such as the TMT or Snellgrove (2006) maze task, although it is acknowledged that no single cognitive screen will be 100% accurate; thus, more than one screen might need to be considered. There is also the opportunity to introduce other possibly more valid screening devices in the future.

It is also recommended that an insight screen be included, such as the CERAD (clinician scored) or an AQ-D (comparison of examinee and informant perceived changes of intellectual function and behaviour). Other matters need to be considered, such as expressions of concern from informants, including family members and/or other health practitioners. If these expressions lead to sufficient concern, depending on the outcome of the in-office review, they might lead to recommendation for cancellation of licence, request for further information (such as a follow-up neuropsychological review) or, in many cases, referral for a comprehensive on-road review, which is considered to be the gold standard. It is noted that this leads to a *clinical* decision based on all matters described above. The outcome of an on-road review would then lead to recommendation for licence cancellation, need for follow-up, or recommendation of continuance of licence. Once again, the recommendation for continuance of licence will need to be reconsidered at a later date. At this time, feedback, counselling and discussion about possible future outcomes should be included as part of the clinician's role. If further information is required after the on-road review, this should also be discussed with the participant and family. Finally, in the event of recommendation for licence cancellation, it is important for the clinician to provide feedback, counselling and discussion about transport alternatives.

It is acknowledged there are a number of weaknesses with this system. Specifically, these include the possibility that the client's CDR score of either 0.5 or 1.0 will not necessarily draw the clinician's attention to the possibility of significant

underlying deficits (Chang et al., 2011). Additionally, as noted above, the CDR is required to be completed by an experienced clinician, who should preferably be formally trained in the examination (e.g., Dorflinger, 2012) and who is able to assess and then interview both the driver and informant. If these steps cannot be ensured, the CDR cannot be validly completed.

9.4 Recommendations for Policy

It is recommended that a training package be produced for GPs and geriatricians. While this is beyond the scope of this project, a number of pointers arose from this study's findings. First, as indicated, there must be recognition that there is dementia present, and ideally the form of dementia should receive a specific diagnosis. Second, some form of in-office screening is required. Other projects have recommended simple screens in the GP office. While these may have unacceptably high error rates, they do at least represent some attempt at measuring cognition in the older driver.

Neuropsychological review is important and should also be strongly considered. Notably, the rate of agreement between on-road driving and neuropsychological review is conventionally in the order of 90% (Carr & Ott, 2010; Silva et al., 2009). However, the fact that this is not 100% does suggest that one cannot simply use a neuropsychological review in lieu of a practical drive. In fact, there were several notable cases in the current series where it seemed likely that the participant would fail the on-road test on the basis of neuropsychological review, and then the participant passed. The opposite scenario (failed drive, yet preserved TMT performance) was also observed. If there is suspicion of loss of cognitive function, a practical drive with an appropriately experienced assessor is recommended.

Finally, given the relatively high rate of failure in the current series, it seems essential to establish some form of follow-on for those who have lost their driving licence, as mentioned in Section 9.3. This should include ongoing counselling and, if

possible, establishment of alternative transport strategies, such as taxi vouchers and access to and use of community buses (Stephens et al., 2005). While this already occurs to an extent, there is considerable variation in the way this matter is managed by individual medical practitioners.

It has previously been noted that Alzheimer's Australia (2004, 2016) and the Australian and New Zealand Society for Geriatric Medicine (Cameron, 2009; Snellgrove & Hecker, 2003) have established policies regarding dementia and driving. While these are generally considered appropriate, it is also believed that more detailed recommendations should be made on the basis of the current findings. The data from the current series support the suggestion that recommendations could be made to appropriate learned societies, such as Alzheimer's Australia and the Australian and New Zealand Society of Geriatric Medicine, with regard to updating their published form of recommendations for managing drivers with dementia.

9.5 Possible Future Developments

This study includes data from an ongoing clinic, and the opportunity exists for inclusion of other possible candidate screeners. Several newer screeners have been published and/or proposed since the commencement of the current series, and might be considered for future inclusion. One screener with face validity is the 'Ten Minute Office Based Dementia and Driving Check List for Use by Physicians and Healthcare Professionals' developed by Dr Bill Dalziel and described by Molnar et al. (2009) (see Appendix 13, reproduced with permission), which may be examined in the future as a screening device. As previously noted (Chapter 2), Molnar et al. (2009) emphasised that this is 'based on clinical opinion and experience, not evidence' (p. 87). Unfortunately, no validation appears to have been attempted with this screener, although it contains a number of interesting elements. For example, item 3 refers to family concerns and the so-called 'granddaughter question': 'Would you feel it was safe if a five-year-old

granddaughter was alone in the car with the person driving?' This represents a question commonly used informally by clinicians when interviewing carers of drivers with dementia. Item 10 refers to judgement and insight and asks the driver: 'What would you do if you were driving and saw a ball roll out on the street ahead of you?' and 'With your diagnosis of dementia, do you think at some time you will need to stop driving?'

The 'Ten Minute Screener' also incorporates the TMT as item 8, although caution should taken here because the recommendation is to use the time to completion and number of errors both singly and in combination, without any particular rationale or attempt to control for age or premorbid intelligence level. However, it is widely recognised that this and all other timed tasks yield longer completion times for older people (Ashendorf et al., 2008; Lezak et al., 2012). Thus, it is advisable to offer a norm-based comparison, as is typically undertaken in a comprehensive neuropsychological review. Once again, there are some objections to using the TMT in this form as a standalone screening task.

It has already been noted that the DriveSafe DriveAware process is now available via an iPad app (Kay & Bundy, 2015), and this could be added to a later clinic protocol. One further possibility might be to develop verbal fluency–based tasks as driving dementia screeners, especially as these may be rapidly completed and do not require preserved fine motor control and visual acuity, as do pencil-and-paper cognitive tasks (Lezak et al., 2012). Verbal fluency—especially phonemic (initial letter) fluency—has long been recognised as a valid measure of executive function (Crowe, 1996). Starkstein et al. (2007) also suggested the use of fluency among other measures for measuring anosognosia, and fluency as a measure of self-awareness of cognitive loss has also been suggested (Loebel, Dager, Berg, & Hyde, 1990). The Delis–Kaplan Executive Function System (DKEFS) format (Delis et al., 2001) fluency task adds a new category switching condition that is also considered a good measure of ability to

inhibit impulsive responses secondary to loss of executive function. Trails-based tasks (Amieva et al., 1998) are considered efficient measures of inhibitory deficits; thus, it appears that the DKEFS fluency task category switching condition could also potentially be recruited as a further or alternative measure of impulsivity, suitable for screening purposes. Newer format fluency tasks, such as action (verb) fluency, have been suggested as more sensitive measures of frontal-basal ganglia loop efficiency than conventional fluency tasks (Woods et al., 2005), and could also be considered.

The Snellgrove maze has already been examined extensively (Carr et al., 2011; Snellgrove, 2006) and appears to represent an excellent candidate screen for further confirmation of its utility. A recently developed task, the SIMARD—a modification of the DemTect (B. M. Dobbs & Schopflocher, 2010)—has been recommended as an appropriate driver screener, although it contains no driving-related items and instead contains word recall and fluency (executive) measures.

While results of the current study for the composite Caregiver Questionnaire was non-contributory (see section 9.6 below), it is still possible that a different carer-informant questionnaire may be more useful in alerting health professionals to the issue of decreased driving skill in older drivers with or without cognitive decline. Classen, Velozo, Winter, Wang, and Lanford (2012) have developed a 54 item questionnaire (Safe Driving Behavior Measure, SDBM) for drivers and informants, which has been shown (Classen, Wang, Winter, Velozo, Lanford, & Bédard, 2013) in the latter group to have good concurrent criterion validity for criterion of on-road outcome. The same study noted that a similarly worded questionnaire presented to older drivers had limited criterion validity.

Subsequent studies could also provide validation of and possible refinement of the decision tree detailed in Fig 9.1 above.

9.6 Limitations of the Study

There are certain limitations and caveats to this study. The sample size for the on-road assessments (n = 215) was considered large in comparison to other on-road assessment studies using drivers with diagnosed dementia or MCI; however, the overall sample size was still relatively small for statistical analysis purposes, especially for some of the in-office questionnaires. The sample of drivers who completed neuropsychological reviews was smaller (n = 93 for the MMSE, n = 100 for the TMT). For the in-office questionnaires, the sample size was n = 73 for the DDQ, n = 81 for the CERAD and n = 45 for the AQ-D—the latter being introduced more recently than some of the other measures. For the components of the Caregiver Questionnaire, the sample size was smaller still, within the range of 25 to 41. This is of particular concern and it is acknowledged that a high proportion of respondents declined to fill in all sections, especially towards the latter part of the document. It is also noted that, in some cases, several sections of the proformas were returned blank or with a line drawn straight thorough all questions. Thus, the findings based on this section should be treated with particular caution.

For the on-road assessment, a fully standardised route was not possible due to operational limitations; however, as much as possible, routes were selected to sample a range of on-road conditions, including: (i) major roads and intersections controlled by traffic lights and featuring turn arrows and slip lanes; (ii) side streets controlled by roundabouts, stop signs and give-way signs; and (iii) children's crossings, railway crossings and shopping centre carparks. However, it was not possible to control external variables, such as weather, traffic exposure due to time of day, and the uniformity of traffic. It is also noted that the use of standardised or limited-variation courses of this type has been criticised (Lovell & Russell, 2005) in comparison to assessment conducted in a driver's familiar environment; however, it was believed that any such

accommodation would have compromised the generalisability of the obtained on-road results.

This study compared in-office assessments and questionnaires in referred drivers who passed or failed their on-road assessments. There was no opportunity to recruit an older driver group without known or suspected dementia; therefore, there is limited potential to discuss the results of the performance of the driver with dementia in comparison to healthy older drivers.

Additionally, as this study presents data for a specialised driver dementia clinic, it is acknowledged that recruitment to the study would necessarily comprise a biased and 'preselected' group. Thus, drivers with a diagnosis of early dementia who were showing no signs of deteriorated driving skill were unlikely to be recruited. The sample was recruited from a small sector of the community with identified cognitive decline. Thus, the data should be seen as relating to community dwelling older drivers with known or suspected dementia or MCI at presentation to a specialised clinic. The data are not generalisable to other select older populations. The level of impairment seen in drivers referred to this clinic can be expected to be higher than that of driving populations of any medical practice that is the likely venue of a screening program. Unfortunately, random sampling of the general population of all older drivers was neither possible nor practical for this study.

The issue of identifying a gold standard for criterion measure of driving confidence is central to studies attempting to screen for future driving problems. An on-road test that challenges the participant to make active and informed cognitive decisions as a client is the gold standard of driving ability with cognitive impairment. In this study, the driving test was a single assessment and the driver participant was aware that he or she was being 'examined'. Thus, it is possible that, under these conditions, the driver was on his or her 'best behaviour' and that the drive was not an accurate sample

of a larger block of on-road behaviour. Similarly, it is possible that the participants were experiencing anxiety due to the assessment and the necessity to adapt to an unfamiliar car or route, with the possibility of a negative effect on driving performance.

It should also be noted that the study was conducted using an accredited driving assessor using Transport South Australia's VORT procedures, which is mandated by that authority, such that a candidate must pass this task before obtaining a South Australian drivers' licence. Driving assessments of clinical populations are often performed by specialist occupational therapists; however, an occupational therapist was not enlisted in the current study due to cost and availability issues. Thus, the fairness of the on-road assessment using the VORT procedure, as used in this study, remains a moot point; however, the VORT represents the reality of assessment of driving competence in South Australia. Further, it is noted that the inter-rater reliability of a VORT on-road driving assessment was high in a previous study using an identical format and personnel (Snellgrove, 2006).

9.7 Closing Remarks

This project has considered the issue of driving competency among older drivers with dementia or MCI. It is evident from the current results that some drivers with dementia may begin to lose driving competence earlier in the process than has hitherto been recognised, and that drivers with diagnosis of MCI may be at risk for losses in driving competence. Some of these drivers also appear to have diminished recognition of their deterioration in driving skill. The establishment and maintenance of further dedicated dementia driving units is recommended to enable the canvassing of issues of actual on-road driving skills, and the valuable opportunity to provide education and debriefing sessions following the on-road evaluations.

Finally, it is hoped that, sometime in the future, the driver (or, more correctly, 'vehicle user') suffering dementia or other significant medical disability may be able to

use road vehicles operating under the auspices of artificial intelligence. Recent advances in artificial intelligence–based vehicle operation systems are now beginning to yield access to on-road environments (R. Anderson & Woolley, 2015), with systems of this type previously successfully applied to autonomous flying vehicles that are now widely used (Glover, Cross, Lucas, Stecki, & Stecki, 2010; Lucas, Lyons, Glover, & Cross, 2010). South Australia has also recently been the first state in Australia to introduce legislation to allow use of driverless vehicles on the state's roads (Government of South Australia, Office of the Premier, 2016). It is believed that a widespread use of driverless vehicles is likely to pre-date the development of a comprehensive cure for dementia, and may eventually be a significant aid to benefit individuals diagnosed with that disorder.

10. Afterword

10.1 Christmas 2016

It should be noted that two recent sets of coroners' findings (Coroners Court of Queensland, 2016; Coroners Court of South Australia, 2016) (see Appendix 14) relate directly to the issues raised in this thesis's Discussion. Each involves a finding relating to deaths in motor vehicle accidents, in which there were issues with regard to fitness to drive among two older drivers. While it is uncertain whether the drivers involved were suffering from primary dementia, the two cases have in common the issue of an older driver with multiple medical conditions, some of which are likely to have resulted in cognitive decline. The other commonality is that in each case, there was significant available background documentation regarding the medical status of the driver, which had not been adequately accessed and/or considered in reissuing drivers' licences following earlier medical suspension. In each case, the road and weather conditions were clear, and the involved vehicles were judged to be in good mechanical condition.

In the South Australian case, a government driving auditor had given a marginal pass to the driver, not taking into account two recent prior assessments that had yielded clear fails. In the Queensland case, a GP who had not furnished himself with sufficient background information regarding the medical conditions of the driver, had passed the driver on the basis of what appeared to be an idiosyncratic and unsystematic assessment. In each case, the coroner was strongly critical of the unsystematic process of renewing licences among older drivers with significant medical conditions, and of failing to access apposite past documentation.

The author believes that, if clear and consistent guidelines for renewing licences among older drivers had been followed as recommended in Chapter 9, it is likely that these tragic outcomes could have been averted.

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Appendix 1:

Repatriation General Hospital (RGH) Participant Information Sheet and Consent Forms (I and II)

MEMORY DISORDERS STUDY UNIT
Department of Rehabilitation & Aged Care
Repatriation General Hospital
Daws Road DAW PARK SA 5041
Telephone: (08) 8275-1033, (08) 8275-1103
Fax: (08) 8275-1106

Patient Information Sheet

Aged Care Dementia Driving Clinic.

This clinic has been established to provide on road assessments of older drivers who are suffering from dementia or other forms of memory loss. This is important because in the presence of dementia or other forms of memory loss, driving skill may be progressively diminished to the point where the driver is no longer safe. It is difficult to determine when this point has occurred without direct evidence from an on road review, and for that reason your doctor would like you to complete this review today.

This assessment will take place on a set route in a dual control car for safety reasons, with a licenced and experienced driving instructor.

Depending on the outcome of the on road review the Instructor and / or Mr Field may make a recommendation to your referring doctor regarding your future driving status.

Please note that the referring doctor has the final say as to whether you should continue to hold your licence, however in most cases this recommendation will be accepted.

Yours sincerely

Colin Field
Senior Clinical Neuropsychologist
Aged Care Medicine

Aged Care Dementia Driving Clinic.
Consent form I

I, _____ have had explained to me by the investigator Mr Colin Field (or his representative) the reason for and possible outcomes of, this on road driving assessment.

I have been provided with an information sheet, which I have read and understood.

I understand that the study involves an on road assessment of my driving skills.

I understand that, depending on the outcome of the on road review the Instructor and / or Mr Field may make a recommendation to my referring doctor regarding my future driving status.

I understand that the referring doctor has the final say as to whether I should continue to hold your licence, however in most cases this recommendation will be accepted.

I declare that that I am over the age of 18 years.

_____

Signature: _____ Signature of witness: _____

Date: _____

Printed name of witness: _____

Consent Form II

Appendix I.

You will be aware that you previously completed a neuropsychological review with Mr Field. By signing this consent form this will allow us to tabulate your previous test results to look at the tests which tell us most about your actual on road performance.

I understand that these results may be published at a later time but the results will only be published in a tabulated form and I will not be identifiable in these results.

_____

Signature: _____ Signature of witness: _____

Date: _____

Printed name of witness: _____

Appendix 2:

Dementia Driving Clinic (DDC) Participant Information Sheet and Consent Forms (I, II, and III)

Dr Colin D. Field
BBSc (Hons.), B Litt (Hons.), MSc (Clinical Neuropsychology)
DPsych (Forensic), FAPS
Member, APS College of Clinical Neuropsychologists
Member, APS College of Forensic Psychologists

Registered Psychologist (Psychology Board of Australia).
Approved areas of practice: clinical neuropsychology and forensic psychology

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Phone: (08) 8267-5547
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Mobile: 0409-672-614

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Provider No: 2655634T
ABN 48 566 533 940

Dementia Driving Clinic

Patient Information Sheet

This clinic has been established to provide on road assessments of older drivers who are suffering from dementia or other forms of memory loss. This is important because in the presence of dementia or other forms of memory loss, driving skill may be progressively diminished to the point where the driver is no longer safe. It is difficult to determine when this point has occurred without direct evidence from an on road review, and for that reason your doctor would like you to complete this review today.

This assessment will take place on a set route in a dual control car for safety reasons, with a licenced and experienced driving instructor.

Depending on the outcome of the on road review the Instructor and / or Dr Field may make a recommendation to your referring doctor regarding your future driving status.

Please note that the referring doctor has the final say as to whether you should continue to hold your licence, however in most cases this recommendation will be accepted.

Dementia Driving Clinic
Consent form I

I, _____ have had explained to me by the investigator Dr Colin Field (or his representative) the reason for and possible outcomes of, this on road driving assessment.

I have been provided with an information sheet, which I have read and understood.

I understand that the study involves an on road assessment of my driving skills.

I understand that, depending on the outcome of the on road review the Instructor and / or Dr Field may make a recommendation to my referring doctor regarding my future driving status.

I understand that the referring doctor has the final say as to whether I should continue to hold your licence, however in most cases this recommendation will be accepted.

I declare that that I am over the age of 18 years.

_____

Signature: _____ Signature of witness: _____

Date: _____

Printed name of witness: _____

Consent Form II

Appendix I.

You will be aware that you previously completed a neuropsychological review with Dr Field. By signing this consent form this will allow us to tabulate your previous test results to look at the tests which tell us most about your actual on road performance.

I understand that these results may be published at a later time but the results will only be published in a tabulated form and I will not be identifiable in these results.

_____

Signature: _____ Signature of witness: _____

Date: _____

Printed name of witness: _____

Consent Form III

Appendix II.

As we are also interested in using questionnaires filled out by yourself and your (carer/ spouse/ children) to predict your actual on road driving performance, we are also asking you to sign this agreement which will allow us to ask you and your (carer) to complete these brief questionnaires about your driving history, and their opinion and also your own opinion as how well you are currently driving a car.

I understand that these also may be published at a later time but the results will only be used in a tabulated form and you will not be identifiable in these results.

_____

Signature: _____ Signature of witness: _____

Date: _____

Printed name of witness: _____

Appendix 3:

Task 30 Assessment Sheet (SA Dept of Transport, Energy & Infrastructure)

Government of South Australia
Department for Transport, Energy and Infrastructure

TASK 30 ASSESSMENT SHEET
Review of Traffic Management Skills

MR 272
10/07

Applicant Name: _____ **Permit Number:** _____

TYPE	CONTENT	SYSTEM OF VEHICLE CONTROL	LAW	Totals	
				Faults	All
Left Turns	**On** to busy road				
	From busy road				
	Traffic lights				
	Minor roads				
Right Turns	**On** to busy road				
	From busy road				
	Traffic lights				
	Roundabout				
	Minor roads				
Straight and **General** Driving	Lane change **(L)**				
	Lane change **(R)**				
	Laned road				
	Roundabout				
	Traffic lights				
	Other				
	Other				
Signs *(Included in items above)*	Stop				
	Give way				
	School Zone				
	Ped. crossing				
Bends	Sealed **(L)**				
	Sealed **(R)**				
	Unsealed **(L)**				
	Unsealed **(R)**				
			Sub-totals		
			Result		

Start Time: _____ **Finish Time:** _____

LAW ASSESSMENT (FULL DRIVE)	RE-ASSESSED	RESULT

Re-assessment of System of Vehicle Control.*

	SYSTEM OF VEHICLE CONTROL	Result %
Left		
Right		
Lane		
Other		

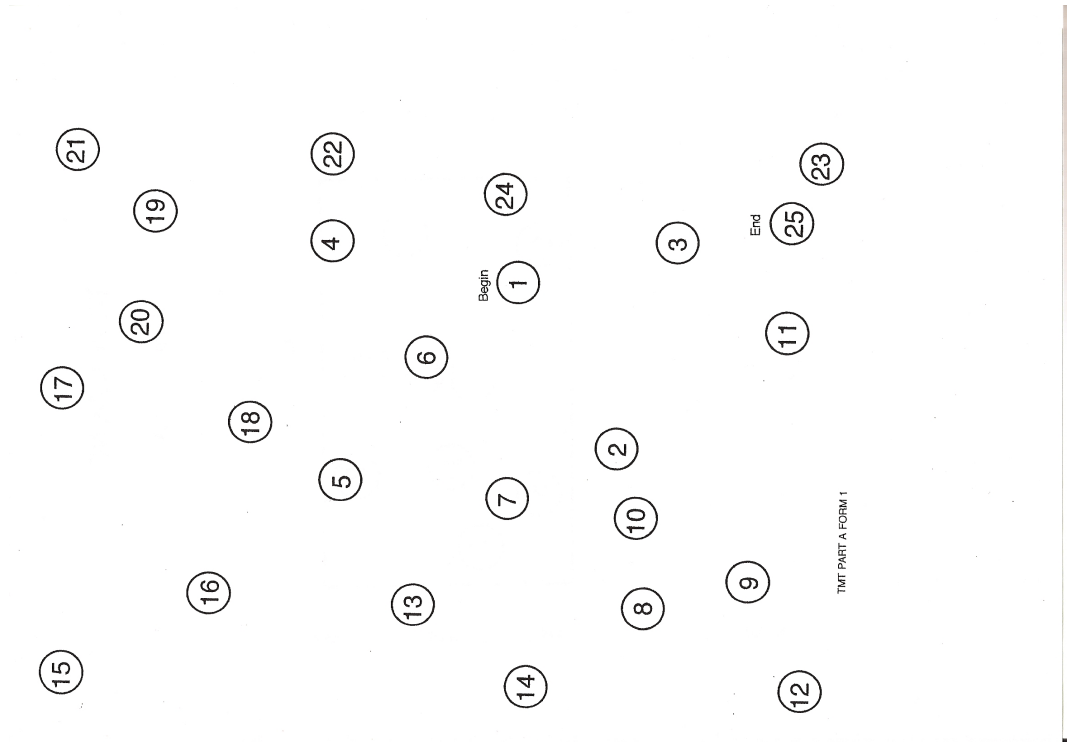
NOTE: Only one re-assessment allowed.

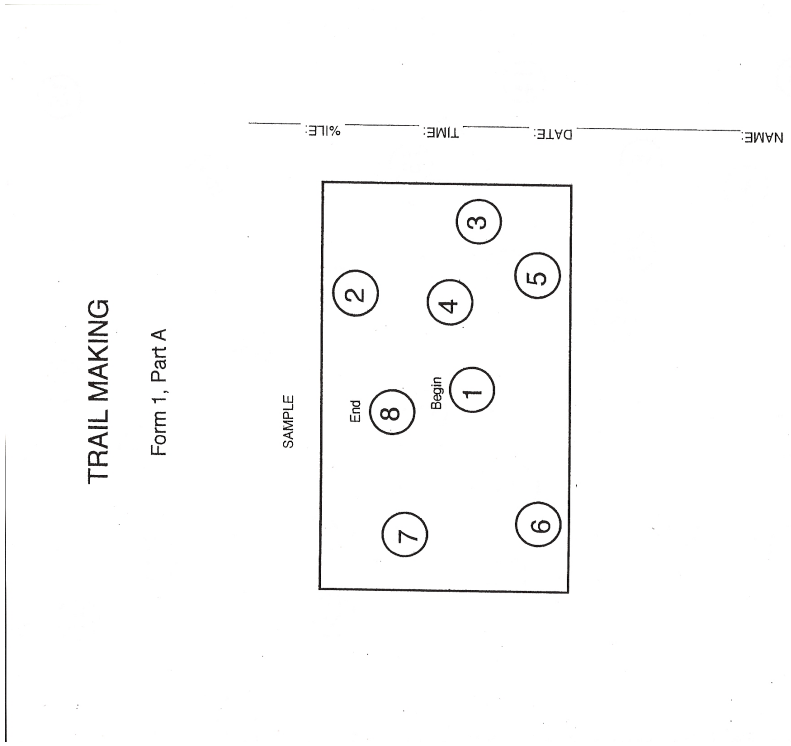
ACCREDITED INSTRUCTOR'S SIGNATURE: _____ **MDI NO:** _____

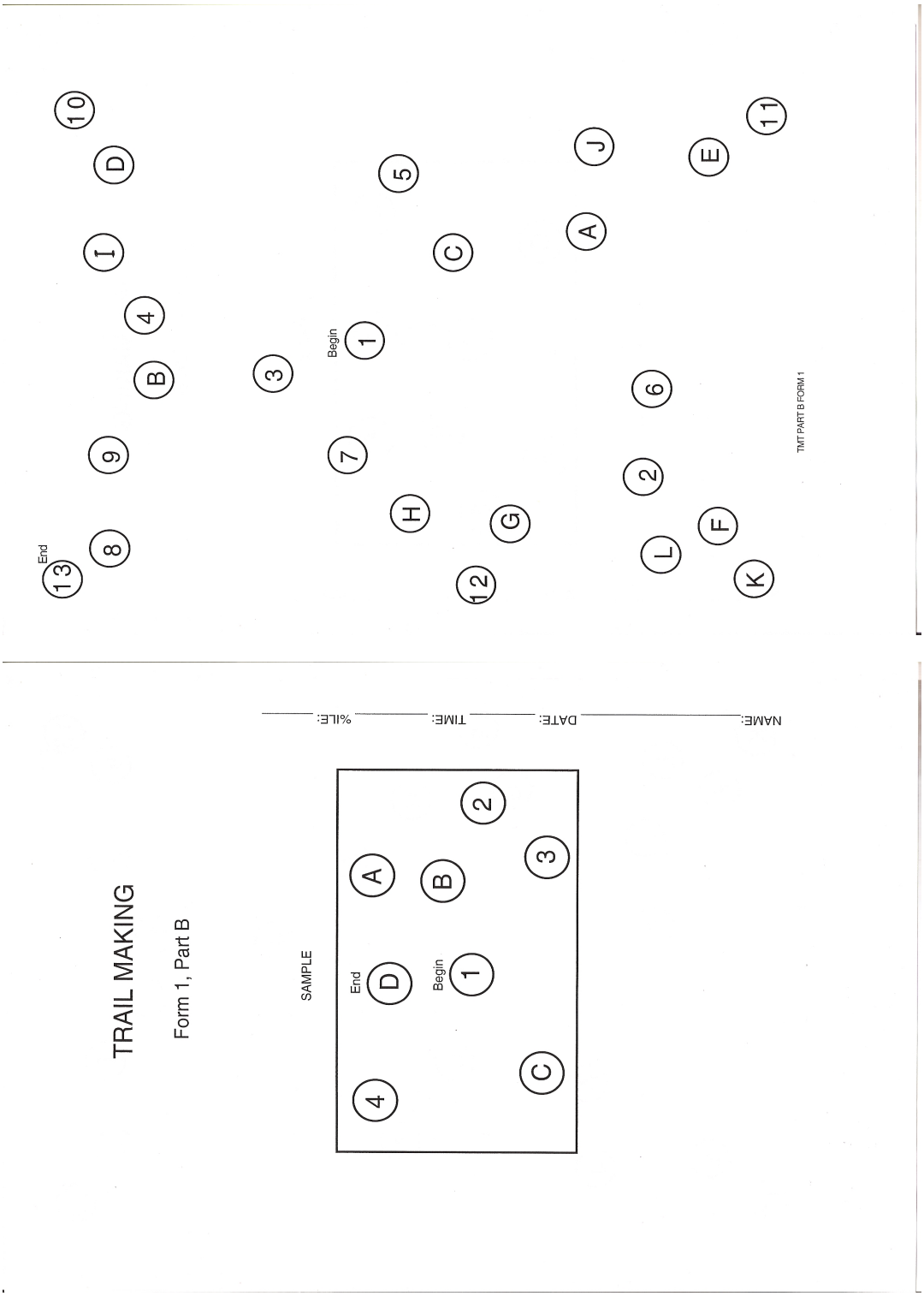
APPLICANT'S SIGNATURE: _____ **DATE:** ____/____/____

Appendix 4:

Trail Making Test Parts A & B (reduced size)


Begin
End
TMT PART A FORM 1


TRAIL MAKING
Form 1, Part A
SAMPLE
End
Begin
NAME
DATE
TIME
%ILE


TRAIL MAKING
Form 1, Part B
SAMPLE
Begin
End
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DATE:
TIME:
%ILE:
TMT PART B FORM 1
Begin
End

Appendix 5:

Dementia Driver Questionnaire
(Byszewski, 2001)

Name: _____

Date: _____

Driving Clinic
Patient questionnaire

1. Have you noticed any change in your driving skills? 1 yes[ ] 2 no [ ]

2. Do others toot at you or show signs of irritation? 1 yes[ ] 2 no [ ]

3. Have you lost any confidence in your overall driving ability, leading you to drive less often or only in good weather? 1 yes[ ] 2 no [ ]

4. Have you ever become lost while driving? 1 yes [ ] 2 no [ ]

5. Have you ever forgotten where you were going? 1 yes[ ] 2 no [ ]

6. Do you think that at present you are an unsafe driver? 1 yes[ ] 2 no [ ]

7. Have you had any car accidents in the last year? 1 yes[ ] 2 no [ ]

8. Have you had any bumps or dents with other cars in car parks? 1 yes[ ] 2 no [ ]'

9. Have you received any tickets for speeding, going too slow, improper turns, failure to stop etc? 1 yes[ ] 2 no [ ]

10. Have others criticised your driving or refused to drive with you? 1 yes[ ] 2 no [ ]

Appendix 6:

Caregiver Questionnaire; after Snellgrove (2006), based on:
Caregiver confidence (Marottoli et al 1998)
Driving Style (French et al 1993)
Driver Behaviour (Norris et al 2000; Dobson et al 1999)
Accident History (Parker et al 2000)
Patient Driver Modifications (Marottoli et al 1998; Ball, et al 1998)
Families Questionnaire (Dementia Network of Ottawa-Carleton, 2001)

CAREGIVER QUESTIONNAIRE

Patient Name:	
Caregiver Name:	
Date:	

CAREGIVER DEMOGRAPHICS

First some questions about your background. Please remember that all information you provide will be treated in the strictest confidence.

1.	**Are you a licensed driver?**	YES	NO
2.	**Are you male or female**	YES	NO
3.	**What is your age?**		years

4.	**What is your relationship to the patient?**			
Spouse ❒	Child ❒	Other family ❒	Friend ❒	Paid Carer ❒
Other ❒ Please specify:				

5.	**What country were you born in?**	Australia ❒	Outside Australia - please specify: ❒

6.	**What is the highest level of education you have completed?**		
Primary School ❒	Secondary School ❒	Trade/Certificate/Diploma ❒	University Degree ❒

7.	**What is your employment status?**	
Full or part-time paid work ❒	Full or part-time voluntary work ❒	Not working ❒

8.	**What was/is your occupation?**	
Unskilled ❒	Trade/Service/Clerk ❒	Manager/professional/para-professional ❒

9.	**What is your marital status**	
Married/defacto ❒	Separated/widowed/divorced ❒	Single/never married ❒

DRIVING CLINIC **Families questionnaire**			
1.	Do you feel uncomfortable in any way driving with the patient?	YES	NO
2.	Have you noted any abnormal or unsafe driving behaviour?	YES	NO
3.	Has the patient had any recent crashes?	YES	NO
4.	Has the patient had any near misses that could be attributed to mental or physical decline?	YES	NO
5.	Has the patient received any tickets or traffic violations?	YES	NO
6.	Are other drivers forced to drive defensively to accommodate the patient's errors in judgement?	YES	NO
7.	Have there been any occasions when the patient has got lost or experienced navigational confusion?	YES	NO
8.	Does the person need many cues or direction from passengers?	YES	NO
9.	Does the patient need a co-pilot to alert him/her to potentially hazardous events or conditions?	YES	NO
10.	Have others commented on the patient's unsafe driving?	YES	NO

CAREGIVER KNOWLEDGE OF DRIVING LEGISLATION

Now, answer some questions regarding your knowledge of the laws relating to older people who drive. Please don't think of this as a test. It doesn't matter if you are unsure of the correct answer.

1.	**At what age is there a legal responsibility to reapply for a driver's licence in South Australia?**	Years		
2.	**Is it the legal responsibility of your general practitioner to notify the Licensing Authorities, if he/she considers a person unfit to drive?**		YES	NO
	If not, is notification to the licensing Authorities the responsibility of:	The caregiver ❒	A medical specialist ❒	
3.	**Can a general practitioner break patient confidentiality and inform the Licensing Authorities if their patient ignores his/her advice to stop driving, or refuses to take a driving test?**		YES	NO

CAREGIVER RATING OF PATIENT'S MEMORY

1.	**How many years ago did you first notice problems with the memory of the patient?**		
Less than 12 months ❒	1-2 years ❒	2-5 years ❒	No memory problem ❒
2.	**How many years ago did you first notice that the patient was becoming confused more easily?**		
Less than 12 months ❒	1-2 years ❒	2-5 years ❒	No memory problem ❒

1. CAREGIVER OBSERVATIONS OF PATIENT DRIVING BEHAVIOUR

I'd like you to tell me about the patient's recent driving habits. When answering these questions, think about the last three months.

1.	**For how many years has the patient been a licensed driver?**	Years
2.	**During an average week, on how many days does the patient drive?**	Days per week
3.	**During an average week, how many kms does the patient drive?**	km

4. a. How does the patient usually travel to the Shops?

Doesn't go shopping	Public transport	Taxi	Passenger in car	Drives car
❒	❒	❒	❒	❒

b. How does the patient usually travel to medical appointments?

Doesn't go to medical appointments	Public transport	Taxi	Passenger in car	Drives car
❒	❒	❒	❒	❒

c. How does the patient usually travel to social/recreational events?

Doesn't go to these events	Public transport	Taxi	Passenger in car	Drives car
❒	❒	❒	❒	❒

5. How do you rate the patient's driving ability compared to other drivers of his/her age and gender?

Much worse	A little bit worse	About the same	A little bit better	Much better
❒	❒	❒	❒	❒

2. CAREGIVER CONFIDENCE IN PATIENT DRIVING

The next series of questions about how confident you feel as a passenger in certain driving situations with the patient as the driver. You will probably feel more confident in some situations than others. Remember to consider the patient's driving over the last three months.

1. How confident do you feel as a passenger with the patient driving at night

1	5	10
Not at all confident	Somewhat confident	Completely confident

2. In bad weather

1	5	10
Not at all confident	Somewhat confident	Completely confident

3. In rush hour or heaving traffic?

1	5	10
Not at all confident	Somewhat confident	Completely confident

4. On the freeway or expressway

1	5	10
Not at all confident	Somewhat confident	Completely confident

5. On long trips?

1	5	10
Not at all confident	Somewhat confident	Completely confident

6. Changing lanes on a busy street?

1	5	10
Not at all confident	Somewhat confident	Completely confident

7. Reacting quickly while driving?

1	5	10
Not at all confident	Somewhat confident	Completely confident

8. Pulling into traffic from a stop?

1	5	10
Not at all confident	Somewhat confident	Completely confident

9. Making a right turn across traffic?

1	5	10
Not at all confident	Somewhat confident	Completely confident

10. Parking the car?

1	5	10
Not at all confident	Somewhat confident	Completely confident

Scoring Average response (1-10)

3. DRIVING STYLE

Everybody has their own driving style in terms of speed, calmness, focus and planning. I'd like to know about the driving style of the patient that you have observed over the last three months. Let's start with speed ...

SPEED

a. Does the patient break the speed limit in rural areas?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

b. Does the patient drive fast?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

c. Does the patient exceed the speed in urban areas?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

CALMNESS

a. Does the patient become flustered?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

b. Does the patient remain calm?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

c. Does the patient respond to pressure from other drivers?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

SOCIAL RESISTANCE

a. Is the patient happy to receive advice from people?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

b. Does the patient dislike people giving advice?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

FOCUS

a. Does the patient drive cautiously?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

b. Does the patient find it easy to ignore distractions?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

c. Does the patient ignore passengers?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

PLANNING

a. How often does the patient set out without looking at a map?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

b. Does the patient plan long journeys in advance?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

ERRORS

a. Does the patient overtake on the inside lane?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

b. Does the patient ever drive though a red traffic light?

Never or very infrequently 1	Infrequently 2	Quite infrequently 3	Quite Frequently 4	Frequently 5	Very frequently or always 6

SCORING FOR: SPEED, CALMNESS, SOCIAL RESISTANCE, FOCUS, PLANNING, & ERRORS - SUMMED TOTAL SCORE: _____

4. DRIVER BEHAVIOUR QUESTIONNAIRE

Now, I'd like you to think about some common mistakes that all drivers make on the road, and I'd like you to indicate how often, in the last three months, you have observed the patient make these mistakes:

ERRORS

a. How often, if at all, does the patient underestimate the speed of an oncoming vehicle when overtaking?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

b. How often, if at all, does the patient brake too quickly on a slippery road, or steel the wrong way into a skid?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

c. How often, if at all, does the patient when queuing to turn right onto a main road, pay such close attention to the main road that he/she nearly hits the car in front?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

d. How often, if at all, does the patient fail to check the rear vision mirror before pulling out, changing lanes, etc?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

e. How often, if at all, does the patient fail to notice pedestrians crossing on turning into a side road?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

f. How often, if at all, does the patient miss Give Way signs and narrowly avoid colliding with traffic having right of way?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

g. How often, if at all, does the patient on turning left, nearly hit a cyclist who has come up on the inside?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

h. How often, if at all, does the patient attempt to overtake someone he/she had not noticed to be signalling a right turn?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

LAPSES

a. How often, if at all, does the patient misread signs and take the wrong turn off a roundabout?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

b. How often, if at all, does the patient get into the wrong lane approaching a roundabout or junction?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

c. How often, if at all, does the patient forget where he/she left the car in a car park?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

d. How often, if at all, does the patient realise that he/she has no recollection of the road along which he/she has just been travelling?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

e. How often, if at all, does the patient intending to drive to destination A, suddenly notice that he/she is on the road to destination B, perhaps because B is the more usual destination?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

f. How often, if at all, does the patient switch on one thing, such as the headlights, when he/she is meant to switch on something else, such as the wipers?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

g. How often, if at all, does the patient hit someone when reversing, that he/she had not previously seen?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

h. How often, if at all, does the patient attempt to drive away from traffic lights in too high a gear?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

RULEBREAKING

a. How often, if at all, does the patient disregard the speed limits late at night, or early in the morning?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

b. How often, if at all, does the patient become impatient with a slow driver in the outer lane and overtake on the inside?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

c. How often, if at all, does the patient cross a junction knowing that the traffic lights have already turned red?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

d. How often, if at all, does the patient drive especially close to the car in front as a signal to its driver to go faster or get out of the way?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

e. How often, if at all, does the patient drive even though you realise that he/she may be over the legal blood-alcohol limit?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

f. How often, if at all, does the patient get involved in unofficial 'races' with other drivers?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

g. How often, if at all, does the patient angered by another driver's behaviour, give chase with the intention of giving a piece of his/her mind?

Never	Hardly ever	Occasionally	Quite often	Frequently	Nearly all the time
1	2	3	4	5	6

SCORING SUM TOTALLED FOR ERRORS, LAPSES AND RULEBREAKING

_____

5. PATIENT CAR ACCIDENTS We are always hearing of car accidents on the news. I'd like to know if you the patient has been involved in any car accidents in the last three years, and if so, how serious the accidents have been.		
a. In the last three years, was the patient the driver in an accident serious enough to cause injury to him/herself or others?	YES	NO
b. In the last three years, was the patient the driver in an accident serious enough to cause damage to the vehicle being driven, damage to another vehicle, or damage to property?	YES	NO
c. In the last three years, was the patient the driver in an accident that was not serious enough to cause injury to him/herself or others, or damage to property?	YES	NO
d. In the last three years, was the patient the driver in a really close call, where he/she almost had an accident, but managed to avoid it?	YES	NO

SCORING: 'Yes' response to Item a. and/or b. = serious MV category (3), 'Yes' response to Item c. and/or d. = minor MVA category (2) "No" to all items = nil MVA category.

6. PATIENT DRIVING MODIFICATION

As we get older, we change our behaviour in many ways. Our driving behaviour is no different. Please tell me how the patient has changed his/her driving?

a. On how many days during an average week does the patient avoid driving at night time?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

b. On how many days during an average week does the patient avoid driving on high-traffic roads?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

c. On how many days during an average week does the patient avoid driving during morning or afternoon rush hour?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

d. On how many days during an average week does the patient avoid driving on freeways or expressways?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

e. On how many days during an average week does the patient avoid driving alone?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

f. On how many days during an average week does the patient avoid driving in the rain?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

g. On how many days during an average week does the patient avoid driving in their own familiar neighbourhood?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

h. On how many days during an average week does the patient avoid driving outside their neighbourhood?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

i. On how many days during an average week does the patient avoid making right-turns across oncoming traffic?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

SCORING SUMMED TOTAL (9-45) _____

Thank you very much for your time.

Appendix 7:

CERAD Insight Scale (Mendez & Shapira, 2005)

Name:_____

CERAD ANOSOGNOSIA (INSIGHT) SCALE, after Mendez & Shapira 2005.

	Do not agree completely	Agree slightly	Agree a lot	Agree
	0	1	2	3
1. Tell me why you are here?				
2. Do you have an illness or a problem which requires medical attention?				
3. Is your behaviour significantly different now, compared to a few years ago?				
4. Do family and friends think that you have an illness or that something is wrong with you?				

4 point likert scale

Scoring:

Normal or awareness of an illness or a problem requiring medical attention (score 3)

Partial awareness or unawareness of illness or problem requiring medical attention but awareness of significant chnge in behavior (score 2)

Unawareness or denial of both an illness and a behavioural change but aware that the family or friends think something is wrong (score 1)

Total unawareness or concern about health or behaviour (score 0).

Appendix 8:

Anosognosia Questionnaire-Dementia (Starkstein et al., 1996), Driver Participant (D) and Carer (C) versions

DRIVER AND CARER SELF-EVALUATION

Name:_____ Date:_____

Driving Clinic
Anosognosia Questionnaire (patient version)

Please tick the relevant box with your answer

A. Intellectual Functions

	Never	Sometimes	Often	Always
1. Do you have problems remembering the date?	☐	☐	☐	☐
2. Do you have problems orienting yourself in new places?	☐	☐	☐	☐
3. Do you have problems remembering telephone calls?	☐	☐	☐	☐
4. Do you have problems understanding conversations?	☐	☐	☐	☐
5. Do you have problems signing your signature?	☐	☐	☐	☐
6. Do you have problems understanding what you read in the newspaper?	☐	☐	☐	☐
7. Do you have problems keeping personal belongings in order?	☐	☐	☐	☐
8. Do you have problems remembering where you leave things in the house?	☐	☐	☐	☐
9. Do you have problems writing notes or letters?	☐	☐	☐	☐
10. Do you have problems handling money?	☐	☐	☐	☐
11. Do you have problems orienting yourself in the neighbourhood?	☐	☐	☐	☐
12. Do you have problems remembering appointments?	☐	☐	☐	☐
13. Do you have problems practicing your favourite hobbies?	☐	☐	☐	☐
14. Do you have problems communicating with people?	☐	☐	☐	☐
15. Do you have problems doing mental calculations?	☐	☐	☐	☐
16. Do you have problems remembering things to buy when you go shopping?	☐	☐	☐	☐

	Never	Sometimes	Often	Always
17. Do you have any toilet accidents?	☐	☐	☐	☐
18. Do you have problems understanding the plot of a movie?	☐	☐	☐	☐
19. Do you have problems orienting in your house?	☐	☐	☐	☐
20. Do you have problems in doing home activities (cooking, cleaning, fixing things)?	☐	☐	☐	☐
21. Do you have problems feeding yourself?	☐	☐	☐	☐
22. Do you have problems keeping your cheque book, accounts, payments?	☐	☐	☐	☐

B. Behaviour

1. Are you more rigid in decisions, with less capacity to adapt to new situations?	☐	☐	☐	☐
2. Are you more egotistic, paying less attention to other people's needs.	☐	☐	☐	☐
3. Are you more irritated? Do you easily lose your temper?	☐	☐	☐	☐
4. Do you have crying episodes?	☐	☐	☐	☐
5. Do you laugh in inappropriate situations?	☐	☐	☐	☐
6. Are you more interested in sexual themes, talking or reading about sex?	☐	☐	☐	☐
7.Have you lost interest in hobbies or activities you used to like?	☐	☐	☐	☐
8. Do you feel more depressed?	☐	☐	☐	☐

DRIVER AND CARER SELF-EVALUATION

Name:_____ Date:_____

Driving Clinic
Anosognosia Questionnaire (partner-carer version)

Please tick the relevant box with your answer

A. Intellectual Functions

	Never	Sometimes	Often	Always
1. Does <x> have problems remembering the date?	☐	☐	☐	☐
2. Does <x> have problems orienting <him/her> self in new places?	☐	☐	☐	☐
3. Does <x> have problems remembering telephone calls?	☐	☐	☐	☐
4. Does <x> have problems understanding conversations?	☐	☐	☐	☐
5. Does <x> have problems signing <his/her> signature?	☐	☐	☐	☐
6. Does <x> have problems understanding what is read in the newspaper?	☐	☐	☐	☐
7. Does <x> have problems keeping personal belongings in order?	☐	☐	☐	☐
8. Does <x> have problems remembering where <he/she>leave things in the house?	☐	☐	☐	☐
9. Does <x> have problems writing notes or letters?	☐	☐	☐	☐
10. Does <x> have problems handling money?	☐	☐	☐	☐
11. Does <x> have problems orienting <him/her> self in the neighbourhood?	☐	☐	☐	☐
12. Does <x> have problems remembering appointments?	☐	☐	☐	☐
13. Does <x> have problems practicing <his/her> favourite hobbies?	☐	☐	☐	☐
14. Does <x> have problems communicating with people	☐	☐	☐	☐
15. Does <x> have problems doing mental calculations?	☐	☐	☐	☐
16. Does <x> have problems remembering things to buy when shopping?	☐	☐	☐	☐

	Never	Sometimes	Often	Always
17. Does <x> have any toilet accidents?	☐	☐	☐	☐
18. Does <x> have problems understanding the plot of a movie?	☐	☐	☐	☐
19. Does <x> have problems orienting in the house?	☐	☐	☐	☐
20. Does <x> have problems in doing home activities (cooking, cleaning, fixing things)?	☐	☐	☐	☐
21. Does <x> have problems feeding <him/her>self?	☐	☐	☐	☐
22. Does <x> have problems keeping the cheque book, accounts, payments?	☐	☐	☐	☐

B. Behaviour

1. Is <x> more rigid in decisions, with less capacity to adapt to new situations?	☐	☐	☐	☐
2. Is <x> more egotistic, paying less attention to other people's needs.	☐	☐	☐	☐
3. Is <x> more irritated? Does <he/she> easily lose <his/her> temper?	☐	☐	☐	☐
4. Does <x> have crying episodes?	☐	☐	☐	☐
5. Does <x> laugh in inappropriate situations?	☐	☐	☐	☐
6. Is <x> more interested in sexual themes, talking or reading about sex?	☐	☐	☐	☐
7. Has <x> lost interest in hobbies or activities <he/she> used to like?	☐	☐	☐	☐
8. Does <x> feel more depressed?	☐	☐	☐	☐

Appendix 9:

Ethics approval

Southern Adelaide Clinical Human Research Ethics Committee

Government of South Australia
Southern Adelaide Health Service

12 June 2012

Dear Dr. Field

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC). Whilst this official title of the committee has changed the committee is still properly constituted under AHEC requirements with the registration number EC00188. This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." This department only uses email correspondence for all documents unless prior arrangements have been made with the manager.

Application Number: 199.12

Title: Dysexecutive syndrome, anosognosia, driver and carer self evaluation of on road driving performance: Results from a dementia driving clinic.

Chief investigator: Dr Colin Field

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and approved the above application. Your project may now commence. The approval extends to the following documents/changes:

- Modified - General research application
- Trail making Form 1 part A
- Trail making Form 1 part B
- RGH - Participant information sheet and consent form
- DDC – Participant information sheet and consent form
- Questionnaire –
    - Anosognosia
    - Caregiver
    - Patient – Driving toolkit
- Evidence of indemnity from SA Health and FU
- Insurance policy and Policy invoice

Approval Period: 12 June 2012 to 12 June 2015

Please retain a copy of this approval for your records.

Flinders Medical Centre

Bedford Park SA 5042

Level 2

Room 2A221

Telephone

08 8204 4507

Facsimile

08 8204 4586

TERMS AND CONDITIONS OF ETHICAL APPROVAL

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions.

As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below.

Researchers have a significant responsibility to comply with the *National Statement 5.5.* in providing the SAC HREC with the required information and reporting as detailed below:

1. **Compliance** with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
2. To **immediately report to SAC HREC** anything that may change the ethical or scientific integrity of the project.
3. **Report Significant Adverse events (SAE's)** as per SAE requirements available at our website.
4. **Submit an annual report on each anniversary of the date of final approval** and in the correct template from the SAC HREC website.
5. **Confidentiality** of research participants MUST be maintained at all times.
6. A copy of the **signed consent form** must be given to the participant unless the project is an audit.
7. Any **reports or publications derived from the research** should be submitted to the Committee at the completion of the project.
8. All requests for **access to medical records** at any SAHS site must be accompanied by this approval email.
9. To **regularly review the SAC HREC website** and comply with all submission requirements, as they change from time to time.
10. The researchers agree to use **electronic format** for all correspondence with this department.

Yours sincerely

Monika Malik
Administration Officer
SAC HREC

Appendix 10:

South Australian GP Divisions

GP Divisions and Networks identified in South Australia, April 2016.

Metropolitan

GP Partners Adelaide,
(Formerly Adelaide Central & Eastern Division of General Practice),
1st Floor,
120 Hutt Street,
ADELAIDE SA 5000.

General Practice Network South,
(formerly Southern Division of General Practice),
Box 1, Level 3A,
Mark Oliphant Building,
5 Laffer Drive,
BEDFORD PARK SA 5042.

Adelaide Hills Division of General Practice,
PO Box 208,
Nairne SA 5252.

Adelaide North East Division of General Practice,
Level 1, Education Centre,
Modbury Hospital,
Smart Road,
MODBURY SA 5092.

Adelaide Northern Division of General Practice,
2 Peachey Road,
ELIZABETH WEST SA 5113.

Adelaide Western Division of General Practice,
98A Woodville Road,
WOODVILLE SA 5011.

Regional

Riverland Division of General Practice,
3 Vaughan Court,
BERRI SA 5343.

Eyre Peninsula Division of General Practice,
PO Box 804,
Port Lincoln SA 5606.

Yorke Peninsula Division of General Practice,
73 Taylor Street,
KADINA SA 5554.

Limestone Coast Division of General Practice,
121 Commercial Street,
Mt GAMBIER SA 5290.

Mid North Division of Rural Medicine,
(formerly Mid North Rural Division of General Practice),
PO Box 842,
CLARE SA 5453.

Flinders & Far North Division of General Practice,
Hospital Road,
PORT AUGUSTA SA 5700.

Barossa GP Network,
(formerly Barossa Division of General Practice),
PO Box 868,
NURIOOTPA SA 5355.

Murray Mallee GP Network,
(formerly Murray Mallee Division of General Practice),
PO Box 292,
MURRAY BRIDGE SA 5253.

Appendix 11:

Anosognosia Handout
(Doty, 2007)

Doty, L. (2007). Caregiving Topics: Anosognosia (Unawareness of Decline of Difficulties). Available online: : http://alzonline.phhp.ufl.edu/en/reading/Anosognosia.pdf

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AlzOnline.net
Caregiver Support Online
CAREGIVING TOPICS

Anosognosia (Unawareness of Decline or Difficulties)

Prepared by: Leilani Doty, PhD, Director, University of Florida Cognitive & Memory Disorder Clinics (MDC), Box 100236, McKnight Brain Institute, Gainesville, FL 32610-0236, Office (352)273-5555; Memory Disorder Clinic Appointments: (352)265-8408. Partially supported by the Florida Department of Elder Affairs Alzheimer's Disease Initiative. (2007)

Purpose of Session on Anosognosia (Unawareness of Decline or Difficulties):

The purpose of this educational session on ***Anosognosia (Unawareness of Decline or Difficulties)*** *is to provide some information on a condition in which changes in brain cells lead to some or complete unawareness of decline in ability, such as decline in short-term memory or judgment.*

Anosognosia (Unawareness of Decline or Difficulties)

Being aware of how we are feeling and how we are functioning helps us take care of our daily personal needs, work or home tasks, and relationships. When we are aware that we have a tendency to forget an appointment, we write it down on a calendar. After doing yard work when we feel sweaty and dirty, we bathe and put on clean clothes. If we break a leg or arm, we know that we have to take special care of the limb until it is fully healed.

If we are unaware of a problem, there is no expectation that we need to act, take care of matters, or change anything. If there is no mismatch between how we expect to function and how we actually function, then there is no attempt to change, adjust, or fix anything.[1] We assume that everything is fine. We do not try to compensate, such as writing a list of errands for the day, because we are unaware of any memory difficulties and we never used such a list anyways.

Anosognosia
A lack of awareness of impairment, not knowing that a deficit or illness exists, in memory or other function is called *anosognosia*. The term *anosognosia* refers to brain cell changes that lead to a lack of self-awareness. Credit for the term to describe being unaware of illness or deficit goes to Joseph Francois Babinski, a French neurologist, who coined the term in 1914.[2] The impairment may be in memory, other thinking skills, emotion, or movement.

Anosognosia – not being aware of impaired function in:

1. the memory
2. general thinking skills such as language or math skills
3. the emotions
4. body movement

Anosognosia comes from three Greek word stems, 1) "a" meaning without, 2) "nosos" meaning disease, and 3) "gnosis" meaning knowledge. Put together the word stems form "a" + "nosos" + "gnosos" (or gnosia) which forms anosognosia. Loosely translated, anosognosia means "without knowledge of disease".[3,4]

Anosognosia versus Denial

Anosognosia differs from *denial*. *Denial* is a strategy used to reject something that a person wants to ignore, partially avoid, or reject outright because it is too difficult or causes too much stress. The person may minimize a problem or accept part of the truth, for example, the person may accept the fact of being chronically ill but want to avoid dealing with it by not taking medicine. Sometimes a person is in denial in order to avoid taking any responsibility for an issue or situation. *Anosognosia is not denial*.

Anosognosia is not denial.

Brain Cell Changes

Anosognosia is a condition that results from physical changes in brain cells most typically in the right front side of the brain (right pre-frontal lobes, located in the front and top part of the brain) as well as in part of the parietal lobes (just behind the frontal lobes).[5]

The condition does not seem to result from faults in hearing, seeing, touching, smelling or tasting; these sensory systems usually work well. This condition is different from a stroke that often quickly leads to impaired sensory or motor systems. The mixing of the sensory information coming into the body seems to disconnect in some way with an understanding and ability to use the information, almost as if information is not coming in or does not exist.

For example, the person may be looking at a book on the table, but not able to "see" it. The visual information has entered the eye and optic nerve (the main front nerve that carries information to the back of the brain) but the information is not being translated so that the person can understand and use the information.

The body seems unable to pay attention to or apply the information that it receives. Often the unawareness concerns the left side of the body. The person may be unaware of disabilities in motor movement, such as being unaware that the left arm is paralyzed and not showing concern about the disability. [5,6]

Decreasing self-awareness results from brain cell changes. The changes may result from brain trauma such as a head injury from a car accident, vascular changes such as from a stroke or an ongoing brain cell decline such as seen in Alzheimer's disease or a related dementia (dementia refers to a progressive decline in memory or thinking skills and is sometimes referred to as a memory disorder). Some people in psychotic crisis experience anosognosia and are helped by psychiatric therapy including medicines.

Brain cell connections that provide us with information about a situation, the people around us, and emotions in ourselves as well as others may not work well. If we do not get complete feedback, our response to our emotions or the emotions of others may be disturbed or not appropriate. Having an emotion and then paying attention to it raises an expectation of responding or acting in some way upon the emotion.

A disconnection may result in not paying attention to the emotion, not understanding the meaning and application of the emotion, and not reacting in any way, either physical or emotional, to the emotion. It may seem as if the unaware person is without feeling when, in truth, they are not receiving any translation of what the emotion means or how they should respond with appropriate emotion.

A Rating Scale
Some researchers have developed an *Anosognosia Rating Scale* used by for health practitioners to use in order to rate the level of awareness in people.[7] The scale considers four levels of self-awareness and is summarized below with the example of rating self-awareness of memory loss:[7]

1. easily admits memory loss
2. admits (sometimes inconsistently) to small amount of memory loss
3. not aware of any impairment in memory
4. angrily insists that no memory problem exists

Anosognosia in Alzheimer Disease
Anosognosia may occur in different progressive memory disorders. Often the progressive dementia (sometimes referred to as a progressive memory disorder) is of the Alzheimer's disease type, sometimes it fits into the category of Lewy body disease or a frontal-temporal lobar degeneration (see the web site www.AlzOnline.net for more information about Lewy body disease or frontal-temporal lobar degeneration).

When the person who has anosognosia has a health history which includes many years of heavy daily alcohol intake and no other physical findings to explain the decline, the anosognosia may be an early sign of alcoholic dementia. Sometimes in progressive dementia when anosognosia occurs early on, there also occur problems in short-term memory, decision-making and judgment. At

the same time, however, good functioning may remain in language skills, visual-spatial skills (finding ones way around and not getting lost), and math skills until much later in the course of the disease.

The population that is the focus of this session are people who suffer from anosognosia that results from physical changes in brain cells during the decline that is part of a progressive dementia such as Alzheimer's disease or a related dementia.

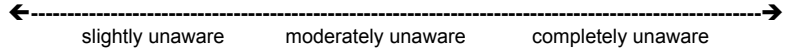
In progressive decline such as Alzheimer's disease, memory and thinking functions, such as short-term memory, difficulty recalling specific words when talking, planning an event, and making appropriate decisions, may suffer. Early on in the course of the disease the person may be aware of subtle deficits before other people become aware of them. As the disease continues, it is common among those who have a diagnosis of Alzheimer's disease to have anosognosia.[8] Some researchers have estimated that as many as 60 % of people with Mild Cognitive Impairment[9] and 81% of people with Alzheimer's disease have some form of anosognosia.[7]

As the dementia progresses, the anosognosia may progress. The person may be unaware that their memory is declining or that they have difficulty with routine tasks such as keeping fuel in the car and preparing fresh food and water for a pet.

Range of Self-Awareness
In anosognosia the self-awareness may range from being completely unaware to being somewhat aware of the deficits. For example, the person may not realize that there is a short-term memory problem. The person may insist that memory ability is fine. Or, the person may be somewhat aware of occasional episodes of forgetting and create an excuse such as saying, "We all forget things once in a while". The person may respond to family members who bring up the forgetfulness with the response, "Don't you forget once in a while!" The person may make the excuse that "all people over the age of 60 have problems with their memory".

Anosognosia may range from:

being *slightly unaware* to being *completely unaware* !



Confabulation
People with anosognosia will often confabulate. Confabulation is making up an answer or responding with remarks that link pieces of information, time, places, and people that do not belong together. Sometimes people will combine memories from different events and insist that the event unfolded that way. They may describe an event as recent but it actually happened decades ago with different people. Sometimes they mix information from the newspaper or television with a personal event.[10]

A confabulation is not a lie. People who confabulate believe that their words are true. The response is essentially false, sometimes a mixing of past events, sometimes a mixture of past real events with imaginary details. The confabulation may be simple or hold great detail and elaboration. Sometimes the confabulation has such rich details such as describing a festive family gathering. Sometimes it is a simple, unimportant remark such as what was eaten at lunch a couple of hours before. To a stranger the remarks make sense; to the family member, who knows the person well, however, the remarks are distorted or untrue.

A confabulation is not a lie.

The purpose of the confabulation is not to mislead or lie. Typically, the person is trying to answer a question or contribute to a conversation. To those who do not know the person, the responses are reasonable, believable, socially acceptable (usually they are not outrageous or extremely bizarre), and appropriate. However, the significant other will testify that the statements are inaccurate or never occurred. People who know the individual will wonder about the confabulation because they know that the response is not accurate nor accurately reflects the normal behavior or functioning of that person. They know that the person's value system honors truth, not "tall tales", and that normally the memory is much better than the current responses indicate. Family members realize there is a problem.

The person may be self-aware of some memory problems but not completely aware of the extent of the problem…in other words they may realize that some unpaid bills have piled up, but not realize that the are notices are serious about the cut-off of utility services. They may not realize that they have stopping bathing and doing laundry on a regular basis though their body odor and stained clothing reflect such neglect.

Caregiver Challenges

Anosognosia may be difficult for family caregivers because they are trying to help a person who insists there is no need for help. Not only may self-estimates of functioning be inaccurate, but people with anosognosia may overestimate their abilities to perform tasks especially when their estimates are compared with what their primary caregivers know.[11-13] The person with anosognosia may refuse to go for a medical evaluation. They may refuse any medical treatment.

They may become angry when others accuse them of forgetfulness, making poor decisions, making up stories, mishandling money, or not taking care of themselves. They are at risk because they may insist on driving[14] and operating hazardous machines such as power tools or kitchen appliances such as a food chopper. They may not keep up with personal hygiene.

The refusals are based upon being anosognosic, unaware and convinced that there is no problem in daily functioning. They may become more spontaneous and make embarrassing or intimate comments; they may be less inhibited and start conversations with strangers without acting uncomfortable or concerned about their own behavior[15].

It may be quite a challenge to provide help to a person who is unaware that abilities are changing and that help is needed. The caregivers may be expressing more concern about the deficits and about future implications than the person with anosognosia[16]. The person with anosognosia may not react appropriately or quickly enough to an unsafe situation; they may minimize the sense of threat to their safety[16].

Interaction Tips

Providing regular assistance with daily chores, transportation, and personal care and restricting unsafe activities are important. For example, someone may need to make sure that meals are readily available, that spoiled food is discarded, and that alcoholic beverages are not accessible. The controls for operating the stove and water heater should be inaccessible. Someone should be responsible for setting the home thermostat at an appropriate temperature and then locking the thermostat so that the person who is not accurately interpreting body temperature cannot reset the room temperature at too high or too low. Soiled clothing should be laundered immediately or kept unavailable (out of sight – out of mind) until the clothing is clean.

The Checklist for Family Matters, located at www.AlzOnline.net is a useful tool to help families with planning for long-term care management. Regular respite for the family caregiver(s) is essential!

Examples of how to approach, interact and speak to someone who has anosognosia:

1. **Down-size and decrease unnecessary chores and responsibilities.**

   Use a positive approach, such as, "It is time to plan ahead about moving to a retirement community where there are kind people and some of your friends so you have more time to do what you like, such as read and go for a walk every morning."

   Don't use a negative approach, such as, "This house and yard are too much work for all of us. It is hard for you to take care of the house, the yard, and yourself. You need to move to a place where people are always around to help you."

2. **Partner with the person**.

   Use a positive approach, such as, "Let's work together on the front porch, then go out for a nice dinner."

   Don't use a negative approach, such as, "You really need to clean up that mess of old magazines, newspapers and piles of trash on the front porch."

3. **Focus on the person's concern and subtly include your concern**.

   Use a positive approach, such as, "When you take this multi-vitamin, how about taking these "brain-vitamins" that the doctor prescribed to keep your memory strong?"

   Don't use a negative approach, such as, "The doctor prescribed these pills and you have to take them every morning."

4. **A gentle, positive voice should be part of a positive empathic approach**.

   Use a positive approach, such as, "To keep up with these bills, we should work as a team. I will come over on Saturday mornings with your favorite breakfast and we will write out the checks together. After you sign the checks, we will put them in their envelopes and take them to the mailbox."

   Don't use a negative approach, such as, "You have to pay these bills on time. The utility companies have sent notices threatening to shut off the gas and electricity. I'll handle the bills from now on."

5. **Provide available assistance and a structured schedule of tasks including personal care, activities including chores and leisure activities, and "down-time" including a favorite activity or no activity.**

   Use a positive approach, such as, "After we walk the dog, we will finish the laundry and then sit down for some of that applesauce I cooked this morning."

   Don't use a negative approach, such as, "There is so much to do? What do you want to do this morning? We have to walk the dog, finish the laundry, and clean the kitchen. The work really piles up fast around here."

Summary

The person who has anosognosia is unaware of deficits or the progressive decline in abilities to manage tasks and self-care. The person with anosognosia is not in denial; they have limited awareness or are unaware of the decline. When people with anosognosia confabulate, they believe what they are saying; they are not lying. Their remarks should be treated with respect, followed by a smooth transition to whatever tasks or activities need to occur next. Regular help for the home and family, planning ahead and working with a positive, partnership approach will help with the long-term, daily care management.

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Appendix 12:

Hartford driver checklist (Hartford/ MIT AgeLab, 2013)

Reproduced with kind permission of The Hartford Corp.

FOR THE FAMI

Warning Signs for Drivers with Dementia

A diagnosis of mild dementia alone is not an automatic reason to stop driving. Families can use this list as an objective way to monitor any changes in driving skills over time. Written notes of observations can help you make informed decisions and may be useful in conversations with healthcare providers.

Consider the frequency and severity of incidents. Several minor incidents or an unusual, major inciden may warrant action. Look for patterns of change over time. Isolated or minor incidents may not warran drastic action. Avoid an alarming reaction. Take notes and have conversations at a later time, instead of during or right after an incident.

Driving Behavior Warning Signs – When Noticed, How Often	
1. Decrease in confidence while driving	16. Uses a "copilot"
2. Difficulty turning to see when backing up	17. Bad judgment on making left hand turns
3. Riding the brake	18. Near misses
4. Easily distracted while driving	19. Delayed response to unexpected situations
5. Other drivers often honk horns	20. Moving into wrong lane
6. Incorrect signaling	21. Difficulty maintaining lane position
7. Difficulty parking within a defined space	22. Confusion at exits
8. Hitting curbs	23. Ticketed moving violations or warnings
9. Scrapes or dents on the car, mailbox or garage	24. Getting lost in familiar places
10. Increased agitation or irritation when driving	25. Car accident
11. Failure to notice important activity on the side of the road	26. Failure to stop at stop sign or red light
12. Failure to notice traffic signs	27. Confusing the gas and brake pedals*
13. Trouble navigating turns	28. Stopping in traffic for no apparent reason*
14. Driving at inappropriate speeds	29. Other signs:
15. Not anticipating potential dangerous situations	

* Stop driving immediately

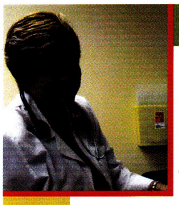
THE HARTFORD

Appendix 13:

The Ten Minute Office-Based Dementia and Driving Checklist

Reproduced with kind permission of Dr Bill Dalziel

DRIVER AND CARER SELF-EVALUATION



10 MINUTE OFFICE BASED DEMENTIA AND DRIVING CHECKLIST

(Based on Clinical Opinion and Experience not Evidence. Development lead by and copyright held by Dr. W. Dalziel).

The checklist can take 10 minutes or less to complete as it is not necessary to complete all 10 items if it is obvious the patient is unsafe to drive based on early items.

PROBLEM

1. ☐ **Dementia Type:**
Generally Lewy Body dementia (fluctuations, hallucinations, visuospatial problems) and Frontotemporal dementias (if associated behaviour or judgment issues) are unsafe.

2. ☐ **FUNCTIONAL IMPACT of the Dementia** - According to *CMA guidelines* **Unsafe** if:
- impairment of more than 1 Instrumental ADLs due to cognition
(IADLs = **SHAFT**: Shopping, Housework/Hobbies, Accounting, Food, Telephone / Tools)
- OR impairment of 1 or more Personal ADLs due to cognition (PADLS = **DEATH**: Dressing, Eating, Ambulation, Transfers, Hygiene)

3. ☐ **Family Concerns: (ask in a room separate from the person)**
Family feels safe/unsafe (make sure family has recently been in the car with the person driving)
* The grand daughter question - Would you feel it was safe if a 5 year old grand daughter was in the car alone with the person driving (often different response from family's answer to previous question)
Generally if the family feels the person is unsafe they are unsafe. If the family feels the person is safe, the person may still be unsafe as family may be unaware or may be protecting patient.

4. ☐ **Visuospatial: (intersecting pentagons/clock drawing numbers)**
If major abnormalities – likely unsafe

5. ☐ **Physical inability to operate a car (often a "physical" reason is better accepted):**
Medical/Physical concerns such as musculoskeletal problems, weakness/multiple medical conditions (neck turn, problems in the use of steering wheel/pedals), cardiac/neurologic (episodic "spells")

6. ☐ **Vision/Visual Fields:**
Significant problems including visual acuity, field of vision.

7. ☐ **Drugs: (if associated with side effects: drowsiness, slow reaction time, lack of focus)**
Alcohol/Benzodiazepines/Narcotics/Neuroleptics/Sedatives
Anticholinergic–antiparkinsonian/muscle/relaxants/tricyclics/antihistamine(OTC)/antiemetics/antipruritics/antispasmodic others

PROBLEM

8. ☐ **Trailmaking A&B: (available at www.rgpeo.com)**
Trailmaking A - Unsafe = > 2 minutes or 2 or more errors
Trailmaking B - Safe = < 2 minutes and < 2 errors (0 or 1 error)
Unsure = 2-3 minutes or 2 errors: (consider qualitative dynamic information regarding HOW the tes was performed: slowness/hesitation/anxiety or panic attacks/impulsive or perseverative behaviour /lac of focus/multiple corrections/forgetting instructions/inability to understand test etc.)
Unsafe = > 3 minutes or 3 or more errors

9. ☐ **Ruler Drop Reaction Time test** (Accident Analysis & Prevention 2007; 39(5): 1056 – 1063): The bottom end of a 12" ruler is placed between thumb and index finger (1/2" apart) let go and person tries to catch ruler (normal = 6-9"/abnormal = 2 failed trials)

10. ☐ **Judgment/Insight (Ask the person):**
What would you do if you were driving and saw a ball roll out on the street ahead of you?
With your diagnosis of Dementia, do you think at some time you will need to stop driving?

CONCLUSION:

Safe	Unsafe	Unsure
↓	↓	↗ If only driving an issue – refer to Specialized On Road Assessment
Reassess 6-12/12	Report to Provincial Registrar	↘ If driving and other dementia related issues refer to specialized dementia assessment services.

(reference Age and Aging 2009 and https://akeontario.editme.com/Driving)

Appendix 14:

Summary of Coroners' findings

Relating to two recent cases in South Australia and Queensland.

Summary of Coroners' findings.

Relating to two recent cases in South Australia and Queensland.

NB: These summaries preserve the form of words used by the Coroner on each occasion.

From: Coroners Court of South Australia (2016): The inquest of the death of Mr S a bicyclist occurring in 16 June 2012. This notes that Mr S was struck from the rear by a car driven by Mr R aged 83. It was considered by the Coroner that the circumstances that led to Mr S's death manifestly would have been avoided Mr R had been a driver of even basic competence. An eyewitness had noted that immediately prior to the accident Mr R's vehicle was travelling to close left-hand side of the road with both left side wheels encroaching on the fog line. It was seen occasionally to veer right across the centre of the carriageway, then back to the fog line on the left. The cyclist Mr S was observed by the witness to be consistently riding to the left of fog line. The witness stated she could see the vehicle being driven by Mr R still straddling the left-hand fog line. She observed the front left of Mr R's car hit the back of Mr S's bicycle. The witness pulled over and the other car continued to drive past the accident. Mr S received fatal injuries as a result of the collision. A mechanic subsequently examined the vehicle and formed the opinion that vehicle was in good condition prior the collision, and found nothing mechanically wrong. An interview with Mr R indicated that he saw nothing of the collision despite the fact that he was driving one of the involved vehicles. He told investigating police that he had not seen the cyclist even though he had been looking straight ahead. He had asserted however that the steering of his vehicle was not operating correctly.

At the inquest Mr R's son described his father's competency to drive in uncomplimentary terms, noting a series of previous near misses. He had previously encouraged his father to give up driving but his father stubbornly refused.

It was noted that Mr R had multiple medical issues including recent CVAs, limb weakness, and eyesight issues, and he was continuing to hold driver's licence in spite of the fact that he failed two practical driving assessments conducted by Department of Planning, Transport, and Infrastructure (DPTI). Notwithstanding these failures he was permitted to sit a third driving test and somehow passed. It was noted as a result of the GP's fitness certificate and the DPTI Registrar's directions, Mr R underwent practical driving assessments on 11 November 2011, 6 December 2011, and 4 January 2012. The recommendation of the accreditation audit officers involved in the first two tests was that Mr R's licence be suspended that he should be restricted to driving only in the presence of a driving instructor, and further tests could be conducted after completion of training or practice. It was noted that the three practical driving assessments were conducted by three different audit officers. The second auditor indicated to the Coroner that he knew nothing of the details of the previous test. The third assessment occurred on 4 January 2012. There is no evidence that Mr R received any training in the period between his tests in December and the date of his third test. The third audit officer indicated that he had no recollection of Mr R's test. He indicated that he must have had knowledge that Mr R had undergone two previous failed tests. The same route in the country town was used on each occasion. For the third test Mr R was described as involving only minor faults. The Coroner considered that the notwithstanding the fact that Mr R had passed this third test, there was little confidence in his ability to avoid accidents in future. The Coroner observed that Mr R had been accompanied to his third exam by his friend Mr L who had claimed that he had received comments from the auditor that Mr R had passed his drive but would not pass next year because his results were '50-50'. The Coroner saw an implication behind any such comment that Mr R had been passed despite his overt incompetence.

The Coroner considered that such an attitude would have been highly unprofessional. He indicated that he would require powerful evidence before making such a serious finding. The auditor however indicted that that it was not possible that he would have used those words.

From: Coroners Court of Queensland (2016): The inquest of the death of Mrs C delivered on 21 December 2016. Mrs C was 75 at the time of her death. She suffered from injuries suffered a motor vehicle accident occurring on 18 July 2013. The vehicle which Mrs C was driving was seen to cross the centre of the carriageway and collide head-on with another vehicle.

Crash analysis revealed that the roadway was sealed with bitumen in good condition, no obstructions or debris on the road, and the weather was considered good. Subsequent mechanical inspection of the victim's car indicated that the vehicle was considered to be in satisfactory mechanical condition prior to collision.

Mrs C was reported as having a significant medical history including history of TIA, type II diabetes, hypertension, chronic insomnia, chronic low back pain and recurrent falls, sleep apnoea and peptic ulcer disease. There was also a recent history of benzodiazepine use, reports of depressed mood, and recent opiate analgesic use. She was noted to have been have a tendency to fall asleep at any time including when drinking a cup of tea at a café. She was reportedly prone to falls and to have poor mobility. She had had a series of prolonged admissions to a local hospital during 2011 and 2012, and she was not considered by hospital staff to be fit to drive at that time due to limited mobility and slow reaction time.

Mrs C's friends Mrs K, Mr K, and Mr M, had written a letter to police stating

that she had been sick in hospital, could barely walk, requiring assistance of a walking stick or walker. She has been observed on numerous occasions to have slow reaction time, would fall asleep easily, and did not appear to be in control of the vehicle. As a result of the letter she was visited in hospital by a senior constable of police. The senior constable described her as very frail struggling to get to the door, and in his opinion she would struggle to get into a car let alone drive the car. He thought it was fairly obvious that she would not have the ability to drive the vehicle. The matter was referred to medical unit of Department of Transport and Main Roads (DTMR) and as a result on 30 March 2012 she underwent an OT driving assessment. The on-road assessment demonstrated that the medical conditions impact on her ability to drive safely, and the OT considered that she was unable to demonstrate overall safety and competence in driving areas observed due to multiple vehicle positioning, steering, and speed modulation difficulties, and errors noted. The recommendation was that the licence be surrendered.

Mrs C then attended medical practice different to her usual one seven days prior the fatal crash, on 11 July 2013. At that time her licence was reinstated after being provided with medical clearance by Dr P. He signed the medical certificate with no conditions attached at that time. The Coroner considered Mrs C's propensity for sleep and felt it critical that such conditions should have been added to her licence. The Coroner noted that the previous OT drive should have been taken into account by Dr P when he determined that she was fit to drive. Dr P examined her and completed a medical fitness drive certificate on 11 July 2013, but his notes do not indicate which tests were performed regarding the driving fitness. It was noted that apart from an earlier consultation on 26 November 2012, Dr P had not seen Mrs C for some seven years prior to his review, and had made no attempt to source medical records from the

local health trust or local hospitals. He admitted that he relied upon previous medical history, his own recollection, and her self-reporting. He considered that it was unnecessary to obtain further medical records. He indicated that at the inquest that he was largely unable to recall details of Mr C's medical history and his treatment of her. He could not recall what Mrs C had told him about her medical history during the earlier consultation on 26 November 2012, nor how she had presented physically. He indicated that he was unable to recall why he had previously prescribed her sleeping tablets, whether he'd been aware that she suffered sleep apnoea, or if she mentioned her recent history of recurrent falls.

Dr P stated that he had conducted numerous fitness to drive assessments, some 1500 in the last 10 years, and said he was very familiar with the Guidelines of Medical Practitioners in assessing fitness to drive. He said that he was aware that her licence had been cancelled in the past, but had never obtained a copy of the correspondence sent to Mrs C from DTMR re cancelling her licence, and never asked if she had undergone OT assessment.

Dr P indicated that during his assessment on 11 July 2013 he had asked her to perform hand and feet tapping and rotation, finger-pointing, lifting and moving lower limbs. He also asked her to perform a well-coordinated dance step (waltz step) during the consultation. As a result of the assessment he concluded that she should be issued with an unconditional licence to be reviewed on an annual basis.