



March 2013

**FOOTBALL,  
HEAD INJURIES  
AND THE RISK  
OF DEMENTIA**

**TACKLING ALZHEIMER'S  
BACKING AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

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## **ACRONYMS USED IN THIS PAPER**

ABC	Australian Broadcasting Corporation
AFL	Australian Football League
ARU	Australian Rugby Union
CTE	Chronic Traumatic Encephalopathy
FFA	Football Federation Australia
FIFA	Fédération Internationale de Football Association
F-MARC	FIFA Medical and Research Centre
FTD	Frontotemporal Dementia
IRB	International Rugby Board
NFL	National Football League
NRL	National Rugby League
NSW	New South Wales
SCAT2	Sports Concussion Assessment Tool 2
TBI	Traumatic Brain Injury
USA	United States of America

# EXECUTIVE SUMMARY

**Alzheimer's Australia NSW hopes to raise public awareness of the potential risks of later-life cognitive impairment and dementia for football players who suffer multiple concussive and subconcussive injuries throughout their playing career. This paper examines the research emerging from the USA, reports of impaired cognitive functioning in current and retired football players in Australia, and the possible implications for Australian football codes.**

Football players may sustain concussive or subconcussive injuries throughout their playing career, with research suggesting this may increase their risk of developing dementia. The relationship between concussions and traumatic brain injuries (TBIs) sustained in football and dementia is complex and further research in Australia is needed.

Alzheimer's Australia NSW believes that the association between concussions and other head injuries sustained in football and the development of dementia is worrying and that steps must be taken to protect players. We must ensure that the likelihood and impact of risk events is reduced to protect players' current welfare and future well-being.



# BACKGROUND AND PURPOSE

**In recent years public awareness of the potential long-term effects of concussions and mild traumatic brain injuries sustained in sport, especially different types of football, has increased. There is a growing understanding of the link between blows to the head suffered in football and other contact sports, such as boxing, and the potential for increased risk of dementia in later life.**

The association between traumatic brain injury and dementia risk is becoming increasingly evident. An analysis of case control studies found a 58% increased risk of Alzheimer's disease for those with a history of head injury<sup>1</sup>. Another review found that moderate and severe head injuries increase the risk of developing dementia by two to four times<sup>2</sup>.

Research being conducted in the USA on former football players with neurodegenerative diseases may point to potential dementia risks for Australian football players. In this paper, the term 'football' is used to describe the four main football codes popular in Australia – rugby league (National Rugby League - NRL), rugby union (Australian Rugby Union - ARU), 'Aussie rules' (Australian Football League - AFL) and soccer (Football Federation Australia - FFA).

As the level of concern increases and the evidence from overseas mounts, it is timely that Alzheimer's Australia NSW contributes to the public discussion. Alzheimer's Australia NSW is the peak advocacy organisation for people with dementia and their carers in NSW. We provide education about risk reduction strategies to delay the onset of dementia and strive towards a vision of a society free from dementia. This paper examines the research emerging from the USA, reports of impaired cognitive

functioning in current and retired football players, and the possible implications for Australian football codes.

***"The Price of Glory: Footballers such as Berrick Barnes expect hard knocks – but are they risking long-term brain damage?"***

The Weekend Australian Magazine, September 03-04 2011<sup>3</sup>

***"AFL Players at High Risk of Brain Damage"***

The Saturday Age, June 2 2012<sup>4</sup>

***"Knockout Worries Mount"***

The Courier Mail, June 13 2012<sup>5</sup>

***"The Brain Injuries That Destroyed a Football Superstar"***

Sydney Morning Herald, July 21 2012<sup>6</sup>

***"Doctors Call for Fans to Accept Concussion Risk"***

ABC Radio, PM, December 4 2012<sup>7</sup>

# HEAD INJURIES, CONCUSSIONS AND DEMENTIA

**Football players may sustain concussive or subconcussive injuries throughout their playing career. Concussion is defined as a complex pathophysiological process affecting the brain, induced by traumatic biomechanical forces. Concussion may be caused either by a direct blow to the head, face, or neck, or a blow elsewhere on the body with an impulsive force transmitted indirectly to the head<sup>8</sup>. Simply put, concussion is caused by a direct or indirect force to the head which makes the brain move around inside the skull and results in a disturbance to brain function. A person does not have to lose consciousness to suffer a concussion.**

*“Tell Brownie to put me back on.”*

Dean Young, rugby league player, refers to his coach from three seasons prior after suffering concussion during a game, in *The Daily Telegraph*, July 2012<sup>9</sup>

This disruption to normal brain function is a traumatic brain injury (TBI). TBIs are classified as mild, moderate or severe, depending on whether the injury causes unconsciousness, how long unconsciousness lasts and the severity of symptoms. Although most TBIs are classified as mild because they are not life-threatening, even a mild TBI can have serious and long-lasting effects<sup>10</sup>. Severe decline in thinking skills, characteristic of dementia, may develop years after the injury took place and the person seems to have recovered from its immediate effects<sup>11</sup>.

*“I got pains in my neck; on the field I’d get tunnel vision. You’re playing on autopilot. You don’t know where you are. It’s a weird sensation.”*

Berrick Barnes, rugby union player, describes playing with a concussion in *The Weekend Australian Magazine*, September 2011<sup>12</sup>

Symptoms of concussion include: inability to remember the cause of the injury or events that occurred immediately before or up to 24 hours after it happened; confusion and disorientation; difficulty remembering new information; headache; dizziness; blurry vision; nausea and vomiting; ringing in the ears; trouble speaking coherently; and, changes in emotions or sleep patterns. Symptoms often appear at the time of the injury or soon after, yet sometimes they do not develop for days or weeks. Symptoms are usually temporary and clear up within hours, days or weeks, but they can last months or longer. Cognitive changes are among the most common, longest-lasting and most disabling symptoms that can result directly from concussions. The ability to learn and remember new information, the capacity to pay attention, organise thoughts, plan and make sound judgements can be affected<sup>13</sup>.

The term ‘dementia’ describes the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning such as loss of memory, intellect, rationality, social skills and physical functioning. Dementia is fatal and there is currently no cure.

Research is emerging on a progressive neuro-degenerative disease caused by repetitive brain trauma including concussive or subconcussive blows to the head. Known as Chronic Traumatic Encephalopathy (CTE), it involves a build-up of the toxic tau protein and the progressive death of brain cells<sup>15</sup>. It was first noticed in boxers and described as being ‘punch drunk’ in 1928. Punch drunk was later termed ‘dementia pugilistica’, literally meaning ‘dementia of a fighter’. In the 1960s the condition was renamed CTE when the symptoms were also identified in athletes of other sports. In recent years,

awareness of CTE has heightened as it has become associated with sports such as American football, ice hockey, and wrestling<sup>16</sup>.

Research into CTE is still in its infancy, however, there is a growing body of evidence building in the USA. Much of this research has been conducted by the Boston University Centre for the Study of Chronic Traumatic Encephalopathy<sup>17</sup> which has a 'brain bank' of former players, other athletes and war veterans who experienced repetitive traumatic brain injuries and concussions throughout their careers. Brain autopsies conducted on former gridiron football players indicates that some, but not all, former players are at risk of developing CTE. Another recent study<sup>18</sup> of the cognitive functioning of former gridiron players suggests that cognitive deficits and depression appeared to be more common in the former players than in the general population.

***"Well you know, the stuff I hear coming out of you know those American studies is that long term you know, it doesn't look so good. But you know, I had a good time and would I do it again? I probably would, but I'd stop a bit earlier, you know...I don't blame rugby for what happened to me, it was good to me..."***

Steve Devine, former rugby union player, in the ABC program Four Corners, May 2012<sup>19</sup>

The onset of CTE is often in midlife, years or decades after recovery from the initial effects of concussive or subconcussive brain trauma. It has been reported that symptoms initially present as poor concentration, attention and memory loss as well as disorientation, dizziness and headaches. People with CTE typically progress to experience irritability, outbursts of violent or aggressive behaviour, confusion and speech abnormalities. There is a high frequency of suicide, drug overdose and depressive disorders during this stage. As the disease progresses there is a greater loss of motor functioning.<sup>20</sup>

CTE may be misdiagnosed as Alzheimer's disease or frontotemporal dementia (FTD) which share similar presenting clinical symptoms. Clinical diagnosis is difficult due to a lack of consensus on diagnostic criteria. The only way to definitively diagnose CTE is through post-mortem neuropathological autopsy and there is no evidence-based pharmacological treatment available for CTE<sup>21</sup>.

***"It became quite apparent to me a couple of years ago that I was starting to see very eminent ex-rugby league footballers, men in their 60s and in some cases their late 50s, presenting with early onset of dementia symptoms and Parkinson's disease. These are men who had been forwards playing in the scrum, and they're presenting 10 years before the majority of the people I see, with the kind of damage I have seen in boxers... it's anecdotal, and I don't want to overstate things...But it does mirror what the Americans are seeing."***

Dr George Stathers, a senior geriatric consultant in Southern Sydney, in The Weekend Australian Magazine, September 03-04 2011<sup>14</sup>

The relationship between concussions and TBIs sustained in football and dementia is complex and may be complicated by other factors such as drug and alcohol abuse, depression, and diagnostic difficulties. The existing research does indicate that "for some athletes there may be severe and devastating long-term consequences of repetitive brain trauma that has traditionally been considered only mild"<sup>22</sup>. However, it is known that TBIs increase the risk of developing dementia and that football players can suffer TBIs throughout their playing career.

In commentary about the research from the USA on CTE in football players, it has been noted that there are significant differences between gridiron football played in America and the types of football played in Australia<sup>23</sup>. In particular, the way in which gridiron players use their heads to ram into each other has been identified as



a manoeuvre which does not take place in Australian football codes. Gridiron players receive repetitive hard knocks to the head in training and games. In addition, some experts believe that the wearing of helmets in gridiron could add to the problem as players do things that they would not otherwise do if they were not wearing a helmet and therefore put themselves at greater risk of injuries; whereas Australian football players who do not wear helmets are aware of their limitations and play to protect their safety<sup>24</sup>.

Dr Andrew Gardner, an Australian clinical neuropsychologist with an interest in the long-term consequences of head injuries in sport, has visited the Centre for the Study of CTE at Boston University. He told Alzheimer's Australia NSW,

*“Most people agree that repeated head trauma cannot be good for you, however, the media has been quite alarmist with their reporting of the neuropathology findings coming out*

*of the USA, which does not serve anybody well... We can't ignore the current data and pretend we are immune here in Australia but we need to conduct sound research of our own before we can draw conclusions.”*

Dr Andrew Gardner, clinical neuropsychologist, Neurogard.<sup>25</sup>

Australian research into dementia risk for football players who suffer concussions and other head injuries has only just begun. The AFL established a concussion working group in 2010 to assist the AFL Research Board develop concussion projects and identify steps to ensure a best practice approach. The Research Board conducts a range of projects to increase knowledge and awareness and enhance the concussion management strategies of the AFL<sup>26</sup>. The Rugby League Research Board has commenced research into recurrent episodes of concussion and links to the onset of dementia in former players<sup>27</sup>. Alzheimer's Australia NSW commends the AFL and NRL, and eagerly awaits the results of this research.



# HEAD INJURIES AND CONCUSSIONS IN FOOTBALL IN AUSTRALIA

**Although the research evidence about the association between head injuries sustained in football and dementia is thus far limited, it is sufficiently concerning. Alzheimer's Australia NSW believes we need to err on the side of caution and limit the possible risk events in each code to protect the welfare of players at all levels of the game, from junior players through to professionals.**

*"My short-term memory these days is terrible. Based on what I went through, I don't want my kids to play footy. I'd rather they did something safer like tennis and golf."*

Willie Carne, former rugby league and union player in The Courier Mail, 22 September 2012<sup>28</sup>

*"I get dizzy spells here. I have flashbacks; I forget things constantly - that's probably the biggest one... What don't I forget, more to the point? Phone calls, where I put things around the house, bath - I flood the house probably once a week. Like, in the mornings when I'm going to work, it'll take us 15 minutes to find my keys and wallet and I put them in the same place every day, or I think I do, but I still can't find them."*

Shaun Valentine, former rugby league player in the ABC program Four Corners, May 2012<sup>29</sup>

Potential risk events include:

- Accidental head clashes
- Poor tackling techniques
- Striking
- Heading the ball
- Falls

Many of these risk events are accidental in nature, making it difficult to change the games' rules to entirely remove risks. Protective soft headgear is often seen as a way of reducing a players' risk of head injury. However, according to international

experts on concussion in sports, there is no good clinical evidence that the protective equipment currently available will prevent concussion. Headgear and mouthguards are not effective at preventing concussions or head injuries as they do not stop the brain from moving around inside the skull which is what causes concussion<sup>32</sup>. Proper management of concussions when they do occur is therefore critical to protect players' current and future wellbeing.

*"I had a couple of instances where I couldn't picture parts of relatively new memories. It felt like there were three pieces missing out of 500-piece puzzle. It didn't matter how hard I tried to remember, it would still come up blank."*

Daniel Bell, former AFL player - de-listed at age 25 after repeated concussions, in the Readers Digest, October 2012<sup>30</sup>

*"On short-term memory, yeah, I struggled a bit. I'd trace out two pictures and then, a few minutes later, be asked to draw one again. Or we'd pair 10 words and, after going through them, the doc would start over; saying one and waiting for me to say the other."*

Josh Miller, former rugby league player - retired after tests revealed he had cognitive issues from too many concussions, in the Sydney Morning Herald, November 17 2012<sup>31</sup>



# CONCUSSION MANAGEMENT

**At the 4th International Consensus Conference on Concussion in Sport held in November 2012, the 2008 Consensus Statement on Concussion in Sport was updated. This statement acknowledged that the science of concussion is evolving and therefore management and return-to-play decisions remain in the realm of clinical judgement on an individualised basis. The updated 2012 Statement will be published in March 2013. The foundation of concussion management is physical and cognitive rest until symptoms resolve and then a graded program of exertion prior to medical clearance and return-to-play.<sup>33</sup>**

The Sports Concussion Assessment Tool 2 (SCAT2) is a standardised method of acutely evaluating injured athletes for concussion and has been developed to assist medical staff in managing incidents of concussion in accordance with the Consensus Statement on Concussion in Sport. It can be used in athletes aged 10 years or older.<sup>34</sup>

The four football codes in Australia each have concerns about the welfare of their players and have developed concussion management guidelines which adhere to these international guidelines. Some codes have separate guidelines for professional and community level players, whilst others have guidelines that apply to all players.

Concussion is “relatively common” in rugby league; between five and seven concussions per team per season have occurred in recent years, with a similar rate of concussion recorded in all levels of competition<sup>35</sup>. The NRL Concussion Management Guidelines are based on international guidelines as well as research conducted on concussion in AFL and NRL over a number of years.

The NRL guidelines state that the most important element in the management of concussion must always be the welfare of the player, in both the short and long term. They summarise the most important points

as: suspecting the diagnosis in a player with symptoms such as confusion or headache after an apparent head injury; referral of the player for medical evaluation and; the player must have medical clearance before being allowed to return-to-play. Any player who is suspected of having a concussion must be removed from the game and be assessed by the sports trainer. If a player has suffered a concussion they must not return-to-play in the same game. The guidelines note that the assessor should not be swayed by the opinion of the player, coaching staff or anyone else suggesting premature return-to-play.<sup>36</sup>

The ARU guidelines are in line with those of the International Rugby Board (IRB). The IRB identified concussion management as an issue and changed its policy in 2011 to reflect the International Consensus Statement. It also established a medical working group to review their pitch-side concussion guidelines. The IRB concussion policy up to 2011 included a mandatory three week stand down period. When this



was adhered to it was a very safe process. However it was recognised that this policy was not adhered to nor well enforced and that diagnosis of concussion was not being made in order to avoid the three week ruling. The new ARU Concussion Management Guidelines were introduced in May 2011 and are based on five principles outlined in the ARU concussion management fact sheet. The ARU strongly promotes these concussion principles at both the elite and community level. How well they are being implemented will be able to be determined in a couple of years' time.<sup>37</sup>

At the elite level the IRB has introduced a new process for pitch side assessment. The team doctor, match day doctor or referee can request that a player be assessed for concussion. Previously once a player was suspected of concussion they were removed from play and were not allowed to return to the field of play. Now if the player is suspected of having concussion, they are removed from the field, medically assessed and if deemed not to have a concussion, they can return-to-play. This process was introduced in August 2012 and is still in the trial phase. All players who leave the field due to a suspected concussion are medically assessed after the game using SCAT2 and so far the trial indicates that those who did return-to-play do not have concussion and those that do not return-to-play do have a concussion.<sup>38</sup>

The AFL acknowledges that concussion is a "relative common injury" in AFL; there are approximately 6-7 concussions per AFL team per season<sup>39</sup>. The AFL Concussion Management Guidelines state that an AFL player with suspected concussion must be withdrawn from playing or training until medically evaluated and cleared. They note that a more conservative approach of a longer time to return to sport be used in cases where there is any uncertainty about the players recovery.

At the elite level, an AFL player diagnosed with concussion cannot take any further part in the game. Decisions regarding

return-to-play after concussive injuries should only be made by a medical doctor with experience in concussive injuries. It is stated that the guidelines must be adhered to at all times, yet note that the guidelines should serve only as a general guide for the management of concussive injuries based on the most up-to-date evidence available, with treatment of individual players to be determined by the experience of the examining practitioner, the specific clinical circumstances presented and the resources available for assessment and testing.<sup>40</sup>

The AFL has separate concussion management guidelines for community level games. At this level, any player suspected of concussion must be withdrawn from playing or training immediately and is required to have an urgent medical assessment. In the days or weeks following concussion, the player should not be allowed to return-to-play or train until they have had formal medical clearance.<sup>41</sup>

Concussions are less likely to occur in soccer matches than other codes of football. There were three reported concussions in the A-League 2011/12 season<sup>42</sup>. The most common causes of concussion in soccer are an accidental clash of heads or an arm or hand contacting the head<sup>43</sup>. There are some concerns that heading of the ball, particularly in repetitive training drills, may be linked to brain injury and cognitive deficits however the research into this is inconclusive<sup>44</sup>.

The FFA's concussion guideline is in line with that of the Fédération Internationale de Football Association (FIFA). FIFA has a Medical Research and Research Centre (F-MARC) that reviews the prevention and management of concussion in football. All A-League and national teams have a doctor and physiotherapist who are suitably knowledgeable about concussion management including on-field assessment and graduated return-to-play.<sup>45</sup>

Proper management of concussion is an important issue for junior players. The

human brain is not fully developed until the age of 25 years. The prefrontal cortex is one of the last regions to develop. This brain region is responsible for cognitive analysis and abstract thought, and the moderation of behaviour in social situations<sup>46</sup>. Head injuries to a young developing brain therefore have the potential to result in significant damage.

The ARU also has specific guidelines for children and adolescents which note that children under ten may display different concussion symptoms. They advise that children and adolescents with suspected concussion must be referred to a medical practitioner immediately as they may need specialist medical assessment. A more conservative graduated return-to-play approach is recommended for younger players.<sup>47</sup>

Although concussion management guidelines are in place for all codes, it is difficult to ascertain to what extent these are being enforced, at both elite and community levels. Certainly there are instances of guidelines not being adhered to in professional games, with players suspected of concussion remaining on or returning to the field.

***“With player welfare becoming increasingly paramount, the NRL introduced guidelines this season that if a player shows signs of concussion he must be replaced and can’t return until he’s cleared by the club’s medical officer. Yet Ryan Hoffman was knocked into Disneyland after attempting a tackle early in the win over South Sydney and was seen staggering around for a couple of minutes but stayed on the field... If there’s a rule in place it must be enforced for all matches, regardless***

***of whether they are trials, regular season games, finals or representative fixtures.”***

As reported by Yahoo Sports in 2012<sup>48</sup>

Furthermore, these are ‘guidelines’ only – it is not clear what the implications are for clubs if they are not followed. There is also no clear rule about what happens if a player suffers multiple concussions in one season. It appears that it is up to the discretion of the treating medical professional as to whether a player ceases or continues to play.

***“People only do what is inspected of them, quite often not what is expected of them, and given that sport is such a performance-driven entity, keeping your best players in play is a great temptation for all clubs competing at all levels of competition but particularly at the elite level.”***

Dr Andrew Gardner, clinical neuropsychologist, Neurogard<sup>49</sup>

Yet the football codes administrative bodies and team management officials have an obligation to provide a safe work environment for their players. Failure to ensure that concussion management guidelines are adhered to could leave them legally exposed should players develop later life cognitive impairments. In the USA, former National Football League (NFL) players and the families of deceased players have launched a class action lawsuit claiming that the league hid the links between concussion-related and other head trauma and permanent brain damage. The lawsuit aims to hold the NFL and helmet maker Riddell responsible for the cognitive damage, including dementia, sustained by players<sup>50</sup>.

# CONCLUSION AND RECOMMENDATIONS

**Alzheimer's Australia NSW hopes to raise public awareness of the potential risks of later-life cognitive impairment and dementia for football players who suffer multiple concussive and subconcussive injuries throughout their playing career. Alzheimer's Australia NSW believes that the association between concussions and other head injuries sustained in football and the development of dementia is worrying and that steps must be taken to protect players. We must ensure that the likelihood and impact of risk events is reduced to protect players' current welfare and future well-being.**

**Alzheimer's Australia NSW proposes the following recommendations:**

1. All Australian football codes undertake revision of game rules to minimise the risks of concussion and traumatic brain injuries.
2. All Australian football codes contribute to further research about dementia in retired football players in Australia.
3. All Australian football codes review and revise their concussion guidelines in the light of new research on Chronic Traumatic Encephalopathy (CTE) and dementia risk amongst football players.
4. All Australian football codes strictly enforce concussion guidelines so as to minimise the risks of brain injury and cognitive disorders.
5. Graduated return-to-play rulings following concussion be strictly enforced by all Australian football codes as a risk reduction measure against potential long-term cognitive damage.

6. Age-related rulings on concussions and return-to-play be developed and enforced by all Australian football codes. Younger players should have a longer graduated return-to-play period.
7. All Australian football codes undertake communication with players, former players and families to educate them about the potential risks of cognitive impairment and dementia.

Photo: Paul Rovere / Fairfax Syndication



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## OTHER PUBLICATIONS

Social Research Publications by  
Alzheimer's Australia NSW

### **The most difficult decision - Dementia and the move into residential aged care - Discussion Paper #5, Oct 2012**

Adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyond<sup>i</sup>. While policy direction<sup>ii</sup> and the wishes of the person with dementia and their carer can dictate that people with dementia may stay living at home for as long as possible, the impacts of the symptoms and behaviours of dementia mean that ultimately a large number of people with dementia will move into residential aged care.

### **What prevents people with dementia making plans for their future? - Discussion Paper # 4, Mar 2012**

Planning ahead is important for the whole population. We all need to make sure if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes. People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

<http://www.fightdementia.org.au/common/files/NSW/20120328-REP-DiscussionPaper4.pdf>

### **Building Dementia and Age- Friendly Neighbourhoods - Discussion Paper # 3, July 2011**

The needs of people with dementia and

other types of cognitive impairment have helped shape the design of residential facilities, but the issue of accessibility to public places and spaces for people with dementia and their carers has been almost completely neglected. In a series of focus group consultations we asked members of the eight Alzheimer's Australia NSW regional consumer committees to describe how they experienced their surrounding neighbourhoods once they stepped outside the safety and familiarity of their front gate and made their way to the local shopping centre, park, doctor's surgery or club.

[Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper 3 July 2011\(PDF\)](#)

### **Addressing the stigma associated with dementia - Discussion Paper # 2, Sep 2010**

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

[Addressing the Stigma associated with Dementia Discussion Paper 2 \(PDF\)](#)

Dementia is a condition that carries a heavy burden of stigma. People's attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

[Alzheimer's Australia NSW – Addressing the Stigma associated with Dementia - Executive Summary \(PDF\)](#)

### **Driving and dementia in New South Wales - Discussion Paper #1, Apr 2010**

A new discussion paper, Driving and Dementia in NSW, indicates there is little clear, accessible information about the

rights and responsibilities of a driver after a diagnosis of dementia.

### [Driving and Dementia in New South Wales Discussion Paper 1 \(PDF\)](#)

Issues raised include:

- Driver testing for people with dementia must be improved
- Legal obligations for a driver with dementia are unclear
- Call for improved transport alternatives for a person with dementia
- Need for better support for transition from driver to non-driver in NSW

### [NSW Discussion Paper Key Recommendations \(PDF\)](#)

## Quality Support Groups Research Project

There is little knowledge of the way support groups in New South Wales are currently functioning, or how effectively they are providing support to their participants. The purpose of the Quality Support Groups Research Project is to understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

Quality Support Groups Research Project - Phase 3 The purpose of Phase 3 is to analyse findings from Phase 1 and Phase 2 of the Project. The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service to carers of people with dementia. This research upholds the mission of Alzheimer's Australia NSW to minimise the impact of dementia through leadership, innovation and partnerships. This is the third and final report into a research project that spanned 5 years and looked at what comprises a quality support group. This is the first comprehensive state-wide Australian study of ongoing support groups for carers of people with

dementia. Over the five years of the project more than 350 people took part, including leaders of the groups and carers who had at some time attended a support group.

Significant findings of the report are:

- Huge benefits of supports groups for people who attend on a regular basis
- The uncelebrated capacity of mutual aid amongst group members to assist each other
- The unexpected finding of the profound impact of grief and loss on the health and well-being of a carer of a person with dementia
- Some carers reported the grief and loss felt at the time of diagnosis was equal to or even greater than the grief felt when the person with dementia dies

### [Quality Support Groups Research Project - Phase 3 Executive Summary \(pdf 45 KB\)](#)

The full Phase 3 report is available to purchase from Alzheimer's Australia Online Bookshop.

### [Quality Support Groups Research Project - Phase 2 \(pdf 1.92 MB\)](#)

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

### [Quality Support Groups Research Project - Phase 1 \(pdf 764\)](#)

The focus of phase one of the Quality Support Groups Research Project is a literature review of research conducted into dementia support groups and a survey of existing support groups in New South Wales to investigate the views of support group leaders.

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