

**Research Project**

**The Impact of War Experiences on Dementia in Veterans**

**Final Report**

**March 2012**

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## **ACKNOWLEDGEMENTS**

We are grateful to service providers, case managers and coordinators for their valuable input and to family carers and veterans for contributing to the study. Lynne Terry, project officer Department of Veterans' Affairs provided valuable advice throughout the study. Professor David Dunt oversaw the project and directed statistical analyses. Dr Colleen Doyle designed the study and the previous EACHD survey, analyzed data and wrote sections of this report. Dr Cecily Hunter recruited participants and wrote sections of this report. Dr Susan Day managed data sets, wrote the literature review and analyzed results. Professor Alexander McFarlane provided advice on measurement of PTSD, assisted with the grant application and commented on the final report. Professor Philip Morris provided advice on the ethics application and commented on the final report.

This study was funded by a Department of Veterans' Affairs applied research grant.

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# EXECUTIVE SUMMARY

## Background

This project was funded by the Department of Veterans' Affairs to investigate the relationship between post-traumatic stress disorder (PTSD) and dementia in veterans. Recently, links have been made in the medical literature between PTSD and the incidence of dementia, with epidemiological evidence that the odds of developing dementia are 1.7 to 2 times greater in veterans with a diagnosis of PTSD. These findings from analyses of USA Veterans' Affairs data led us to pose research questions about dementia and PTSD in Australian veterans. No Australian large scale data bases with variables on PTSD diagnoses and dementia diagnoses were available to replicate the USA analyses for older Australian veterans. However a recent community survey of dementia, the EACHD evaluation survey, included veteran status as a survey item and provided the basis for an opportunity to address questions related to the issue.

We aimed to answer the research questions:

- a) What is the profile of behavioural and psychological symptoms of dementia (BPSD) in Australian veterans?
- b) Is the profile of BPSD different in veterans and non-veterans?
- c) Is the profile of BPSD different in veterans with PTSD and veterans without PTSD?

## Method

To address these research questions we reviewed the literature and analyzed two surveys: The 'EACHD evaluation' survey, referred to above, had been undertaken before this project and included some data on veterans and non-veterans with dementia. Another survey was undertaken during this project to add to the sample of veterans in the EACHD evaluation survey. Information on veterans was collected from carers and case managers of the veteran. 'The Impact of War Experiences on Dementia - Carers Survey' was of a sample of carers of veterans and aimed to find out information about PTSD in veterans with established dementia by using two validated proxy scales. 'The Impact of War Experiences on Dementia - Case Managers Survey' was of a sample of case managers who completed information about the veterans' behavioural and psychological symptoms of dementia and other health indicators. Veterans themselves were not asked to complete survey forms because they were highly dependant and had significant cognitive impairment due to dementia. The project was approved by the DVA Human Research Ethics Committee, University of Melbourne Ethics Committee and five other community service ethics committees.

A list of all community service providers managing EACHD, CACP and EACH packages throughout Australia was used to recruit community service providers into the study. Providers would then act as third party recruiters to invite community care recipients into the study. Veterans in receipt of community care packages were targeted in order to match the existing data set which had been a sample of people with dementia using EACHD services.

In 2010, 103 community service providers from around Australia were invited to participate in the study. A response rate of 64% of providers agreed to participate in the study, but approximately half of these providers indicated that they had no veterans as clients during the study period. Of an estimated 115 veterans and carers available to participate in the study, a response rate of 23% had been achieved after nine months of recruiting. This was lower than the expected 50% response rate that had been achieved in the EACHD study that formed the basis for this recruitment strategy.

Veterans were defined as males with gold, white or orange cards or other DVA entitlements, plus females with either white or orange cards. Females with gold cards were classified as non-veterans. Veterans of any

war were considered eligible to enter the study, including those veterans who served in overseas forces. This resulted in a combined data set from all surveys of 48 veterans, 298 non-veterans and 26 carers of veterans. In consultation with DVA the analyses presented here were restricted to 40 male veterans and 96 male non-veterans as the female veterans in the sample were likely to have not seen active war service.

BPSDs were measured by case managers and by family carers. Case managers described BPSDs using the Cohen Mansfield Agitation Inventory (CMAI). This measure included four subscales in the areas of verbal agitation, verbal aggression, physical agitation and physical aggression covering 33 individual behaviours. Family carers described BPSDs using the BPSD Checklist which is a 14 item checklist for non-cognitive symptoms of dementia.

PTSD was measured using two scales to determine the level of post-traumatic stress symptoms: the Posttraumatic Stress Screen for the Cognitively Impaired Observer Version (PTSS-CI-OV) and the Partner PTSD Checklist (PCL-P). Other measures of functional dependency (Barthel Index) and instrumental dependency (OARS) were also used. To describe dementia severity, the Mini-Mental State Exam (MMSE) and the Global Deterioration Scale were used.

### Statistical analyses

For the first research question, descriptive statistics on the main variables (means, standard deviations) were produced. For the second research question, we examined the CMAI subscales and individual CMAI symptoms and differences between veterans and non-veterans were estimated.

CMAI subscales formed quasi-interval level data and were analyzed initially using t-tests of statistical significance. To test for the effects of confounding and modification of differences between veterans and non-veterans in subscale scores, multiple regression analyses were performed based on stepwise addition of other variables with independent effects on subscale scores. An 'a priori' exclusion rule of  $p > 0.20$  was used as part of an iterative process to add the main effects of the variables one at a time into the regression models. The variables that were added to the models were:

- Veteran status
- Age
- Living arrangements
- Psychotropic medication
- Modified Barthel Index of functional dependency
- OARS measure of instrumental dependency
- Score on the Global Deterioration Scale.

Unstandardized and standardized  $\beta$  coefficients, t-values and significance levels are reported as well as R square values (and their significance) for the whole model.

Next, CMAI individual items based on ordinal data were analyzed using the Mann Whitney U test. Median ranks in veterans and non-veterans are also reported.

For the third research question, differences in levels of BPSDs in veterans with and without PTSD were estimated.

## Findings

A series of statistical tests explored differences between veterans and non-veterans. The main findings were as follows:

- T-tests showed no statistically significant differences between veterans and non-veterans in CMAI subscale scores in bivariate analysis although mean scores for veterans appeared to be higher. True differences between veterans and non-veterans may however have been masked by confounding variables in the t-test results.
- After adjusting for the effects of other confounding variables using multiple regression, mean scores of the CMAI subscale of Physical Aggression were statistically significantly higher for veterans than non-veterans. It should be noted that Physical Aggression levels in both groups were not high and the effect of veteran status on Physical Aggression levels is likely to be small. There were no statistically significant differences in veterans' and non-veterans' subscales of Verbal Agitation, Verbal Aggression or Physical Agitation.
- Male veterans scored higher (not necessarily significantly) on all Verbal Agitation symptoms, and all but one Verbal Aggression symptom ( $P=0.006$  using the Sign test).
- BPSD scores assessed using the BPSD Checklist in veterans with PTSD were significantly higher (33.5) than for non-veterans (18.5) measured using the PCL-P ( $P<0.001$ ). This is despite the small number of veterans involved in this study.
- All 14 symptoms measured in the BPSD Checklist were higher (not necessarily statistically significantly so) in veterans with PTSD than those without. This was highly significant judged using the Sign test ( $P=0.0001$ ).
- Considering individual symptoms rather than subscales or clusters of symptoms, there were statistically significant differences in a number of the symptoms between veterans and non-veterans. Given the small sample size and recruitment issues the results are suggestive rather than definitive.

Together, the above exploratory statistical analyses indicated that there were some differences between veterans and non-veterans in the way dementia was expressed, and some differences between veterans with PTSD and veterans without PTSD, and these differences are worth investigating further. This is the first Australian study to explore the relationship between symptoms of dementia and post-traumatic stress disorder in veterans. A limitation of this study was the small sample size for veterans, although the sample size was not the smallest compared with other published studies in the literature and statistically significant differences were found.

We concluded that:

1. Being a veteran is associated with some differences in the profile of behavioural and psychological symptoms of dementia than shown in non-veterans, with higher sub-scale scores in the area of Physical Aggression as well as a number of individual BPSD symptoms.
2. Veterans with PTSD had higher BPSD scores than veterans without PTSD.
3. Future studies are needed to replicate this finding from this small study in order to understand why specific symptoms of dementia may be more prevalent among veterans than non-veterans.





# 1 INTRODUCTION

Both the causes and the course of dementia are the subject of intense scientific scrutiny, as our population ages and more people are affected by the syndrome. Particular efforts are being made to identify preventable causes of dementia, and recent studies of the potential of lifestyle factors such as exercise and mental activity to alter the course of cognitive decline have been finding promising results (Lautenschlager et al., 2008). The influence of psychosocial experiences has also been studied. For example severe depression episodes have been linked to increasing the risk of dementia (Saczynski et al., 2010). Recently links have been made between post-traumatic stress disorder (PTSD) and the incidence of dementia, with evidence that the odds of developing dementia are significantly increased in people with a diagnosis of PTSD (Yaffe et al, 2010; Qureshi et al, 2010). This report explores the link between traumatic life experiences and dementia, specifically PTSD and dementia. The link is particularly relevant to veterans.

As with all pathology, the manifestation of dementia varies across individuals. Behavioural and psychological symptoms of dementia (BPSD) can include verbal and physical agitation, verbal and physical aggression, apathy or loss of initiative, and neuropsychiatric symptoms such as depression, hallucinations and delusions. Although BPSD are common, their causes, their course and which symptoms cluster together during the progression of dementia have not been established.

A number of studies have investigated when BPSD occur during the course of dementia. Apathy seems to become more common as dementia progresses. Aggression and physical agitation may be more frequent in the moderate stage of dementia, while BPSD decrease as the person moves into very severe dementia. Depression may be more common at the early stages of dementia while the person maintains some insight into their condition. However the literature on the progression of BPSD is scant. Some studies have found no correlation between BPSD and the level of cognitive impairment (Lövheim et al., 2008).

The causes of BPSD, and the impact of life experiences on how dementia is manifested are as yet unclear. Once BPSD emerge, there is substantial and growing evidence for the beneficial effect of some psychosocial interventions to treat BPSD, but whether the immediate psychosocial environment caused the BPSD is unclear. There is a very small literature developing on the impact of life stresses on the incidence of dementia (see Literature Review below). Stress is well known to affect cognitive functioning, including memory. Acute, prolonged exposure to stress is known to impact on memory. A recent animal study showed that psychosocial stress increased corticosterone plasma levels and blood pressure. Stress interacted with A $\beta$  accumulation to exacerbate memory impairment. Other findings have confirmed that chronic stress leads to increased  $\beta$ -amyloid plaque deposition and more profound memory deficits (Alberini, 2009). Chronic psychological distress (depression and anxiety) is associated with the development of mild cognitive impairment and higher risk of Alzheimer's Disease (Wilson et al, 2009). These findings together suggest that those who have experienced stress at the extreme end of the continuum may be especially vulnerable to more severe impacts on memory and cognition, as found in dementia. Whether exposure to chronic or severe stresses such as those from war experiences increases the incidence of dementia even more than that found in non-veterans or alters the course or manifestation of symptoms of dementia is a topic of great interest, because of the implications for prevention and management of both disorders.

A presentation at the Alzheimer's International Conference in 2009 showed that US veterans with PTSD had a 7-year cumulative incident dementia rate of 14.4% while those without diagnosed PTSD had a lower rate of 8.1% (Yaffe et al, 2010). Therefore those with PTSD were nearly twice as likely to develop dementia compared to veterans without PTSD.

In Australia there have been no studies to date of the manifestation of symptoms of dementia in veterans. There have also been no studies up to now of PTSD and BPSD (together) in veterans.

In a recent evaluation of the EACHD community care package program, some of the authors (CD, DD, SD) undertook a detailed study of behavioural and psychological symptoms of dementia in community dwelling people (Doyle et al, 2009). We found that BPSD among people living in the community and receiving these community support packages were moderate to severe. We collected information on BPSD in a cohort of 350 people who started to receive community care over a twelve month period. The most common behavioural and psychological symptoms of dementia were: required prompting to undertake activities of daily living (73.6%); asking repetitive sentences or questions (62.4%); being uncooperative or unwilling to participate (50.7%); being restless or fidgety or always moving around (49.1%) and being up at night (48.3%). Physical aggression was the least common behavioural and psychological symptom, occurring in less than 3% of clients. The most problematic symptoms were: required prompting to undertake activities of daily living; tried to get out inappropriately; was up at night; was uncooperative or unwilling to participate; screamed; and had delusions. Combining frequency and problem perceived, the most difficult behaviours were: required prompting to undertake ADLs; was restless or fidgety; paced or aimlessly wandered; and asked repetitive sentences or questions (Doyle et al, 2009).

It may be that the profile of BPSD as found above is different in veterans who have been exposed to stressful war experiences. Those with diagnosed PTSD may again be prone to particular BPSD that are different to those with less severe war time experiences or less severe response to their experiences. Our data set and experience has provided a unique opportunity to study BPSD in veterans. By building on data already collected, we attempted to answer the research questions efficiently and thereby advance scientific understanding with this exploratory study.

## Definitions of Dementia

Dementia is characterized by multiple cognitive deficits. It is usually progressive and irreversible (Lövheim et al., 2008). There are many different forms of dementia, but the most common variants (accounting for >90% of all cases) are:

- Alzheimer's disease (AD) accounting for > 50% of dementia cases;
- Vascular dementia (VaD) which is caused by cerebrovascular conditions such as multi-infarct disease and stroke and is estimated to affect approximately 20% of all cases;
- Dementia with Lewy bodies which is estimated to account for 15% of cases;
- Fronto-temporal dementia which is estimated to account for approximately 5% of cases;
- Parkinson's disease which accounts for approximately 3-4% of dementia cases (Bartlett et al., 2006).

The progression of dementia has been conceptualized as involving stages in which people gradually lose their capacity for independent living. Progression can vary considerably, often depending on the type of dementia, but the stages are often labeled as mild (early stage), moderate (middle stage) and severe or advanced (late stage) (Doyle et al., 2006).

- **Early Stage:** In the early stages, symptoms may be subtle and not immediately obvious. It generally commences with a small decline in a person's cognitive function including mild memory loss and confusion, followed by the emergence of problems with performing some routine activities of daily living (ADL). The person with dementia is often aware that there is a problem, which can then lead to experiencing distress. The person may attempt to minimize or

compensate for their difficulties by adjusting their daily activities and arrangements as a means of covering up the problem (Doyle et al., 2006).

- Middle Stage: As the dementia progresses into the middle stage, performing ADL becomes increasingly difficult and can escalate to the point where the person's independence is significantly compromised. The person with dementia may experience emotional instability and become disoriented when attempting to make changes. At this point the person may need constant supervision and support with daily living (Doyle et al., 2006).
- Late Stage: In the later stages, the person is no longer able to cope without the assistance of others for ADL and the person may no longer recognize themselves or others, and may lose the ability to speak or walk (Doyle et al., 2006).

The average rate of moderate to severe dementia in Australia for those aged 65+ years is about 1-in-15. For those aged 80-84 years the rate is 1-in-9, and among those aged 85+ years the rate is 1-in-4 (Australian Institute of Health and Welfare, 2007; Jorm et al., 2005).

## **Definitions of Behavioural and Psychological Symptoms of Dementia (BPSD)**

In addition to cognitive decline, many people with dementia experience some behavioural or psychological symptoms of dementia (BPSD) at some time during the disorder (Lövheim et al., 2008). BPSD are defined by the International Psychogeriatric Association (IPA) Taskforce on BPSD as 'symptoms of disturbed perception, thought content, mood [and] behaviour'. BPSD symptoms include anxiety, depressed mood, hallucinations and delusions, aggression, screaming, restlessness, agitation, wandering, culturally-inappropriate behaviors, sexual disinhibition, hoarding, cursing and shadowing (Brodaty et al., 2003; International Psychogeriatric Association, 2010)..

Recent research has verified a four-factor model of BPSD: psychosis, moods, agitation and behavioural dys-control as measured by the Neuropsychiatric Inventory (NPI). BPSD symptoms that load onto each of the four factors are as follows:

- Psychosis – delusions, hallucinations
- Moods – depression and anxiety
- Agitation – aggression, irritability, disinhibition
- Behavioural Dyscontrol – disinhibition, elation, apathy, aberrant motor activity (Proitsi et al., 2011).

Estimates of the prevalence of BPSD are variable; with estimates ranging from 61% - 88% for people with dementia living in the community, 29-90% for residents of aged care facilities and 95% of hospitalized patients in long-term acute care (Brodaty et al., 2003). According to Lövheim (2008) prevalence has been estimated to be between 79% and 92% (Lövheim et al., 2008).

A number of studies have investigated the change in prevalence of various symptoms with the progression of the dementia disorder. Results have been mixed and the picture of symptoms also differs depending on type of dementia (Lövheim et al., 2008). Lövheim (2008) found that the relations between the BPSD and level of cognitive impairment were non-linear, with higher prevalence rates in the middle stage of dementia apart from the symptom of passiveness, which increased almost linearly with the severity of cognitive impairment (Lövheim et al., 2008). Doyle et al (2006) have also noted that once the dementia progresses to later stages, BPSD often diminish as the person becomes more dependent on others and receives more support from a broader range of services (Doyle et al., 2006).

## Definitions of Post-traumatic Stress Disorder (PTSD)

A diagnosis of PTSD has only been possible since 1980 when the disorder as we understand it today was first described. Many older veterans may refer to the symptoms they experienced using older terminology such as survivor syndrome, shell shock, combat fatigue or war neurosis.

PTSD is initiated by exposure to extraordinarily stressful life events (eg military combat, violent personal assault, being taken hostage, natural or manmade disasters, and severe car accidents). PTSD diagnosis is unusual in that it includes a requirement for a causal criterion of a 'stressor' or an event that is considered traumatic. PTSD has three symptom clusters – intrusive recollections where the person re-lives the traumatic experience; avoidant/numbing symptoms, where the person feels disengaged or 'watching' real events, and hyper-arousal symptoms such as shaking or sweating. The symptoms have to be experienced at a sufficient intensity and persistence over time in order to meet the criteria for diagnosis. Six criteria need to be satisfied in diagnosing PTSD:

- a) stressor criterion, having been exposed to a catastrophic event involving actual or threatened death or injury;
- b) intrusive recollection, where the trauma is re-experienced in daytime fantasies, re-enactments of the trauma, recollections of the event triggered by exposure to trauma-related stimuli;
- c) avoidant/numbing; in which people attempt to protect themselves from the trauma by avoiding situations that remind them of the event. Psychic numbing refers to lack of tolerance for strong emotions which may make it difficult to engage in interpersonal relationships;
- d) hyper-arousal; resembling panic or anxiety disorder, including symptoms such as insomnia, hyper-vigilance and startle reflex;
- e) duration criterion; symptoms have to be experienced for at least one month;
- f) functional significance criterion; symptoms have to be causing significant distress or functional disturbance.

A diagnosis of PTSD requires symptoms of at least 1 month duration. The current *Diagnostic and Statistical Manual of Mental Health Disorder (DSM-IV)* also contains several specifiers to the diagnosis of PTSD, including: an acute versus chronic specifier to indicate whether the duration of symptoms is less than or more than 3 months; and a delayed onset specifier to indicate if the onset of symptoms occurred at least 6 months after the trauma (Averill & Beck, 2000). In addition to avoiding stimuli associated with the trauma that initiated the PTSD, and the possibility of a numbing of normal affective responses which can manifest as depression, affected individuals exhibit symptoms of increased arousal which can present as anxiety, restlessness, disturbed sleep, nightmares, irritability, outbursts of anger, hostile behavior, and exaggerated startle response (Johnston, 2000).

Clearly not everyone who is exposed to traumatic events develops PTSD. Because of individual differences, some people have different trauma thresholds which make them more sensitive to the impact of the traumatic event. Individual differences and their correlates, and what we can infer from the pattern of individual differences, are central to the topic of this study.

## 2 LITERATURE REVIEW

Eleven years ago (year 2000), Johnston wrote that there was 'little or no information about the relationship between PTSD and dementia and none at all regarding the mode of presentation, course, treatment, complications or patterns of service use in either disease when there is comorbidity' (Johnston, 2000). Since that time there has been increasing interest in the relationship between PTSD and dementia in the literature but limited empirical study. This review provides background to the research questions by reviewing studies of the relationship between PTSD and dementia in relation to PTSD as a risk factor for dementia, dementia or cognitive decline as risk factor for PTSD, and finally the relationship between PTSD and the behavioural and psychological symptoms of dementia (PTSD).

### Method

An electronic search of Web of science, Scopus – V.4, Medline, CINAHL PLUS, PsycINFO and PubMed was made using a combination of the terms 'dementia', 'posttraumatic stress disorder', 'behavioural and psychological symptoms of dementia', 'BPSD', and 'PTSD'. The resulting articles rated as most relevant to the search terms were scrutinized online to determine their applicability to the focus of the review. Those articles deemed suitable were retrieved and read in more detail. In addition the reference lists of the retrieved articles were also examined to find articles that had not been captured in the electronic search. The information presented here gives an overview of the literature. It is not exhaustive but presents the main themes in relation to the relationships that were investigated.

### PTSD as a risk factor for dementia

The questions of whether PTSD causes dementia, or increases the risk for developing dementia, have not been studied in Australian veterans before. Two Australian studies were pertinent to the research questions, but neither were conclusive about the link between PTSD and dementia. The first, published in 1996, compared 101 Australian POWs of the Japanese and 108 veteran control subjects. The authors concluded that 'the study did not support the ... theory that severe stress can lead to hippocampal neuronal loss and cognitive deficits. Cognitive deficits in earlier studies of former POWs may have been associated with concurrent depression' (Sulway et al., 1996).

The second Australian study, published in 2003, compared the psychosocial morbidity in an older community sample of Holocaust Survivors with two comparison groups (Immigrant Refugees and Australian/English-Born Non-Refugees). There were no statistically significant differences between the groups in terms of: their age, their educational status, or their Instrumental Activities of Daily Living scores (i.e. their instrumental dependency). The results indicated that 39% of Holocaust Survivors met 'all six' PTSD criteria compared to 12% of the Immigrant Refugees and 4% of the Non-Refugees, and the differences were statistically significant. The study did not directly compare the MMSE score of those with and without PTSD nor does it appear that this risk factor was controlled for in the analysis, which found small but statistically significant differences between the Mini-Mental State Examination (MMSE) score for Holocaust Survivors and Non-Refugees. Although these results might indicate a lower level of cognitive function among Holocaust Survivors, the authors cautioned that there is no way of knowing how representative the participants were of the wider populations from which they were drawn. The authors noted that 'selective attrition through institutionalization or death could have the effect of underestimating the true prevalence of morbidity in the survivors' (Joffe et al., 2003).

In 2003 Wilson and his associates published an article that examined the relationship between psychological distress (as distinct from PTSD) and the development of Alzheimer's disease (AD). According to these authors there was evidence that people differ in their tendency to experience psychological distress in reaction to stressful events - a tendency that can be assessed with self-report scales, and is quite stable throughout adulthood. It is, therefore, an indicator of the 'cumulative level of

psychological distress experienced across the lifespan.' The authors investigated the relationship between a measure of distress proneness and risk of AD in older Catholic nuns, priests, and brothers participating in a longitudinal 'clinico-pathologic study of aging and AD' in the United States. According to the authors their results suggested that chronic psychological distress is a risk factor for AD (Wilson et al., 2003). Rothman and Mattson (2010) reported on two further studies undertaken by Wilson and colleagues published in 2006 and 2007 (Wilson et al., 2006; Wilson et al., 2007) which indicated that patients with a high level of distress proneness were 2.7 times more likely to develop AD than those not prone to distress, and that the distress proneness was also associated with a more rapid progression of the disease (Rothman & Mattson, 2010).

In a study of 1,271 Greek elders, Tsolaki et al (2010) found that those individuals who experienced a stressful event or situation (short or long lasting) of significant severity, though not necessarily PTSD, were subsequently at higher risk of being diagnosed with AD. They concluded that this indicated significant neurological similarities exist between PTSD and dementia (eg hippocampal vulnerability, initial symptoms of memory problems, and increased glucocorticoid levels) and that an epidemiologic relationship exists between PTSD or experiencing traumatic events and the development of dementia (Tsolaki et al, 2010).

Two large scale epidemiological studies undertaken in the US and published in 2010 highlighted this relationship. In the Qureshi et al study, 10,481 veterans 65 years of age and older who had a diagnosis of PTSD or who were recipients of a Purple Heart, and a comparison group in the same age range with no PTSD diagnosis or Purple Heart, were divided into four groups: (i) PTSD + Purple Heart; (ii) No PTSD + No Purple Heart; (iii) PTSD + No Purple Heart; and (iv) No PTSD + Purple Heart. The group of veterans with PTSD + No Purple Heart had a significantly higher incidence and prevalence of dementia – approximately two times as high – as the groups without PTSD (with or without a Purple Heart). There were no statistically significant differences between the other groups. (Qureshi et al., 2010) The study by Yaffe et al (2010) included 181,093 predominantly male veterans 55 years and older from 1997 through 2000. Veterans diagnosed with PTSD were at nearly twice the risk of developing dementia compared to those without PTSD (Yaffe et al., 2010).

Finally, a study by Ravona-Springer et al (2011) found that participants who were exposed to the Holocaust and to concentration camps during late adolescence or adulthood and lived until 1999/2000 were not at increased risk for dementia in late life compared to other victims of the Holocaust. There was no significant increased risk for dementia among Holocaust survivors compared to those who did not experience the Holocaust. PTSD and depression were not assessed in the study. However, anxiety and socio-economic status (SES), two other possible mediators between life exposures and dementia at old age were measured during midlife. Concentration camp survivors exhibited more anxiety in midlife and were more likely to be of lower SES compared to other Holocaust survivors and to people who emigrated from Europe prior to 1939. But they were not at higher risk for dementia in late life even after controlling for these factors (Ravona-Springer et al., 2011).

As Zhou and Chu (2011) pointed out, correlation even post hoc does not equal causation. But a large number of consistent studies lead to the conclusion that a relationship is likely to exist between PTSD and dementia and that further studies are needed to understand the relationships further, including the causal mechanisms (Zhou & Chu, 2011). According to Sorrell (2011), researchers in both the US epidemiological studies noted that it was not clear if having PTSD increases the risk for dementia in older veterans or whether recurring PTSD is an early symptom of dementia (Sorrell & Durham, 2011).

## **Dementia and Cognitive Decline as a trigger for PTSD symptoms**

If there is some causal link between dementia, cognitive decline and PTSD, it is possible that a third factor is related to both conditions and causes some increased vulnerability to both. In that case there could be early cognitive decline that increases vulnerability to developing PTSD. There is considerable variability in the way PTSD is experienced, as well as large individual differences in the way dementia develops. As our understanding about prevention of dementia increases, there is more evidence that precursors to dementia can be found well before a definitive diagnosis is made. However few studies have examined the life course of cognitive functioning and its relationship to PTSD. It has been estimated that just under three quarters (74%) of people with PTSD will experience symptoms for at least six months or more, with an estimated median time to remission of 24.9 months after the traumatic event. However, for some, PTSD symptoms follow a chronic course that can last for many years and which can be characterized by periods of remission and relapse. There are reports in the literature of sufferers who have long periods, up to several decades, without distress only to experience an emergence of PTSD symptoms in later life (Hiskey et al., 2008).

Hiskey et al (2008) reviewed the literature for evidence of PTSD that emerges in older adulthood but is related to earlier life events. They searched for English-language peer-reviewed published literature on PTSD (date range 1980-2005). Search terms included PTSD, and PTSD in conjunction with 'reactivated, reactivation, recurrent, delayed and elderly and old age and later life'. Thirty-two eligible articles were identified: 10 systematic surveys, 22 illustrative case studies or vignettes describing the phenomenon. However, only 16 studies (50%) fulfilled both methodological criteria and three quarters (12) of these were case reports (the other four were surveys) (Hiskey et al., 2008).

Of the 12 case studies, in only three of them was the triggering event related to neurological conditions: neurological illnesses (n=2), cognitive decline (n=3), medical conditions affecting cognition, dementia, or stress (n=15). Dementia or cognitive decline was not mentioned as a trigger for the re-emergence of PTSD symptoms in the two surveys that investigated this issue (Hiskey et al., 2008). Therefore Hiskey's review provided little evidence for a link between cognitive functioning and PTSD.

In 2011, Paratz and Katz stated that 'previously high-functioning Holocaust survivors may become "uncontrollable and highly disruptive following the onset of neurologic illness" (Paratz & Katz, 2011). This statement was based on a case study by Grossman et al (2004)(Grossman et al., 2004) with n=2 which was included in the Hiskey (2008) literature review and in which the triggering event for both was a neurological illness (Hiskey et al., 2008).

## **PTSD and BPSD**

Few studies have considered whether a history of PTSD alters how dementia is manifested in old age. Carlson et al (2008) reported on a study of veterans and aggression, which indicated that those with PTSD symptoms also exhibited more aggression in dementia. A number of studies indicated that aggression is common in elderly persons with dementia, and that it may be more common among those people with PTSD histories. Studies indicated that risk factors for aggression in the elderly include neurological disease, cognitive impairment and male gender. These findings were consistent with the hypothesis that PTSD symptoms can contribute to aggressive behaviours in the elderly, as found in medically ill and cognitively impaired patients in a Veterans' Affairs long-term care facility in the US (Carlson et al., 2008).

Verma et al (2001) analysed a group of 32 patients with dementia of whom 16 had PTSD. They hypothesised that people with PTSD and dementia would exhibit more agitation and disinhibition than people without PTSD, but did not find significant differences between the two groups. A small sub-

group of former prisoners of war had more paranoia and less verbal agitation than other patients. Apart from anti-depressant use, which was higher in the group with PTSD, there were no other differences between the groups (Verma et al., 2001) .

### ***Covariates of the BPSD Factors***

No literature was located that looked at the impact of PTSD on BPSD, however the study by Proitsi et al study (2011) contained modeling of the impact of MMSE score, gender, disease duration age/age of onset and location from which participants were drawn (site) on the four BPSD factors. They found statistically significant effects for the following factors:

- Psychosis - MMSE, female gender, age/age of onset
- Agitation - male gender, disease duration, age /age of onset, site, psychosis factor and moods factor
- Moods - MMSE age/age of onset, psychosis factor
- Behavioural Dyscontrol - MMSE, site, psychosis factor, agitation factor (Proitsi et al., 2011)

### **Summary**

Apart from secondary data set analyses of large data bases held by Veteran Affairs in the US, other literature about the relationship between PTSD and dementia has provided scant but supportive evidence of a relationship. People exposed to trauma and psychological distress do appear more likely to develop dementia, and the manifestation of dementia is altered. However more evidence is needed to clarify the relationships uncovered in previous studies.



### **3 AIMS OF THE RESEARCH**

The aims of this project were to describe BPSD in a group of veterans, and compare symptoms with non-veterans. It was designed to answer the research questions:

- a) What is the profile of BPSD in veterans?
- b) Is the profile of BPSD different in veterans and non-veterans?
- c) Is the profile of BPSD different in veterans with PTSD and veterans without PTSD?

### **4 METHODOLOGY**

#### **Design**

The research questions were addressed by conducting a survey of case managers and family carers of veterans, to supplement an existing data base. The 'EACHD Evaluation' survey had been undertaken previously and permission was obtained to re-analyse the data. 'The Impact of War Experiences on Dementia – Case Managers Survey' was undertaken as a partial replication of the 'EACHD evaluation' survey and data were combined with the first survey. 'The Impact of War Experiences on Dementia – Carers Survey' was a survey to gather judgments of carers about veteran PTSD and provided supplementary information about PTSD which was not collected in the other two surveys.

#### **Data Sources**

##### ***EACHD Evaluation Survey***

The EACHD Evaluation survey was conducted in 2008 and included a survey of case managers of people receiving Extended Aged Care at Home – Dementia (EACHD) packages about the physical and mental health of care recipients. The Australian Department of Health and Ageing gave permission for these data to be re-analysed to examine differences between veterans and non-veterans in the frequency and severity of the symptoms of BPSD.

##### ***Impact of War Experiences on Dementia - Case Managers survey***

Case managers were asked to complete a questionnaire about the physical and mental status of each veteran whose carer had provided permission and a survey, so that case managers completed information about the veteran's functional and instrumental dependency, dementia status, and behavioural and psychological symptoms of dementia. Case managers were given a guide to completion of the questionnaire and support from the project office if required. Completed questionnaires were mailed back to the project office in reply paid envelopes provided. Each case manager only had a small number of veterans among their clients, so data collection burden was not high.

##### ***Impact of War Experiences on Dementia – Carers Survey***

This survey was designed to collect information about veterans' war service, PTSD and BPSD. Service providers were sent a letter inviting them to participate in the study. If they agreed, case managers employed by the service then identified veterans in receipt of their services and passed a project pack consisting of letter from DVA, information sheet, questionnaire and reply paid envelope to the carer of the veteran. When a completed carer questionnaire was received at the research project office, the

case manager was contacted and asked to complete a companion questionnaire and also return it to the project office.

## **Measures**

### ***BPSD***

#### **Cohen Mansfield Agitation Inventory (CMAI) (Case Manager Questionnaire)**

BPSD were measured using the Cohen Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1991). The purpose of the CMAI is to assess the frequency of agitated behaviour in the elderly. This scale has been shown to have good internal and inter-rater reliability and validity. It is available in a seven different forms, including community versions and residential care versions. In this study a 37 item community version was used. We adapted the questionnaire by adding a question about how much of a problem each symptom was for the carer. The CMAI can provide information at a number of levels – the overall level of agitation, being the sum of frequencies of 37 behaviours, although this sum is not considered clinically meaningful (Cohen-Mansfield, 1991); four subscales cover BPSD in the areas of verbal agitation, verbal aggression, physical agitation and physical aggression ; and the frequency of individual behaviours can be examined. For each behaviour, the rater indicates how frequently the behaviour occurred during a two week period, scored on a seven point frequency scale from the symptom never occurring to occurring several times an hour.

The Cohen Mansfield Agitation Inventory data were used to compare BPSD in the veterans and non-veterans study (research questions (a) and (b) above).

#### **BPSD Checklist (Carer questionnaire)**

Family carers were also asked about veterans' BPSD. The BPSD Checklist is a 14 item checklist for non-cognitive symptoms of dementia, each scored from 1 to 4 and completed by a family caregiver. This checklist has been shown to have high internal consistency, reliability and good criterion and construct validity. Two items are reverse scored before total BPSD scores are calculated by summing the scores on each of the 14 items. Total scores range from 4 to 56 and higher total scores indicate greater frequency of non-cognitive disturbance associated with dementia (Snellgrove & Hecker, 2005).

The BPSD Checklist data were used to answer research question (c) above.

### ***PTSD***

One methodological difficulty we encountered in studying the relationship between PTSD and BPSD was that it was hard to identify research participants in Australia with definitive diagnoses of both PTSD and dementia. Older veterans with dementia may not have a formal diagnosis of PTSD as many veterans of earlier conflicts had no formal diagnosis. Younger veterans with a formal diagnosis of PTSD may not yet be showing symptoms of dementia as the incidence of dementia in people under 65 is very small (approximately 1 percent).

Because of these ascertainment difficulties, we used proxy measures to study veterans compared to non-veterans, assuming that the war-time experiences of veterans will have lead to a greater likelihood of undiagnosed or diagnosed PTSD in that group than in the civilian group, and to attempt to estimate PTSD in veterans with cognitive impairment on the basis of family observations.

We based this approach on evidence that proxy views can give legitimate though not perfect insight into PTSD (Gallagher et al, 1998). We used two scales to determine the level of post-traumatic stress symptoms: the Posttraumatic Stress Screen for the Cognitively Impaired Observer Version (PTSS-CI-OV; Carlson et al., 2008) and the Partner PTSD Checklist (PCL-P; Gallagher et al., 1998).

- PTSS-CI-OV

This scale has been designed specifically to measure PTSD symptoms in people with cognitive impairment, and is a version suitable for completion by an observer. The observer version is completed by a family member or health worker who rates each item based on observations over one week. It contains eight items that represent DSM-IV reexperiencing, avoidance and hyperarousal symptoms described in very simple language.

Re-experiencing Symptoms

B1- having memories of terrible things that happened in the past

B2 having nightmares

Avoidance Symptoms

C1 trying to avoid reminders of terrible things that happened in the past

Hyper-arousal Symptoms

D1 restless sleep

D2 feeling angry or irritable

D4 feeling jumpy or nervous

D5 getting upset by sudden noises,  
being surprised by someone coming up behind you.

PTSS scores are obtained by summing scores on each of the eight items (Carlson et al., 2008).

We asked carers for their perceptions of PTSS before the onset of dementia, and then again their perceptions of current symptoms, after the onset of dementia.

- PCL-P

This checklist is based on the PTSD Checklist-Military (PCL-M). The 17 items contained in the PCL-P are nearly identical to the PCL-M, with minor working changes that ask partners to rate the extent to which veterans were bothered by each symptom during the previous month. As with the PCL-M a score of 3 or greater determines the symptom presence (Gallagher et al., 1998).

The PCL can be scored in different ways. A total symptom severity score (range = 17-85) can be obtained by summing the scores from each of the 17 items. A diagnosis can be made by:

1. Determining whether an individual meets DSM-IV symptom criteria, i.e., at least one B item (questions 1-5), three C items (questions 6-12), and at least two D items (questions 13-17) are checked. Symptoms rated as "Moderate" or above (responses 3 through 5) are counted as present.
2. Determining whether the total severity score exceeds a given cut point.
3. Combining methods (1) and (2) to ensure that an individual has sufficient severity as well as the necessary pattern of symptoms required by the DSM.

Scrutiny of the data indicated that using the cutoff US Veterans' Affairs PTSD specialty mental health clinic for screening of a score of 48 was most suitable for the data and maximized the detection of possible cases.<sup>1</sup>

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<sup>1</sup> <http://www.ptsd.va.gov/professional/pages/assessments/ptsd-checklist.asp>

## ***Other Measures***

Other measures included measures of functional dependency (Barthel Index) and instrumental dependency (OARS). The Barthel Index is a well-known scale designed to measure functional dependency through assessment of Activities of Daily Living in a series of questions with ordinal item responses (Mahoney et al, 1965). Ten questions describe activities of daily living and mobility. A higher score indicates greater independence. The OARS scale measures instrumental independence and again a higher score indicates greater independence in instrumental activities of daily living such as use of the telephone (Fillenbaum, 1978). To describe dementia severity, case managers were asked to provide scores if available in existing records for the Mini-Mental State Exam (MMSE; Folstein et al, 1975) and to estimate dementia severity using the Global Deterioration Scale (Reisberg et al, 1982). In addition, psychotropic medication use, war service details and demographics were collected (see Appendices 5 and 6 for copies of questionnaires).

## **Sample**

A list of all community service providers managing EACHD, CACP and EACH packages throughout Australia was used to recruit community providers into the study. Providers would then act as third party recruiters to invite community care recipients into the study. Veterans in receipt of community care packages were targeted in order to match the existing data set that had been a sample of people with dementia using EACHD services. Selection criteria for participants were:

- Veterans (any service, any war) receiving community care services in Australia from a list of community care providers;
- Case manager available to complete survey
- Family carer available to complete survey
- Diagnosis or clinical indication of dementia as judged by the case manager of the client
- Over 60 years

Exclusion criteria for veteran status, as described to service providers, were:

- Widows or dependants of veterans

Selection criteria for participants in the family carer survey were:

- Primary carer of the veteran
- Able to complete the survey in English

## **Recruitment Method**

Third party recruitment was employed for the study to replicate methods used in the EACHD Evaluation survey and to comply with privacy guidelines from the DVA Human Research Ethics Committee. Community service providers were sent a letter or email inviting them to participate in the study (see Appendix 2 for a listing of service providers approached to participate in the study). If the service provider agreed to participate, any additional ethics approvals were obtained. Then case managers employed by the service identified veterans in receipt of EACHD or other community care packages and passed a project pack to the carer of the veteran.

The researchers kept a list of questionnaire research numbers distributed to each service. Case managers retained an identification code sheet that linked research numbers with client names so that when the researchers contacted them with a research number, they were able to complete a questionnaire for the corresponding client. Carers completed the questionnaire and mailed it directly to the researchers using the reply paid envelopes that were provided. When a completed carer questionnaire was received at the project office, the case manager for the veteran was contacted and

asked to complete a companion questionnaire and return it to the researchers. This method had been used successfully in studies by the researchers previously.

## **Barriers to recruitment**

### **(i) Third party recruitment**

Not contacting veterans and family carers directly, and contacting them via community service providers proved a barrier to recruitment that caused considerable delays to fieldwork. The intention initially was to seek permission to send information about the study to the most appropriate person by post or email. After permission was given and the information was sent then a follow-up phone call was made around one week later. In some cases it took several follow-up calls to service providers, often spread over six or more weeks, to secure an answer about participation. This situation arose in some service providers because the information had not gone to the appropriate person in the first place and had to be resent. In other cases the appropriate person was on leave or busy over an extended period of time. At this stage some organisations said immediately that they were either not interested in participating or unable to do so because their clients did not include any eligible veterans. Six organisations did not offer any reason for declining. Others cited the press of business activity at that particular time or being in the middle of a restructuring process as reasons for delays. In several cases they simply failed to respond to follow-up telephone calls/emails so that after around eight weeks it was assumed that the organisation was not interested.

### **(ii) Identification of veterans**

The identification of eligible veterans within their client base posed problems for some organisations. Data systems do not necessarily allow the ready identification of veterans among DVA beneficiaries or the identification of veterans with dementia. This tended to lead to a dramatic overestimation of their number of eligible veterans on the part of some organisations.

### **(iii) Size of organisation**

It was notable that, overall, the smaller organisations made a decision to participate one way or the other, fairly quickly. When a smaller organisation did decide to participate, the decision was also implemented quickly. With the larger organisations the decision to participate or not, was, in some cases, made several months after the initial contact. Sometimes interest in participating was expressed soon after contact but the process of returning the consent form and allocating responsibility to someone within the organisation for implementing participation was, in general, prolonged over an extended period of time, in some cases as much as six months.

In some cases the delivery of information regarding the study was followed by as much as four months of delay while this information was sent around the organisation to the appropriate person. That person then had to take steps to find out the likely number of eligible veterans and which section of the organisation provided the service to those veterans. When delays of this nature were combined with delays in speaking to the organisation's contact person because of absences arising from illness or annual leave, it was not unusual for a period of 3-4 months to elapse between the initial contact with the organisation and their agreement to participate in principle and the implementation of participation. In other cases this process dragged along until it became clear that it was not going to come to any useful end. In some cases the person engaged in negotiating the organisation's participation depended on information regarding eligible veterans provided by managers in outlying service provision centres. This process of internal communication took a month or more in some cases, and in others the absence of the cooperation that was required curtailed implementation of the decision to participate.

**(iv) Competing priorities within organisations**

In some cases an organisation's participation was delayed for an extended period by processes of restructuring, merging or other form of internal upheaval. Some organisations agreed readily to participate in the study but implementation was delayed for some months because of factors such as these. In many cases participation in research was not a high priority for service organisations.

**(v) Extra ethics approvals**

Delay also arose from the requirement that the study be submitted for approval by organisational Ethics Committees despite ethics approval already secured by the researchers. Six organisations made this requirement. At best this extra requirement for external ethics approval delayed participation by as much as six months. At worst it meant that when organisations followed their ethics protocol it was only after a lengthy delay and investment of project resources that the organisation addressed the issue of whether it had any eligible veterans amongst its clients. Only one organisation established that it did not have any eligible veterans amongst its clients before requiring researchers to embark on the organisational ethics process. In another case the financial cost of undergoing the organisation's ethics process led researchers to decide against inviting this organisation to participate in the study. A further delaying factor associated with the requirement to go through organisational ethics processes was that the acknowledgement of approval was not linked to information regarding contact within the organisation to get the participation process underway. It was up to the project coordinator to make whatever enquiries were necessary to do this.

## Response Rates

As reported in the progress report for the study and as shown above, considerable efforts were made to recruit participants, but disappointingly few veterans were recruited. While response rates at the service provider level were good and community service providers were interested in the study, a substantial number of providers reported that they had no veterans among their clients during the study period. Appendix 1 shows providers that agreed to participate in the study, and Appendix 2 shows a list of service providers approached to participate in the study. As shown in Table 1, of 103 service providers contacted, 66 (64%) agreed to participate in the study. However of those, over half (56%) indicated that they had no veteran clients during the study period.

**Table 1 Response rates**

Response rates	N	%
Community Service Provider level		
Agreed to participate and had veteran clients during study period	29	28%
Agreed to participate but no veterans during study period	37	36%
Declined to participate	37	36%
Total providers agreed to participate	66	64%
Total community service providers invited to participate	103	100%
Carer/veteran level		
Total responses	26	23%
Total veterans and carers invited to participate (estimate)	115	100%

An estimate was made of the response rates among veterans as in most cases an accurate figure for the number of veterans receiving community care was not available. Among those providers that agreed to participate, an estimated 115 veterans were identified as potential participants (see Appendix 1). At the time of writing, 26 responses were received from carers and the veterans' case managers, a response rate of 23 percent. This was lower than the response rate from carers in the EACHD survey, when a 50% response rate was secured with similar third party recruitment. It was not clear why a lower response rate was achieved in this project despite the best efforts of the project team. We can speculate that it was a combination of inaccurate estimates of the number of veterans available; numbers not being accurately ascertained by case managers; case managers not being sufficiently motivated to invite all eligible clients to participate in the study; family carers being unwilling to participate in the study because of perceived burden of completion of the questionnaire or inadequate understanding of the study or stress.

## Defining Veteran Status

In consultation with the Department of Veterans' Affairs, veterans were classified as those males with gold, white or orange cards or other DVA entitlements, plus females with either white or orange cards. Females with gold cards were classified as non-veterans, as 99% of those survey respondents have been found in previous studies to be dependants of veterans (widows or other dependants) and so would not be considered veterans for the purposes of this analysis (AIHW, 2006). Veterans of any war were considered eligible to enter the study, including those veterans who served in overseas forces. Where there was uncertainty on the part of service providers about veteran status, the client was invited to participate.

To ensure, as far as possible, that the veteran group contained only those veterans who had served at war and not their widows or widowers, the participants were classified according to their DVA entitlement and gender (see Table 2). This resulted in a combined data set containing 48 veterans and 298 non-veterans. However in subsequent discussion with DVA, it was considered that the eight females categorised as veterans because they had a White Card, Orange card or other DVA entitlement would not have seen active war service overseas, so they were excluded from the main analyses. The results presented here therefore concentrated on a comparison of male veterans with male non-veterans (shaded in yellow in Table 2), substantially reducing the non-veteran sample available for comparison. Thirty-six participants could not be classified due to missing data.

**Table 2 Classification of veterans and non-veterans**

<b>Veterans</b>			
Male	Gold card + White card + Orange card or other DVA entitlement	40	
Female	White Card + Orange card or other DVA entitlement	8	
Sub-Total Veterans			48
<b>Non-Veterans</b>			
Male	No DVA entitlement	96	
Female	Gold card + No DVA entitlement	202	
Sub-Total Non-Veterans			298
<b>Missing Data</b>			36
<b>Total</b>			<b>382</b>

## Analysis

A list of variables that were available to analyse is shown in Appendix 3. The analysis presented here provides descriptive statistics on the main variables (means, standard deviations). In addition, the difference between veterans and non-veterans on sub-scales of the CMAI was tested statistically. For the first research question, the main comparisons of interest were the difference between veterans and non-veterans on subscales of the CMAI, and then on individual symptoms of the CMAI. For the second research question, the main comparison of interest was the difference between veterans with PTSD and veterans without PTSD on the BPSD Checklist.

CMAI subscales that formed quasi-interval level data were analyzed through the use of t-tests in bivariate analysis. To test for the effects of confounding on differences between veterans and non-veterans in subscale scores, a multiple regression analysis was performed based on stepwise addition of other variables with independent effects on subscale scores. An 'a priori' exclusion rule of  $p > 0.20$  was adhered to, and an iterative process was used to add the main effects of the variables one at a time to the regression models. The variables that were added to the models were:

- Veteran status (0=non-veteran, 1=veteran)
- Age
- Living arrangements (0 = lives alone, 1 = lives with family or others)
- Psychotropic medication (0= not taking psychotropic medication, 1 = taking psychotropic medication)
- Modified Barthel Index of functional dependency
- OARS measure of instrumental dependency
- Score on the Global Deterioration Scale (0 = moderate, mild, very mild, no deterioration, 1 = Very severe, severe, moderately severe deterioration).

Un-standardized and standardized coefficients, t-values and significance levels are reported as well as R square values (and their significance) for the whole model.

CMAI individual items based on ordinal data were analyzed using the Mann Whitney U test. Mean ranks in veterans and non-veterans are also reported.

## Ethics Approval

Ethics approval for the DVA Study was received from the Department of Veterans Affairs HREC (Ref E010/006) and registered by the University of Melbourne HREC (ID 1034119). Where service providers requested a formal ethics application to their HREC before considering participation in the research, this was also undertaken. Ethics applications were prepared and obtained for: Uniting Care (Qld), Goulburn Valley Health, Silver Chain, Uniting Care NSW.ACT, Spiritus.



## 5 Results - characteristics of male veterans and male non-veterans

All results presented here apply to male participants only.

### **Demographic profile**

Once the two surveys were combined, data from a total sample of 136 men living with dementia and receiving community care services were available to analyze. Participants in the study were drawn from all states and territories apart from the ACT. Of 133 participants whose location was provided: 54% percent of veterans and non-veterans were located in New South Wales and Victoria, 33%-37% were located in Queensland and South Australia and 8%-13% were located in Western Australia and Tasmania. Most of the participants for the DVA survey were from Victoria (Appendix 4 Table 4c).

As has been found in other comparative surveys, there were some demographic differences between veterans and non-veterans. Among the total sample of 130 participants whose age was provided, the average age was 81 years (95% CI 80.6 – 82.3) but veterans were older on average than non-veterans, and male veterans were significantly older than male non-veterans ( $t=-6.80$ ,  $p<0.01$ ). Compared to non-veterans, veterans were more likely to be male, to be born in Australia, and to speak English at home. There were no statistically significant differences between the veterans and non-veterans groups in terms of whether or not they were Aboriginal or Torres Strait Islander, their living and carer arrangements, or their source of income. Of the veterans, over two-thirds (69%) had a Gold Card DVA entitlement (see Table 3).

**Table 3 Demographic profile for sample of male non-veterans and male veterans**

	MALE NON-VETERANS			MALE VETERANS			t test
	N	Mean (SD)		N	Mean (SD)		p value
Age	90	77.8 (8.1)		40	85.7 (5.0)		0.000
	Total <sup>4</sup>	N	Percent <sup>3</sup>	Total <sup>4</sup>	N	Percent <sup>3</sup>	p value <sup>1</sup>
ATSI	96	2	2%	39	1	3%	0.644
Born in Australia	96	45	47%	40	37	93%	0.000
Speaks English at home	96	79	82%	39	39	100%	0.002
Income	96			38			
Govt Pension		79	82%		33	87%	0.456
Private Income		15	16%		5	13%	
Both		2	2%		0	0%	
Lives alone	96	18	19%	39	14	36%	0.031
Carer (Yes)	96	89	93%	40	37	93%	0.608
Co- Resident Carer	89	77	87%	37	24	65%	0.007
Veterans' DVA Entitlement				40			
Gold Card					33	83%	
White Card					5	13%	
Orange Card or Other <sup>2</sup>					2	5%	

- Notes: 1 Fisher's Exact Test  
 2 Includes Orange Card or other entitlement;  
 3 Percentages may not sum to 100% due to rounding  
 4 Missing data means total  $\neq$  96 non-veterans and 40 veterans

### Dependency Profile

There were no statistically significant differences between the veterans and non-veterans in terms of their functional dependence as measured by Barthel Index overall scores (t-test  $p=0.255$ ; see Table 4) or their instrumental dependence as measured by OARS scores (t-test  $p=0.386$ ; see Table 6). Table 5 shows the range of categories of severity of dependency, indicating that most participants were at least moderately dependent.

**Table 4 Functional Dependency: male veterans and non-veterans**

Barthel Index scores	N <sup>1</sup>	Mean (SD) <sup>2</sup>
Non-Veterans	93	58.2 (24.5)
Veterans	38	63.8 (28.6)

Notes: 1 Missing data means N<sub>r</sub> ≠ 96 non-veterans and 40 veterans;  
2 t-test  $p=0.25$

**Table 5 Severity of functional dependency: male veterans and non-veterans**

Barthel Index categories	MALE NON-VETERANS		MALE VETERANS	
	N <sup>1</sup>	Percent	N <sup>1</sup>	Percent
Total Dependency	9	10%	4	10%
Severe	24	26%	5	22%
Moderate	32	34%	13	34%
Mild	21	23%	8	22%
Minimal dependence - fully independent	7	8%	8	12%
Total	93	100%	38	100%

Notes: 1 Missing data means N ≠ 96 non-veterans and 40 veterans

**Table 6 Instrumental Dependency: male veterans and non-veterans**

OARS scores	N <sup>1</sup>	Mean (SD)
Non-Veterans	87	3.2 (2.1)
Veterans	38	3.6 (2.5)

Notes: 1 Missing data means N ≠ 96 non-veterans and 40 veterans

### ***Dementia diagnosis and severity***

- Just over two thirds of participants (69%) had a formal diagnosis of dementia. There were no statistically significant differences between the groups in terms of their diagnostic status (chi squ = 4.443, df=2, p=0.108; see table 7).
- A wide range of diagnoses were identified for veterans and non-veterans (see Table 8).
- An MMSE score was available for 48 (35%) of the male participants. On average participants' MMSE score was in the moderate to severe range, with no statistical difference between veterans and non-veterans (chi sq = 0.415, df=1, p=0.519; see Table 9).
- Global Deterioration Scale ratings were available for 124 participants. Approximately one third of participants had ratings of 'very severe or severe' dementia, one third 'moderately severe' and one third less impaired. Again there were no statistically significant differences between the ratings for veterans and non-veterans (chi sq=0.71, df=3, p=0.87; Table 10 ).

**Table 7 Dementia diagnosis status: male veterans and non-veterans**

	MALE NON-VETERANS		MALE VETERANS	
	N <sup>1</sup>	Percent	Number	Percent
Formal diagnosis	75	79%	28	70%
Informal diagnosis	17	18%	7	18%
No diagnosis	3	3%	5	13%
Total	95	100%	40	100%

Notes: 1 Missing data means Total ≠ 96 non-veterans and 40 veterans

**Table 8 Type of dementia for those with a formal or informal diagnosis: male veterans and non-veterans**

	MALE NON-VETERANS		MALE VETERANS	
	N <sup>1</sup>	Percent <sup>2</sup>	N <sup>1</sup>	Percent <sup>2</sup>
Alzheimer's disease only	34	37%	9	26%
Unspecified / Unknown	23	25%	15	44%
Other <sup>3</sup>	34	37%	10	29%
Total	91	100%	34	100%

Notes: 1 Missing data means Total ≠ 96 non-veterans and 40 veterans

2 Percentages do not sum to 100% due to rounding

3 Other includes: Vascular dementia (14); Lewy Body dementia (8); Dementia in Parkinson's disease (7); Other dementia type (3); Alzheimer's disease and Vascular dementia (3); Mixed dementia (2); Dementia in alcohol abuse (2); Frontal lobe dementia (1); Dementia in Creutzfeldt-Jakob disease (1); Vascular dementia and dementia in alcohol abuse (1); Dementia of unspecified type and Alzheimer's dementia (1); Lewy Body Dementia and Dementia in Parkinson's Disease (1)

**Table 9 MMSE score: veterans and non-veterans: male veterans and non-veterans**

	N <sup>1</sup>	Mean (SD)
Non-Veterans	36	15.5 (6.8)
Veterans	12	17.9 (8.2)

Notes: 1 Missing data means N ≠ 96 non-veterans and 40 veterans

**Table 10 Global Deterioration Score ratings: male veterans and non-veterans**

	MALE NON-VETERANS		MALE VETERANS	
	N <sup>1</sup>	Percent	N <sup>1</sup>	Percent
Very severe or severe	30	33%	11	33%
Moderately severe	34	37%	12	36%
Moderate	20	22%	6	18%
Mild, very mild, none	7	8%	4	12%
Total	91	100%	33	100%

Notes: 1 Missing data means Total N ≠ 96 non-veterans and 40 veterans

***Psychotropic medication use***

- Male veterans were less likely to be taking psychotropic medication than non-veterans although the numbers were very small (35% vs 53%; Chi sq = 3.718, df = 1, p = 0.054; see Table 11). Table 12 shows the type of psychotropic medications taken by each group.
- Compared to non-veterans, veterans were less likely to be taking anti-psychotics, anti-anxiety, anti-depressant and anti-dementia medication (see Table 12).

**Table 11 Participants taking psychotropic medication: male veterans and non-veterans**

	MALE NON-VETERANS		MALE VETERANS	
	N	Percent	N	Percent
Not Taking/don't know <sup>1</sup>	45	47%	26	65%
Taking	51	53%	14	35%
Total	96	100%	40	100%

Notes: 1 Missing data assumed to be not taking psychotropic medication

**Table 12 Type of psychotropic medication**

	MALE NON-VETERANS		MALE VETERANS	
	N <sup>1</sup>	Percent (N=96)	N <sup>1</sup>	Percent (N=40)
Antipsychotics	28	29%	7	17%
Antianxiety	11	11%	1	2%
Hypnotics/Sedatives	10	10%	3	7%
Antidepressants	21	22%	2	5%
Anti-dementia	22	23%	5	12%

Notes: 1 Multiple responses allowed for these medications

## Results - profile of BPSD in veterans and non-veterans

The research questions being considered in this research were:

- a) What is the profile of BPSD in veterans?
- b) Is the profile of BPSD different in veterans and non-veterans?
- c) Is the profile of BPSD different in veterans with PTSD and veterans without PTSD?

The subsection below considers research questions (a) and (b):

- What is the profile of BPSD in veterans and
- is the profile different in veterans and non-veterans?

### ***Behavioural and Psychological Symptoms of Dementia CMAI Overall and Subscale analyses***

- The research question of whether BPSD profiles were different among veterans than non-veterans was examined firstly by analyzing CMAI scores. The total CMAI score for level of agitation was not considered clinically meaningful when the scale was first developed (Cohen-Mansfield, 1991), although some studies have since used a cut-off point of scores over 14 to indicate excessive or significant behavioural agitation (eg Tractenberg et al., 2002) and some studies continue to report a total score.
- We elected to consider CMAI subscores alone as the clinical meaningfulness of the total score has not been firmly established.
- While mean sub-scale scores were higher for veterans on CMAI Verbal Agitation, Verbal Aggression, and Physical Aggression, none of the t-tests of differences between non-veterans and veterans subscale scores were statistically significant (see Table 13).

**Table 13 CMAI overall score and subscale scores for male non-veterans and veterans**

	MALE NON-VETERANS			MALE VETERANS			t-test p value
	N <sup>1</sup>	Mean	SD	N <sup>1</sup>	Mean	SD	
CMAI Overall Score (FreqCMAI.0a)	92	20.91	18.15	36	25.10	22.37	0.280
CMAI Verbal Agitation	95	8.63	0.91	39	10.96	7.15	0.112
CMAI Verbal Aggression	96	2.95	0.29	39	3.74	5.98	0.406
CMAI Physical Agitation	93	9.14	9.30	38	8.94	9.11	0.913
CMAI Physical Aggression	96	0.78	1.89	39	1.48	3.86	0.287
Other BPSD <sup>2</sup>	93	1.97	3.53	40	0.70	2.17	0.731

Notes: 1 Missing data means N ≠ 96 non-veterans and 40 veterans

2 Other BPSD symptoms were: ate or drank non-food substances; required prompting to undertake activities of daily living; had hallucinations;  
had delusions

The lack of t-test significance may have been because confounding factors were masking differences between non-veterans and veterans. Multiple regression analyses were undertaken to control for factors that were likely to affect CMAI scores on the subscales. The factors included in these exploratory analyses were:

- Veteran status (0=non-veteran, 1=veteran)
- Age

- Living arrangements (0 = lives alone, 1 = lives with family or others)
- Psychotropic medication (0= not taking psychotropic medication, 1 = taking psychotropic medication)
- Modified Barthel Index of functional dependency
- OARS measure of instrumental dependency
- Dementia Severity Score on the Global Deterioration Scale (0 = moderate, mild, very mild, no deterioration, 1 = Very severe, severe, moderately severe deterioration).

Tables 14 to 18 show the variables that increased the goodness of fit of the models (i.e. the R<sup>2</sup>). The model for verbal agitation was not statistically significant at p < 0.05 so the predictor variables listed above were not significantly related to the verbal agitation score. The R<sup>2</sup> was also very small. The models for verbal aggression, physical agitation, physical aggression and 'other BPSD' were statistically significant, indicating that the variables shown in Tables 15 to 18 were statistically significant predictors of verbal aggression, physical agitation, physical aggression and 'other BPSD'. The R<sup>2</sup> for verbal aggression was also very small. R<sup>2</sup>s for physical agitation and physical aggression were higher but not large.

As shown in Tables 14 and 15, the findings of the analyses in relation to the two verbal sub-scales were:

- While being a veteran was a significant predictor of verbal agitation (using an 'a priori' significance of 0.2), the overall model was not statistically significant indicating that this finding should not be emphasised.
- Being a veteran was also not a significant predictor of verbal aggression.
- Dementia severity (obal deterioration scale) was associated with higher verbal agitation scores.
- Higher dependency was associated with higher verbal aggression scores. Higher scores (less dependency) on the OARS were associated with lower verbal aggression scores. Higher scores on the Modified Barthel Index were associated with higher verbal aggression scores

**Table 14 Verbal agitation multivariate analysis**

Variable	Unstandardised β coefficient (SE)	Standardised β coefficient	t	Significance
Veteran status	2.6 (1.6)	0.15	1.6	0.109
Global Deterioration Scale	1.9 (1.5)	0.11	1.2	0.225

Notes: R<sup>2</sup>= 0.034, model not statistically significant (p = .129)

**Table 15 Verbal aggression multivariate analysis**

Variable	Unstandardised β coefficient (SE)	Standardised β coefficient	t	Significance
OARS	-0.80 (0.28)	-0.35	-2.9	0.005
Barthel	0.04 (0.02)	0.18	1.5	0.130

Notes: R<sup>2</sup>= 0.069, model statistically significant (p = 0.016)

As shown in Tables 16 and 17, the findings of the analyses in relation to the two physical subscales were:

- Both regression models were statistically significant.

- More severe dementia (measured on the Global Deterioration Scale) was associated with higher physical agitation scores. Taking psychotropic medication was associated with higher physical agitation scores. Living with family or others was associated with higher physical agitation scores.
- Veteran status was a significant predictor of physical aggression scores though the effect was less than for Dependency status (see below).
- Sociodemographics: Older age was associated with lower physical aggression scores
- Dependency Status: Higher scores on the Modified Barthel Index were associated with lower physical aggression scores.

**Table 16 Physical agitation multivariate analysis**

Variable	Unstandardised β coefficient (SE)	Standardised β coefficient	t	Significance
Global Deterioration Scale	5.3 (1.9)	0.26	2.9	0.005
Taking psychotropic medication	2.3 (1.7)	0.12	1.4	0.160
Living with family/others	2.6 (2.0)	0.12	1.3	0.200

Notes: R<sup>2</sup>= 0.121; model statistically significant (p = 0.002)

**Table 17 Physical aggression multivariate analysis**

Variable	Unstandardised β coefficient (SE)	Standardised β coefficient	t	Significance
Barthel	-0.03 (0.009)	-0.31	-3.6	0.000
Veteran status	1.18 (0.56)	0.20	2.1	0.037
Age	-0.04 (0.03)	-0.13	-1.3	0.190

Notes: R<sup>2</sup>= 0.127; model statistically significant (p = 0.001)

Finally, as shown in Table 18, higher functional dependency (Barthel scores) and older age were associated with lower other BPSD scores and a higher level of global deterioration was associated with higher other BPSD scores.

**Table 18 Other BPSD behaviours multivariate analysis**

Variable	Unstandardised β coefficient (SE)	Standardised β coefficient	t	Significance
Global Deterioration Scale	1.75 (0.85)	0.20	2.06	0.040
Barthel	-0.03 (0.015)	-0.20	-2.00	0.050
Age	-0.06 (0.04)	-0.13	-1.4	0.160

Notes: R<sup>2</sup>= 0.149; model statistically significant (p = 0.001)

### ***Behavioural and Psychological Symptoms of Dementia - CMAI Individual Symptom Analyses***

There were some differences in the rankings for veterans and non-veterans on the individual symptoms listed in the CMAI. As shown in Table 19 these differences were:

- Verbal Agitation: Veterans ranked higher than non-veterans on all the symptoms of verbal agitation but the differences only reached statistical significance (p<0.05) for repetitive sentences and complaining or whining symptoms.

- Verbal Aggression: Veterans ranked higher than non-veterans on five of the six symptoms of verbal aggression but the difference only reached statistical significance for the higher rankings on verbal sexual advances ( $p < 0.05$ ).
- Physical Agitation: Veterans ranked higher than non-veterans on seven of the nine symptoms of physical agitation but the difference only reached statistical significance for the higher ratings on physical sexual advances or exposed sexual parts ( $p < 0.05$ ).
- Physical Aggression: Veterans ranked higher on six and lower on seven of the symptoms of physical aggression. The only differences that reached statistical significance were veterans' higher rankings for throwing and grabbing things ( $p < 0.05$ ).
- Other BPSD: Veterans ranked higher on two and lower on two of the four symptoms of other BPSD but none of the differences in ranking reached statistical significance at  $p < 0.05$ .

**Table 19 Symptom differences between veterans and non-veterans**

	MALE NON-VETERANS		MALE VETERANS		Mann Whitney U
	N <sup>1</sup>	Mean Rank	N <sup>1</sup>	Mean Rank	statistical significance <sup>3</sup>
<b>Verbal agitation</b>					
Asked repetitive sentences or questions	89	58.79	36	73.42	0.024*
Made relevant verbal interruptions to conversations	91	62.23	39	73.13	0.050*
Made unrelated verbal interruptions to conversations	92	62.47	38	72.84	0.087
Complained or whined	93	63.17	38	72.93	0.044*
Made constant requests for attention or help (including nagging, pleading, calling out)	93	63.31	36	69.36	0.259
Was uncooperative or unwilling to participate (e.g. in personal care)	93	65.08	37	66.55	0.824
<b>Verbal aggression</b>					
Cursed or was verbally threatening or insulting	93	63.92	38	71.09	0.207
Was verbally bossy or pushy	95	67.06	38	66.86	0.970
Made strange noises	95	66.29	39	70.44	0.239
Screamed, shouted or howled	95	66.21	38	68.97	0.468
Had temper outbursts	92	63.53	38	70.26	0.214
Made verbal sexual advances	95	63.93	39	76.21	0.000* <sup>2</sup>
<b>Physical agitation</b>					
Was restless or fidgety, always moving around	91	65.32	39	65.91	0.927
Paced, aimlessly wandered	93	66.26	39	67.06	0.889
Was up at night	90	65.73	38	61.59	0.533
Tried to get out inappropriately	95	66.86	39	69.06	0.630
Dressed or undressed inappropriately	95	68.42	40	67.01	0.747
Exhibited repetitious mannerisms	94	65.63	39	70.31	0.383
Handled things inappropriately	93	63.91	37	69.50	0.274
Hid or hoarded things	95	65.78	39	71.69	0.253
Made physical sexual advances or exposed sexual parts	94	65.14	39	71.47	0.036*
<b>Physical aggression</b>					
Hit people, self or others	96	70.09	40	64.68	0.122
Kicked people or objects	96	68.41	39	67.00	0.366
Threw things	96	66.21	39	72.41	0.011*
Tore things or destroyed objects	96	67.15	39	70.10	0.256
Grabbed onto or clung to people	96	67.33	39	69.64	0.419



Grabbed or snatched things from others	96	66.22	39	72.37	0.011*
Pushed other people	96	67.11	40	71.84	0.159
Bit other people or things	96	68.50	40	68.50	1.000
Spat	96	68.71	40	68.00	0.519
Scratched people, self	96	69.13	40	67.00	0.260
Hurt self (burns, cuts etc)	96	68.21	40	69.19	0.529
Hurt others (burns, cuts etc)	96	68.50	40	68.50	1.000
Fell intentionally	96	68.92	40	67.50	0.360
<b>Other behaviours</b>					
Ate or drank non-food substances	96	67.89	40	69.97	0.283
Required prompting to undertake ADL	94	67.83	40	66.72	0.901
Had hallucinations	96	69.13	40	66.99	0.984
Had delusions	95	66.68	40	71.14	0.591

Notes: 1 Missing data means N ≠ 96 non-veterans and 40 veterans 2 rounded up very small number 0.0003 to 0.000 3 \* indicates statistically significant if p< or equal to 0.05

## Results - BPSD & PTSD in male veterans

This section addresses the third research question, is the profile of BPSD different in veterans with PTSD and veterans without PTSD?

- We analysed information on the small sample of male veterans who were recruited into the DVA study (N=26). The analysis excluded participants who were female (N=3). It included the 17 participants who were male and the eight for whom there were no data on gender but who have been assumed to be veterans as they had overseas war experience.
- We had more detail available about these veterans than veterans from the EACHD survey for whom there were no proxy measures of their post traumatic stress, war experiences or their war service. This information was combined with family carers' assessments of behavioural and psychological symptoms of dementia. This was based on the BPSD Checklist not the CMAI scale.

### ***Socio-demographic characteristics and war experience in veterans***

Of 25 veterans included in the analysis:

- Their average age was 87 years (min 70, max 92) and the average length of overseas service was 33 months (min 6, max 120) (see Table 20).
- Just over three quarters had served in World War II (WWII) and four had served in Vietnam (see Table 21).
- Just over half (57%) served in the Army and just over one third had served in the Air Force (35%) (see Table 22).
- Veterans served in a wide variety of locations and came from a variety of ranks (see Table 23).

**Table 20 Age and length of overseas service (males only)**

	Number	Minimum	Maximum	Mean	95% CI Mean	
Age (Years)	20	70	92	86.7	84.4	88.9
Overseas Service (Months)	22	36	120	33.4	20.9	46.9

**Table 21 War in which the veteran served (males only)**

	Frequency	Percent <sup>1</sup>
WWII	18	72%
Vietnam	3	8%
Korean, Malayan	2	8%
Other (Vietnam and Borneo)	1	4%
Missing Data	1	4%
Total	25	100%

1 = Percent of valid cases

**Table 22 Service in which the veteran served (males only)**

	Frequency	Percent
Army	14	53.8%
Air Force	8	30.8%
Navy	3	11.5%
Other (Army and Air Force)	1	3.8%
Total	26	100.0%

**Table 23 Location where the veteran served and rank (males only)**

WAR	SERVICE	OVERSEAS SERVICE	RANK
WWII	Army	Philippines, Port Moresby	Private
		New Guinea	Sapper
			Private
		Indonesia	
		North Africa, Germany as a prisoner for four and half years	Foot Soldier
		Syria, POW Java and Japan	Private
		Solomon Islands & PNG	Private
		New Guinea and Philippines	Lance Corporal
		New Guinea	Private First Class
	Navy	Asia	Leading Seaman
	Air Force	England, Europe	Warrant Officer 1
		England	From F/Lt to W/Cdr
			FI Lt
		Asia	
		Borneo - Pacific Islands	Leading Aircraftsman (LAC)
		New Guinea	Don't know
		England, Iceland, Egypt, Australia	L.A.C.
	Other	Coast Northern Territory	Private
Korean, Malayan	Navy	Korea	Petty Officer
		Tobruk	Petty Officer, Radio Communication
Vietnam	Army	Vietnam	Staff Sergeant
		Vietnam	Lt Colonel
	Air Force	Nuidat, Vietnam	Corporal
Other	Army	Vietnam, Borneo	Lieutenant Colonel

***Mental health diagnoses and pensions (male only)***

We asked carers to indicate whether the veteran had been diagnosed with PTSD, depression or anxiety, and also whether they received disability pensions for PTSD or TPI.

Among this group of veterans:

- Eight had been diagnosed with PTSD, 10 had been diagnosed with depression and 8 had been diagnosed with anxiety (see Table 24).
- Ten veterans had multiple diagnoses (see Table 24).
- One veteran had a disability pension for PTSD and four had TPI pensions – one of these for PTSD (see Table 25).

**Table 24 Diagnosis of PTSD, Depression or Anxiety**

	N	Percentage (N=26)
PTSD + Depression + Anxiety	5	19%
PTSD + Anxiety	3	12%
Depression + Anxiety	2	8%
Depression only	3	12%
Anxiety only	1	4%

**Table 25 Disability pensions**

	Total	N	Percent
Disability Pension for PTSD	26	1	4%
TPI Disability Pension	26	4	14%
Accepted Condition for TPI: Colitis, For knees that were 'blown up', PTSD, Missing data for one			

***PTSD survey scores***

**PCL-P measure of PTSD**

- Using the US Veterans Affairs Department screen cutoff of a score of 48, seven veterans met the screening criteria for PTSD and seventeen did not (see Table 21).

**Table 26 PTSD scores for those above and below the VA screening cutoff**

	N	Median	Mean	95% CI of Mean		Minimum	Maximum
PTSD	7	52.4	57.9	47.9	67.9	49.1	78.0
No PTSD	17	36.8	36.5	32.9	40.2	24.4	47.0

### PCL-P and PTSS

- The two measures (PCL-P and PTSS) of PTSD were significantly correlated. There were statistically significant correlations between the PTSD scores using the PTSS score before a diagnosis of dementia and after and between the current and previous PTSS scores (Table 27).
- The average PTSS scores of veterans with and without PTSD were different and the difference was statistically significant (Table 28).
- As shown in Table 29, there were no differences in PTSD scores for veterans whose PTSS scores had increased, decreased or not changed with the onset of dementia.

**Table 27 Correlation between PTSD and PTSS scores**

		PTSD Score	Current PTSS Score	Previous PTSS Score
PTSD Score	Pearson Correlation	1.000	.798**	.710**
	Spearman's rho		.675**	.519**
Current PTSS Score	Pearson Correlation		1.000	.663**
	Spearman's rho			.517**
Previous PTSS Score	Pearson Correlation			1.000

\*\* Correlation significant at 0.01 level (2 tailed)

Parametric Test: Pearson Correlation

Non-parametric Test: Spearman's rho

**Table 28 Current PTSS scores for veterans with and without PTSD**

	N	Mean	95% CI of the Mean	
			Lower Bound	Upper Bound
No PTSD	17	14.4	11.9	16.8
PTSD	7	23.0	18.1	27.9

Levene's test for equality of variances:  $p = 0.818$

Independent samples t test (equality of variances assumed):  $p = 0.001$

Independent samples Mann Whitney U test:  $p = 0.005$

**Table 29 PTSD scores for veterans by change in PTSS score**

	N	Mean	95% CI of Mean	
			Lower Bound	Upper Bound
PTSS Decreased	15	42.2	35.0	49.4
No Change	2	42.3	22.3	62.2
PTSS Increased	7	44.1	30.2	58.1

ANOVA  $F = 0.052, p = 0.950$

Independent samples Kruskal Wallis test:  $p = 0.926$

### **BPSD Differences in veterans with and without PTSD**

- Veterans with PTSD (defined using the PCL-P and using a cut-off of 48) had significantly higher levels of BPSD (see Table 30).

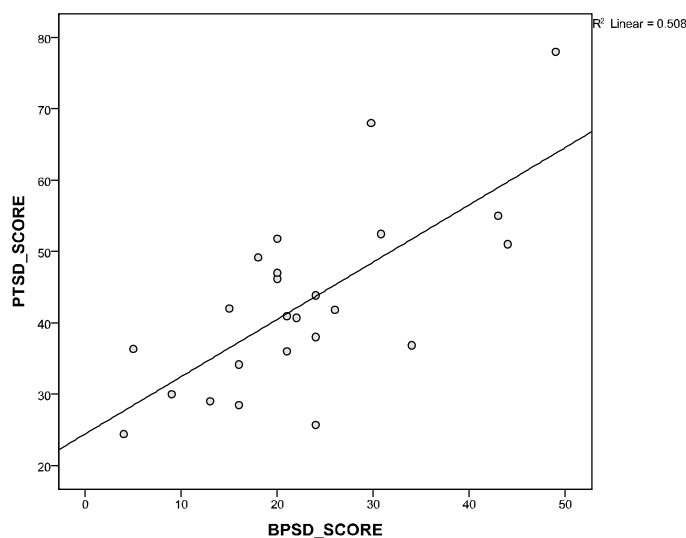
**Table 30 BPSD scores for veterans with and without PTSD**

	N	Mean	95% CI of Mean	
			Lower Bound	Upper Bound
No PTSD	17	18.5	14.5	22.4
PTSD	7	33.5	22.3	44.7

Levene's test for equality of variances:  $p = 0.069$   
 Independent samples t test (equality of variances assumed):  $p = 0.001$

- Veterans with PTSD (defined using the PCL-P but considered as a continuous scale without any cut-off) again had significantly higher levels of BPSD. As shown in Figure 1, there was a statistically significant positive correlation between BPSD and PTSD scores of the veterans ( $R^2 = 0.508$ ;  $r = 0.713$ ); higher PTSD scores are associated with higher BPSD scores. According to Cohen and Halliday (1982), as a rule of thumb, an  $r$  value of 0.70 to 0.89 is a 'strong' correlation (Cohen & Holliday, 1982).

**Figure 1 Correlation between BPSD and PTSD scores**



The mean BPSD item scores on six of the 14 items on the BPSD Checklist were significantly higher for veterans with PTSD compared to those without using the Mann-Whitney test for ordinal data– see Figure 2.

These items were:

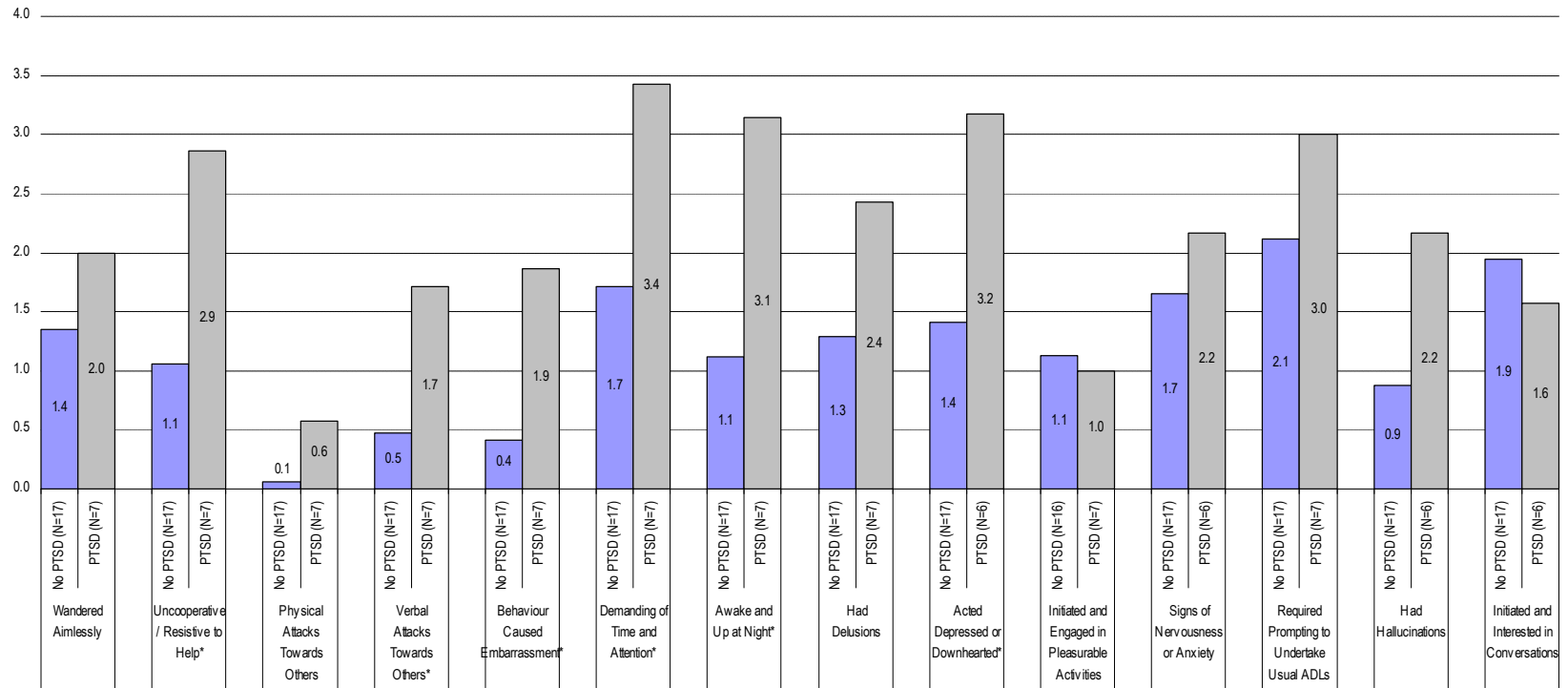
- Uncooperative or resistive to help from others ( $P = 0.028$ )
- Verbal attacks towards others (shouts, swears, curses) ( $P = 0.036$ )
- Behaved in public or at home in a way that cause embarrassment ( $P = 0.025$ )
- Was demanding of time or attention ( $P = 0.027$ )
- Was awake and up during the night for no apparent reason ( $P = 0.011$ )
- Acted depressed or downhearted ( $P = 0.026$ ).

Non-significant items were:

- Wandered aimlessly (P = 0.334)
- Physical attacks towards others (P= 0.466)
- Had delusions (P= 0.245)
- Initiated and engaged in pleasurable activities (P = 0.813)
- Signs of nervousness or anxiety (P = 0.359)
- Required prompting to undertake usual activities of daily living (ADLs) (P = 0.334)
- Had hallucinations (P = 0.060)
- Initiated and interested in conversations (P= 0.577).

All 14 item scores were higher (not necessarily significantly) in veterans with PTSD than those without. This is highly significant according to the Sign test (P=0.0001).

**Figure 2 Average scores on BPSD checklist for veterans with and without PTSD**





## 6 DISCUSSION

This was the first Australian study to explore the relationship between symptoms of dementia and post-traumatic stress disorder in veterans. The present study has provided some exploratory information on the link between traumatic war experiences and dementia, and has added to the body of evidence testing whether PTSD alters the course of dementia. We found some indications that dementia symptoms are different in veterans than non-veterans, and also that the profile of behavioural and psychological symptoms of dementia is different in veterans with indications of post traumatic stress disorder as judged by their carer.

As in other studies of veterans and non-veterans receiving community care services, we found that veterans were older than non-veterans, more likely to be male, born in Australia and English speaking. However there were no significant differences in dependency or level of dementia. Some sub-scale scores were statistically different between veterans and non-veterans and the profile of symptoms showed differences between the groups. After adjusting for these confounding differences between veterans and non-veterans, we still found differences in BPSD between the two groups.

Carer assessments of PTSD before and after the diagnosis of dementia were significantly correlated. For the small number of veterans for whom we had PTSD scores, we found that the BPSD profiles of veterans with and without PTSD were different. Veterans' scores were higher than those of non-veterans for symptoms of: uncooperative or resistive to help from others; verbal attacks towards others (shouts, swears, curses); behaved in public or at home in a way that cause embarrassment; was demanding of time or attention; was awake and up during the night for no apparent reason; acted depressed or downhearted. Further investigation is needed to understand the correlation between BPSD and PTSD scores which may have been due to measurement overlap of the two constructs.

A limitation of this study was the small sample size, although the sample size was not the smallest compared with other studies in the literature. It has to be acknowledged that the absolute numbers of veterans exhibiting rarer BPSD were very small, and so results found here should be verified in further studies. In this project we identified a number of barriers to recruitment. We were unable to recruit more veterans into the study despite extending the recruitment time period and relaxing the inclusion criteria to include veterans receiving any type of packaged community care rather than only EACHD packaged care. Because we were attempting to match recruitment and design procedures used in a previous study in order to combine two data sets, we were reliant on a third party recruitment method which had produced reasonable response rates in a previous survey, but the previous survey had the advantage of government endorsement. In the present study, case managers completed a survey in which they had no vested interest and we were reliant on them acting as go-betweens for carer and veteran participation. The recruitment difficulties were in part due to this third party recruitment method, but also partly due to veterans being few and far between because they were less likely to use community packaged care than veterans' home care. Because of third party recruitment we were unable to determine definitively whether carers were willing to participate in the research. In future studies a different recruitment approach would be used, preferably recruiting carers and veterans directly rather than through community service providers and possibly recruiting participants who were younger, or at an earlier stage of dementia.

Nevertheless we have been able to address the research questions with some validity, and have found some interesting and promising results. Future studies are needed to replicate this finding and to understand why specific symptoms of dementia are more prevalent among veterans than non-veterans. From the family carers' perspective, more information is needed to help carers of veterans to understand how best to manage symptoms of dementia in their veterans. Carers participating in this

study expressed interest in the research, and requested more information about how to manage PTSD symptoms in people with dementia.

During the course of this study we also found that community service providers wanted to know more about PTSD and its interaction with dementia, and in-service seminars provided on the topic to some community services were very well received, even though it was acknowledged that the research is at an early stage.

## **7 CONCLUSIONS**

1. This is the first Australian study of the link between PTSD and BPSD in veterans.
2. Being a veteran is associated with some differences in the profile of behavioural and psychological symptoms of dementia than shown in non-veterans.
3. PTSD symptoms are positively correlated with BPSD.
4. Veterans with PTSD have higher levels of BPSD than veterans without PTSD.
5. Future studies are needed to replicate this finding.
6. Health service providers and carers of veterans living with dementia need more information about the ongoing research into the link between dementia and PTSD in order to keep up to date on the two conditions.

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## Appendix 1: Participating Service Providers and Number of Carer Responses from each provider

Participating Service Providers	Estimated N veteran clients	Carer Responses	% Response Rate
Annecto (Vic)	9	2	22.2
Baptcare Community Services (Vic)	15	5	33.3
Benetas (Vic)	7	0	0
Brightwater At Home (WA)	2	2	100
Brotherhood of St Laurence Community Care	5	1	20
Calvary Silver Circle (National)	5	0	0
Catholic Community Care Hunter-Manning (NSW)	6	0	0
Catholic Community Services (NSW)	2	1	50
Chesalon Community Services (NSW)	2	1	50
Community Care Northern Beaches (NSW)	2	2	100
ECH Inc. (SA)	10	1	10
Forrest Community Services (NSW)	2	1	50
Goulburn Valley Health (Vic)	2	0	0
Hammond Care (NSW)	3	0	0
Helping Hand aged Care Inc. (SA)	9	1	11.1
Home Care Options	1	0	0
Jewish Care (Vic)	2	0	0
Lutheran Aged Care	1	0	0
McLean Care Community Services (NSW)	1	0	0
Masonic Homes (SA & NT)	5	0	0
Mercy Home and Community Care (Vic, NSW, ACT)	30	1	3.3
Novocare (NSW)	5	0	0
Royal Freemasons Homes (Vic)	4	0	0
RSL Home Care (Qld)	19	1	5.3
St Laurence Community Options	6	0	0
St Luke's Community Care (NSW)	4	0	0
Southern Cross Care (Vic)	7	1	14.3
Uniting Church Care NSW,ACT	16	2	12.5
VaseyRSL Care (Vic)	16	3	18.7
Wintringham Community Services	2	2	100
Total	115	27	23.5

## Appendix 2: List of service providers contacted to participate in the study

State	Service Name
ACT	Goodwin Outreach (EACH Dementia)
NSW	ANHF Flexicare - Western Sydney - EACHD
NSW	Anglican Retirement Villages Illawarra
NSW	Anglican Care Wyong Dementia EACH
NSW	Baptist community Services NSW and ACT
NSW	Bankstown Home Services
NSW	Chinese Australian Services Society
NSW	Calvary Silver Circle Community Services (National)
NSW	Care Connect (NSW and Vic)
NSW	Carrington Community Care
NSW	Catholic Community Services
NSW	Catholic Care Hunter-Manning
NSW	Chesalon Care at Home Services (Anglicare)
NSW	Clarence Valley Council Community Services
NSW	Community Care Northern Beaches
NSW	New England Community Care
NSW	Feros Care (NSW and Qld)
NSW	Forrest Community Services
NSW	Griffith Nursing Services
NSW	Hammond Care
NSW	Help at Home (Benevolent Society NSW)
NSW	Integrated Living Australia (NSW and Qld)
NSW	INS Community Care
NSW	Illawarra Retirement Trust Community Services
NSW	KinCare (National)
NSW	Lutheran Aged Care EACH Dementia
NSW	Merimbula Home Nursing Service - Dementia EACH
NSW	Novacare
NSW	Our Lady of Consolation Aged Care
NSW	RSL Life Care
NSW	Rumbalara Indigenous Aged Care Southern Riverina
NSW	St Basil's Homes Flexible Care
NSW	St Carthage's Cathedral Parish Community Care
NSW	St Luke's Community Care
NSW	Stanhope Healthcare Services
NSW	Sue Mann's Community Care
NSW	Uniting Care Ageing NSW and ACT
NSW	Warrigal Community Care - Goulburn EACH Dementia
NT	Golden Glow Coporation
QLD	Blackall Range Aged Care
QLD	Blue Care (Uniting Church Care)
QLD	Home Support Services South Coast
QLD	Islamic Women's Community Aged Care
QLD	Kaloma Home for the Aged Community Services
QLD	Multicultural Aged Care Services (Qld and Vic)
QLD	Ozcare Community Services (St Vincent de Paul)



<b>State</b>	<b>Service Name</b>
QLD	Prescare Community Care
QLD	RSL HomeCare, War Veterans Homes Ltd
QLD	Wesley Mission Community Care (Uniting Church)
SA	ACH Group In Home Care
SA	Alwyndor Community Services
SA	Boandik Lodge
SA	Masonic Homes Community Care (SA and NT)
SA	ECH Inc. Community Care
SA	Eldercare Extended Care
SA	Helping Hand Aged Care Home Based Services
SA	Marion Community Services
SA	Matthew Flinders Home Inc - Community Care
SA	RDNS Extended Aged Care at Home
SA	Rural Extended Care Barossa Village
SA	St Louis Extended Aged Care at Home
SA	Whyalla Home Support Program
TAS	Anglicare Tasmania Disability and Support Aged Care
TAS	Community Dementia Team, Tasmanian State Govt
TAS	Presbyterian Care Tasmania, Extended Aged Care at Home
TAS	Huon Eldercare
TAS	Independent Health Care Services Pty Ltd
TAS	Migrant Resource Centre
TAS	Southern Cross care (Tas)
TAS	Uniting Aged Care (under Victorian Uniting Aged Care)
VIC	Annecto
VIC	Austin Health Community Services
VIC	Baptcare Community Services
VIC	Benetas Community Services
VIC	Brotherhood Community Care Packages (Southern)
VIC	Central Grampians Community Care Options
VIC	Goulburn Valley Health Community and Integrated Care
VIC	Jewish Care (Victoria)
VIC	Lyndoch Warrnambool Inc.
VIC	Royal District Nursing Service
VIC	Vasey RSL Community Care
VIC	Southern Cross Care (Vic)
VIC	St Laurence Community Options
VIC	Uniting Aged Care Victoria
VIC	Villa Maria Society
VIC	Wintringham Community Care Services
WA	Albany Community Services
WA	Amana Living Incorp. Care Services
WA	Bethanie Community Care
WA	Brightwater At Home Services
WA	A.T. & A. Pty. Ltd. Homecare Options
WA	Silver Chain Nursing Association Inc.
WA	Southcare Inc. Community Aged Care
WA	Southern Cross Care WA
WA	St Ives Care Pty. Ltd. Community Care Services

<b>State</b>	<b>Service Name</b>
WA	Strelly Grange Home Care
WA	Uniting Church Homes Community Care

### Appendix 3: List of variables available to analyse

Measure from case manager's survey	Type of measure
Veteran status	Dichotomous (veteran/non-veteran)
Age	
Gender	
Country of birth	
Language spoken	
Aboriginal or Torres Strait Islander status	
Postcode	
Main source of income	
Living arrangement	
Mini mental state examination score	Score / 30
Global deterioration score	Score/7 (very severe to none)
Dementia diagnosis	Formal, informal, none
Type of dementia	13 types
Psychotropic medication	7 types
Cohen Mansfield Agitation Inventory overall score	Total score / 259
CMAI verbal agitation score	Score / 42
CMAI verbal aggression score	Score / 35
CMAI physical agitation score	Score / 63
CMAI physical aggression score	Score / 91
37 Individual CMAI items	Score / 7 (never to several times a day)
Barthel Index score 11 questions	Score/ 105
OARS score 7 questions	Score / 28
Measure from family carers survey - Subset of veterans (n=28) also have variables on:	
War served	3 types
Rank	Types
Where served	
Years served	
Type of pension	
Diagnosis of PTSD	Yes/no
Diagnosis of depression	Yes/no
Diagnosis of anxiety	Yes/no
Disability pension for PTSD	Yes/no
Disability pension for TPI	Yes/no
BPSD Snellgrove scale	Total score /56
14 BPSD individual items	Scale 0 to 4
PTSD score before dementia	Total score /32
PTSD score after dementia	Total score / 32
PTSD score military checklist after dementia	Total score / 105

## Appendix 4: Demographics total sample

**Table A4a Age of all participants**

Group	Number	Mean Age Years	95% Confidence Interval for Mean	
			Lower Bound	Upper Bound
Non-Veterans	289	81	80.0	81.8
Veterans	48	85	82.9	86.4
Total	337	81	80.6	82.3

Missing data means Number ≠ 298 non-veterans

Test for homogeneity of variances:  $F=14.359$ ,  $p = 0.000$

Levene's test for equality of variances:  $F=7.37$ ,  $p = 0.007$

Independent samples t test (equal variances not assumed):  $t = -3.799$ ,  $p = 0.000$

**Table A4b Age of all participants by gender**

	N	Mean	SD	95% Confidence Interval for Mean	
				Lower Bound	Upper Bound
<i>Missing vet status</i>	22	81.7	7.9	78.2	85.2
Male Veteran	40	85.6	5.0	84.1	87.3
Female Veteran	8	79.5	7.9	72.9	86.1
Total Veteran	48	85.0	-	82.9	86.4
Male Non-Veteran	90	77.8	8.1	76.1	79.4
Female Non-Veteran	199	82.3	7.6	81.2	83.4
Total Non-veteran	289	81.0	-	80.0	81.8
Total	359	81.4	7.9	80.6	82.3

**Table A4c Location of all participants**

	NON-VETERANS		VETERANS	
	Number	Percent	Number	Percent
NSW	100	34%	11	23%
VIC	54	18%	12	26%
QLD	67	23%	10	21%
SA	49	17%	7	15%
WA	11	4%	3	6%
TAS	12	4%	4	9%
NT	2	1%	0	0%
Total	295	100%	47	100%

Missing data means Number ≠ 298 non-veterans and 48 veterans

**Table A4d Demographics of all participants**

	NON-VETERANS			VETERANS			p VALUE
	Total	Number	Percent	Total	Number	Percent	
Males	298	96	32%	48	40	83%	0.000*
ATSI	294	3	1%	47	1	2%	0.449*
Born in Australia	298	188	63%	48	42	88%	0.001*
Speaks English at home	298	252	85%	47	46	98%	0.006*
Income							
Govt Pension	293	253	86%	46	41	89%	1.000*
Private Income	293	37	13%	46	5	11%	
Both	293	3	1%	46	0	0%	
Lives with family / others	298	213	72%	47	31	66%	0.491*
Carer (Yes)	298	279	94%	48	45	94%	1.000
Co- Resident Carer	279	210	75%	45	30	67%	0.271
Veterans' DVA Entitlement							
Gold Card				48	33	69%	
White Card				48	7	15%	
Other***				48	8	17%	

Missing data means Total ≠ 298 non-veterans and 48 veterans

\* Fisher's Exact Test

\*\*\* Sig test excludes small number of participants in receipt of both a government pension and private income

\*\*\* Includes Orange Card or other entitlement

Percentages may not sum to 100% due to rounding

## **Appendix 5: Case Manager Questionnaire**



THE UNIVERSITY OF  
MELBOURNE

Centre for Health Policy, Programs and Economics

School of Population Health, The University of Melbourne, Level 4, 207 Bouverie Street, Carlton, Victoria 3010 Australia

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## The Impact of War Experience on Dementia in Veterans

### Research Project Survey for Case Manager

## Instructions

### What is the purpose of this survey?

This survey is designed to capture information about the veteran's functional dependency, instrumental dependency, mental and physical health, and behavioural and psychological symptoms of dementia.

### Which care recipients should the survey be completed for?

Complete this survey for **ALL veterans (but not war widows) currently receiving community care during 2011.**

Care recipients can be identified as veterans from the prefix to their pension number. The first letter identifies state (V=VIC, Q=QLD, S=SA/NT, T=TAS, W=WA, Q=QLD, N=NSW/ACT). The next letters in the pension number are war codes. The following prefixes identify pensioners as veterans: A, AGX, BUR, CN, CNK, CNX, GHA, HKX, IND, IV, KM, KYA, MAU, MLS, MTX, MWI, N, NF, NG, NGR, NK, NX, P, PAD, PAM, PCA, PCR, PK, PMS, PSW, PWO, PX, RD, RDX, SA, SAX, SR, SW, SWP, X.

### Who do I contact for help?

Please ring Cecily Hunter (03) 8344 9111 or email [cehunter@unimelb.edu.au](mailto:cehunter@unimelb.edu.au)

# 1. Service Provider Details

a) Service Provider Name:

e) Person completing this form:

Name	_____
Position	_____
Phone	_____
Email	_____

f) Date completing this form:

D	D	M	M	Y	Y	Y	Y

g) Care recipient's research ID:

Research ID

# 2. Veteran Details

a) Date of birth:

D	D	M	M	Y	Y	Y	Y

b) Sex:

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

c) Country of birth:

Australia	<input type="checkbox"/>	1	
Other	<input type="checkbox"/>	2	→ Please specify: _____

d) Main language spoken at home:

English	<input type="checkbox"/>	1	
Other	<input type="checkbox"/>	2	→ Please specify: _____



e) Aboriginal or Torres Strait Islander:	Yes	<input type="checkbox"/> 1
	No	<input type="checkbox"/> 2
	Don't know	<input type="checkbox"/> 3

f) Suburb/Town/Locality:

g) Postcode:






h) Main source of income:	Government pension	<input type="checkbox"/> 1
	Private income	<input type="checkbox"/> 2

i) DVA entitlement:	Gold card	<input type="checkbox"/> 1
	White card	<input type="checkbox"/> 2
	Orange card or other DVA entitlement	<input type="checkbox"/> 3
	No DVA entitlement	<input type="checkbox"/> 4

j) Living arrangements:	Lives alone	<input type="checkbox"/> 1
	Lives with family/others	<input type="checkbox"/> 2

k) Carer(s):	Co-resident carer	<input type="checkbox"/> 1
	Non-resident carer	<input type="checkbox"/> 2

l) Carer's relationship to care recipient:	Partner/spouse	<input type="checkbox"/> 1	→ Please specify: _____
	Son/daughter/in-law	<input type="checkbox"/> 2	
	Other relative/friend	<input type="checkbox"/> 3	

m) Please list up to five main physical health conditions the care recipient suffers from (formal diagnosis is not required):



### 3. Mental health

a) MMSE score:	Available	<input type="checkbox"/> 1	→ Score: ____ / 30	→ Date scored: ____ month ____ year
	Not available	<input type="checkbox"/> 2		

b) Global Deterioration Scale*:	Very severe	<input type="checkbox"/> 1
	Severe	<input type="checkbox"/> 2
	Moderately severe	<input type="checkbox"/> 3
	Moderate	<input type="checkbox"/> 4
	Mild	<input type="checkbox"/> 5
	Very mild	<input type="checkbox"/> 6
	None	<input type="checkbox"/> 7

Note: \* See Guide for description of each category

c) Dementia diagnosis:	Formal diagnosis	<input type="checkbox"/> 1	→ Year of diagnosis: _____
	Informal diagnosis	<input type="checkbox"/> 2	
	No diagnosis	<input type="checkbox"/> 3	→ Go to Item e

d) Type:	Don't know	<input type="checkbox"/> 88
	Dementia of unspecified type	<input type="checkbox"/> 1
	Alzheimer's disease	<input type="checkbox"/> 2
	Vascular dementia	<input type="checkbox"/> 3
	Mixed dementia	<input type="checkbox"/> 4
	Lewy Body dementia	<input type="checkbox"/> 5
	Frontal lobe dementia (e.g. Pick's disease)	<input type="checkbox"/> 6
	Dementia in alcohol abuse	<input type="checkbox"/> 7
	Dementia in other substance abuse	<input type="checkbox"/> 8
	Dementia in Huntington's disease	<input type="checkbox"/> 9
	Dementia in Parkinson's disease	<input type="checkbox"/> 10
	Dementia in HIV disease	<input type="checkbox"/> 11
	Dementia in Creutzfeldt-Jakob disease	<input type="checkbox"/> 12
	Other dementia type	<input type="checkbox"/> 13

**e) Psychotropic medications currently taken – indicate all that apply:**

None	<input type="checkbox"/> 0
Antipsychotics (typical and atypical) e.g. Risperidone, Olanzapine, Haliperidol, Tegretol	<input type="checkbox"/> 1
Antianxiety e.g. Diazepam Ativan	<input type="checkbox"/> 2
Hypnotics and sedatives e.g. Temaze	<input type="checkbox"/> 3
Antidepressants e.g. Zoloft Avanza	<input type="checkbox"/> 4
Psychostimulants	<input type="checkbox"/> 5
Antidementia drugs e.g. Aricept, Ebixa, Reminol	<input type="checkbox"/> 6
Other	<input type="checkbox"/> 7
→ Please specify: _____	
Don't know	<input type="checkbox"/> 88

If class of medication is unknown, please specify name of medication → \_\_\_\_\_

**f) Cohen-Mansfield Agitation Inventory – Community form (adapted)**

**How often did the veteran exhibit each of the following behavioural and psychological symptoms of dementia during the last two weeks? Then for each symptom, how much of a problem was the symptom for the family carer?**

Verbal agitation symptoms	How frequent during the last two weeks?							How much of a problem for family carer?			
	Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour	No problem	Small problem	Moderate problem	Large problem
Asked repetitive sentences or questions	0	1	2	3	4	5	6	1	2	3	4
Made relevant verbal interruptions to conversations	0	1	2	3	4	5	6	1	2	3	4
Made unrelated verbal interruptions to conversations	0	1	2	3	4	5	6	1	2	3	4
Complained or whined	0	1	2	3	4	5	6	1	2	3	4
Made constant requests for attention or help (including nagging, pleading, calling out)	0	1	2	3	4	5	6	1	2	3	4
Was uncooperative or unwilling to participate (e.g. in personal care)	0	1	2	3	4	5	6	1	2	3	4

Verbal aggression symptoms	How frequent during the last two weeks?							How much of a problem for family carer?			
	Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour	No problem	Small problem	Moderate problem	Large problem
Cursed or was verbally threatening or insulting	0	1	2	3	4	5	6	1	2	3	4
Was verbally bossy or pushy	0	1	2	3	4	5	6	1	2	3	4
Made strange noises	0	1	2	3	4	5	6	1	2	3	4
Screamed, shouted or howled	0	1	2	3	4	5	6	1	2	3	4
Had temper outbursts	0	1	2	3	4	5	6	1	2	3	4
Made verbal sexual advances	0	1	2	3	4	5	6	1	2	3	4

Physical agitation symptoms	How frequent during the last two weeks?							How much of a problem for family carer?			
	Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour	No problem	Small problem	Moderate problem	Large problem
Was restless or fidgety, always moving around	0	1	2	3	4	5	6	1	2	3	4
Paced, aimlessly wandered	0	1	2	3	4	5	6	1	2	3	4
Was up at night	0	1	2	3	4	5	6	1	2	3	4
Tried to get out inappropriately	0	1	2	3	4	5	6	1	2	3	4
Dressed or undressed inappropriately	0	1	2	3	4	5	6	1	2	3	4
Exhibited repetitious mannerisms	0	1	2	3	4	5	6	1	2	3	4
Handled things inappropriately	0	1	2	3	4	5	6	1	2	3	4
Hid or hoarded things	0	1	2	3	4	5	6	1	2	3	4
Made physical sexual advances or exposed sexual parts	0	1	2	3	4	5	6	1	2	3	4

Physical aggression symptoms	How frequent during the last two weeks?							How much of a problem for family carer?			
	Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour	No problem	Small problem	Moderate problem	Large problem
Hit people, self or others	0	1	2	3	4	5	6	1	2	3	4
Kicked people or objects	0	1	2	3	4	5	6	1	2	3	4
Threw things	0	1	2	3	4	5	6	1	2	3	4
Tore things or destroyed objects	0	1	2	3	4	5	6	1	2	3	4
Grabbed onto or clung to people	0	1	2	3	4	5	6	1	2	3	4
Grabbed or snatched things from others	0	1	2	3	4	5	6	1	2	3	4
Pushed other people	0	1	2	3	4	5	6	1	2	3	4
Bit other people or things	0	1	2	3	4	5	6	1	2	3	4
Spat	0	1	2	3	4	5	6	1	2	3	4
Scratched people, self	0	1	2	3	4	5	6	1	2	3	4
Hurt self (burns, cuts etc)	0	1	2	3	4	5	6	1	2	3	4
Hurt others (burns, cuts etc)	0	1	2	3	4	5	6	1	2	3	4
Fell intentionally	0	1	2	3	4	5	6	1	2	3	4

	How frequent during the last two weeks?							How much of a problem for family carer?			
	Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour	No problem	Small problem	Moderate problem	Large problem
Ate or drank non-food substances	0	1	2	3	4	5	6	1	2	3	4
Required prompting to undertake activities of daily living	0	1	2	3	4	5	6	1	2	3	4
Had hallucinations	0	1	2	3	4	5	6	1	2	3	4
Has delusions	0	1	2	3	4	5	6	1	2	3	4

	How frequent during the last two weeks?							How much of a problem for family carer?			
	Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour	No problem	Small problem	Moderate problem	Large problem
Any other behaviours? List them and rate											
	0	1	2	3	4	5	6	1	2	3	4
	0	1	2	3	4	5	6	1	2	3	4
	0	1	2	3	4	5	6	1	2	3	4
	0	1	2	3	4	5	6	1	2	3	4

## 4. Functional Dependency – Modified Barthel Index (Aust. ed.)

Insert score here if you already have this from your records and go to section 5 \_\_\_\_\_

For each item, tick whichever box is appropriate.

### a) PERSONAL HYGIENE - Wash hands & face, comb hair, clean teeth, shave/make-up application

The care recipient is unable to attend to personal hygiene and is dependent in all aspects.	<input type="checkbox"/> 0
Assistance is required in all steps of personal hygiene, but care recipient able to make some contribution.	<input type="checkbox"/> 1
Some assistance is required in one or more steps of personal hygiene.	<input type="checkbox"/> 3
Care recipient is able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.	<input type="checkbox"/> 4
The care recipient can wash his/her hands and face, comb hair, clean teeth and shave. A male care recipient may use any kind of razor but must insert the blade, or plug in the razor without help, as well as retrieve it from the drawer or cabinet. A female care recipient must apply her own make-up, if used, but need not braid or style her hair.	<input type="checkbox"/> 5

### b) BATHING SELF - Use bath tub/shower/or a complete sponge-bathe

Total dependence in bathing self.	<input type="checkbox"/> 0
Assistance is required in all aspects of bathing, but care recipient is able to make some contribution.	<input type="checkbox"/> 1
Assistance is required with either transfer to shower/bath or with washing or drying; including inability to complete a task because of condition or disease, etc.	<input type="checkbox"/> 3
Supervision is required for safety in adjusting the water temperature, or in the transfer.	<input type="checkbox"/> 4
The care recipient may use a bathtub, a shower, or take a complete sponge bath. The care recipient must be able to do all the steps of whichever method is employed without another person being present.	<input type="checkbox"/> 5

### c) FEEDING - From tray or table when food placed within reach

Dependent in all aspects and needs to be fed, nasogastric needs to be administered.	<input type="checkbox"/> 0
Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.	<input type="checkbox"/> 2
Able to feed self with supervision. Assistance is required with associated tasks such as putting milk/sugar into tea, salt, pepper, spreading butter, turning a plate or other "set up" activities.	<input type="checkbox"/> 5
Independence in feeding with prepared tray, except may need meat cut, milk carton opened or jar lid etc. The presence of another person is not required.	<input type="checkbox"/> 8
The care recipient can feed self from a tray or table when someone puts the food within reach. The care recipient must put on an assistive device if needed, cut food, and if desired use salt and pepper, spread butter, etc.	<input type="checkbox"/> 10

### d) TOILET - Transfers, clothing management and hygiene

Fully dependent in toileting.	<input type="checkbox"/> 0
Assistance required in all aspects of toileting.	<input type="checkbox"/> 2
Assistance may be required with management of clothing, transferring, or washing hands.	<input type="checkbox"/> 5
Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.	<input type="checkbox"/> 8
The care recipient is able to get on/off the toilet, fasten clothing and use toilet paper without help. If necessary, the care recipient may use a bed pan or commode or urinal at night, but must be able to empty it and clean it.	<input type="checkbox"/> 10

**e) STAIR CLIMBING - The ability to go up and down 3 steps**

The care recipient is unable to climb stairs.	<input type="checkbox"/> 0
Assistance is required in all aspects of chair climbing, including assistance with walking aids.	<input type="checkbox"/> 2
The care recipient is able to ascend/descend but is unable to carry walking aids and needs supervision and assistance.	<input type="checkbox"/> 5
Generally no assistance is required. At times supervision is required for safety due to morning stiffness, shortness of breath, etc.	<input type="checkbox"/> 8
The care recipient is able to go up and down a flight of stairs safely without help or supervision. The care recipient is able to use hand rails, cane or crutches when needed and is able to carry these devices as he/she ascends or descends.	<input type="checkbox"/> 10

**f) DRESSING - Put on & remove appropriate clothing**

The care recipient is dependent in all aspects of dressing and is unable to participate in the activity.	<input type="checkbox"/> 0
The care recipient is able to participate to some degree, but is dependent in all aspects of dressing.	<input type="checkbox"/> 2
Assistance is needed in putting on, and/or removing any clothing.	<input type="checkbox"/> 5
Only minimal assistance is required with fastening clothing such as buttons, zips, bra, shoes, etc.	<input type="checkbox"/> 8
The care recipient is able to put on, remove, corset, braces, as prescribed.	<input type="checkbox"/> 10

**g) BOWEL CONTROL**

The care recipient is bowel incontinent.	<input type="checkbox"/> 0
The care recipient needs help to assume appropriate position, and with bowel movement facilitatory techniques.	<input type="checkbox"/> 2
The care recipient can assume appropriate position, but cannot use facilitatory techniques or clean self without assistance and has frequent accidents. Assistance is required with incontinence aids such as pad, etc.	<input type="checkbox"/> 5
The care recipient may require supervision with the use of suppository or enema and has occasional accidents.	<input type="checkbox"/> 8
The care recipient can control bowels and has no accidents, can use suppository, or take an enema when necessary.	<input type="checkbox"/> 10

**h) BLADDER CONTROL**

The care recipient is dependent in bladder management, is incontinent, or has indwelling catheter.	<input type="checkbox"/> 0
The care recipient is incontinent but is able to assist with the application of an internal or external device.	<input type="checkbox"/> 2
The care recipient is generally dry by day, but not at night and needs some assistance with the devices.	<input type="checkbox"/> 5
The care recipient is generally dry by day and night, but may have an occasional accident or need minimal assistance with internal or external devices.	<input type="checkbox"/> 8
The care recipient is able to control bladder day and night, and/or is independent with internal or external devices.	<input type="checkbox"/> 10

**i) AMBULATION - Ability to walk, with or without aids. Aid is to be placed within reach**

Dependent in ambulation. <b>Go to Item j</b>	<input type="checkbox"/> 0
Constant presence of one or more assistant is required during ambulation <b>Go to Item k</b>	<input type="checkbox"/> 3
Assistance is required with reaching aids and/or their manipulation. One person is required to offer assistance. <b>Go to Item k</b>	<input type="checkbox"/> 8
The care recipient is independent in ambulation but unable to walk 50 metres without help, or supervision is needed for confidence or safety in hazardous situations. <b>Go to Item k</b>	<input type="checkbox"/> 12
The care recipient must be able to wear braces if required, lock and unlock these braces assume standing position, sit down, and place the necessary aids into position for use. The care recipient must be able to crutches, canes, or a walkerette, and walk 50 metres without help or supervision. <b>Go to Item k</b>	<input type="checkbox"/> 15

**j) WHEELCHAIR MANAGEMENT**

**Only use this item if scored '0' for Ambulation, and then only if person has been trained in wheelchair management**

Dependent in wheelchair ambulation.	<input type="checkbox"/> 0
Care recipient can propel self short distances on flat surface, but assistance is required for all other steps of wheelchair management.	<input type="checkbox"/> 1
Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed, etc.	<input type="checkbox"/> 3
The care recipient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may still be required in "tight corners" or to negotiate a kerb 100mm high.	<input type="checkbox"/> 4
To propel wheelchair independently, the care recipient must be able to go around corners, turn around, manoeuvre the chair to a table, bed, toilet, etc. The care recipient must be able to push a chair at least 50 metres and negotiate a kerb.	<input type="checkbox"/> 5

**k) CHAIR/ BED TRANSFER - Move between lying & sitting & transfer to/from chair**

Unable to participate in a transfer. Two attendants are required to transfer the care recipient with or without a mechanical device.	<input type="checkbox"/> 0
Able to participate but maximum assistance of one other person is required in all aspects of the transfer.	<input type="checkbox"/> 3
The transfer requires the assistance of one other person. Assistance may be required in any aspect of the transfer.	<input type="checkbox"/> 8
The presence of another person is required either as a confidence measure, or to provide supervision for safety.	<input type="checkbox"/> 12
The care recipient can safely approach the bed walking or in a wheelchair, lock brakes, lift footrests, or position walking aid, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely and/or grasp aid and stand. The care recipient must be independent in all phases of this activity.	<input type="checkbox"/> 15



## 5. Instrumental Dependency - OARS – IADL (adapted)

Insert score here if you already have this from your records \_\_\_\_\_

**a) Can the care recipient use the telephone?**

Completely unable to use the telephone	<input type="checkbox"/> 0
With some help (can answer phone or dial in an emergency, but needs a special phone or help in getting the number (or dialling))	<input type="checkbox"/> 1
Without help, including looking up numbers and dialling	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

**b) Can the care recipient get to places outside of walking distance?**

Unable to travel unless arrangements are made for a specialised vehicle such as an ambulance	<input type="checkbox"/> 0
With some help (needs someone to help him/her or go with him/her when travelling)	<input type="checkbox"/> 1
Without help (drives own car, or travels alone on buses or taxis)	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

**c) Can the care recipient go shopping for groceries or clothes (assuming he/she has transportation)?**

Completely unable to do any shopping	<input type="checkbox"/> 0
With some help (needs someone to go with him/her on all shopping trips)	<input type="checkbox"/> 1
Without help (can take care of shopping needs him/herself, assuming he/she has transportation)	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

**d) Can the care recipient prepare his/her own meals?**

Completely unable to prepare any meals	<input type="checkbox"/> 0
With some help (can prepare some things but is unable to cook full meals him/herself)	<input type="checkbox"/> 1
Without help (can plan and cook full meals for him/herself)	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

**e) Can the care recipient do his/her housework?**

Completely unable to do any housework	<input type="checkbox"/> 0
With some help (can do light housework but needs help with heavy work)	<input type="checkbox"/> 1
Without help (can clean floors etc.)	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

**f) Can the care recipient take his/her own medicine?**

Completely unable to take his/her medicines	<input type="checkbox"/> 0
With some help (can take medication if someone prepares it and/or reminds him/her) to take it	<input type="checkbox"/> 1
Without help (can take the right dose at the right time)	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

**g) Can the care recipient handle his/her own money?**

Completely unable to handle money	<input type="checkbox"/> 0
With some help (can manage day-to-day buying, needs help managing chequebook and paying bills)	<input type="checkbox"/> 1
Without help (writes cheques, pays bills etc)	<input type="checkbox"/> 2
Not answered/Unable to assess	<input type="checkbox"/> 88

## 6. Type of community support

**What type of community care is this veteran receiving?**

EACHD	<input type="checkbox"/> 1
EACH	<input type="checkbox"/> 2
CACP	<input type="checkbox"/> 3
Other please specify	<input type="checkbox"/> 4

**Thank-you for completing this form**

Use the reply paid envelope provided to post back to:

Dr Cecily Hunter  
Centre for Health Policy, Programs and Economics  
Melbourne School of Population Health  
The University of Melbourne  
Victoria 3010

**Appendix 6: Carer Questionnaire**



**Centre for Health Policy, Programs and Economics**

School of Population Health, The University of Melbourne, Level 4, 207 Bouverie Street, Carlton, Victoria 3010 Australia

T: +61 3 8344 9111 / 8344 0710

## **Research Project**

### **The Impact of War Experiences on Dementia in Veterans**

#### **Carer Questionnaire**

#### *Instructions*

*This questionnaire asks you for information about your veteran's past health, diagnoses and war time experiences. Please complete the questions to the best of your knowledge. Some information may not be known - just circle the number next to 'don't know' and move to the next question.*

*When you have completed the questionnaire, return it using the reply paid envelope provided, to:*

*Dr Cecily Hunter*

*Centre for Health Policy Programs and Economics*

*The University of Melbourne*

*Victoria 3010.*

### The veteran's war experience

These questions ask about your relative's war experience. Circle the number next to your answer. If you don't know the answer, circle 8

Question	Answer -	Circle number
1. Which war did the veteran serve in?	Korean, Malayan	1
	World War II	2
	Vietnam War	3
	Other ó please write here:	
	Don't know	8
2. Which service did the veteran serve in?	Army	1
	Navy	2
	Airforce	3
	Other ó please write here:	
	Don't know	8
3. What rank was the veteran?	Please write here:	
	Don't know	8
4. Where did the veteran serve overseas?	Please write here:	
	Don't know	8
5. How many years did the veteran serve overseas?	Please write here:	
	Don't know	8
6. Is the veteran in receipt of a pension?	Service pension	1
	Disability pension	2
	None	3
	Don't know	8

Question	Answer -	Circle number
7. Has the veteran ever been diagnosed with post-traumatic stress disorder (PTSD)?	Yes	1
	No	2
	Don't know	8
8. Has the veteran ever been diagnosed with depression?	Yes	1
	No	2
	Don't know	8
9. Has the veteran ever been diagnosed with anxiety?	Yes	1
	No	2
	Don't know	8
10. Has the veteran been granted a DVA disability pension for post-traumatic stress disorder (PTSD)?	Yes	1
	No	2
	Don't know	8
11. Has the veteran been granted a TPI disability pension?	Yes	1
	If yes, what was the accepted condition for the TPI disability pension? Write here:	
	No	2
	Don't know	8

## 11. Health symptoms

Some people with dementia experience the symptoms below. For each symptom, circle a number to indicate about how frequently your relative has had the symptom during the past week.

How often during the past week has your relative:		<i>Never</i>	<i>1-2 days</i>	<i>3-4 days</i>	<i>5-6 days</i>	<i>Every day</i>
1	Wandered aimlessly around the home, or from home, during the day?	0	1	2	3	4
2	Been uncooperative or resistive to help from others?	0	1	2	3	4
3	Made physical attacks towards others (hits, bites, scratches, kicks, spits)	0	1	2	3	4
4	Made verbal attacks towards others (shouts, swears, curses)?	0	1	2	3	4
5	Behaved in public or at home in a way that caused you embarrassment?	0	1	2	3	4
6	Was demanding of your time or attention?	0	1	2	3	4
7	Was awake and up during the night for no apparent reason?	0	1	2	3	4
8	Had delusions (eg thought that spouse was not spouse, home was not home, there were people in the home, people were stealing things)?	0	1	2	3	4
9	Acted depressed or downhearted?	0	1	2	3	4
10	Initiated and was engaged in pleasurable activities?	0	1	2	3	4
11	Showed signs of nervousness or anxiety (eg shakiness, tenseness, shortness of breath, avoidance of certain places or situations)?	0	1	2	3	4
12	Required prompting to undertake usual activities of daily living (eg showering)?	0	1	2	3	4
13	Had hallucinations (eg saw things or people that were not there, heard things or people that were not there)?	0	1	2	3	4
14	Initiated, and was interested in, conversations with you and other people?	0	1	2	3	4

## 12. Severity of symptoms

In the following table, circle a number to indicate how much each symptom is a problem for your relative.

- Circle 2 Mild - if the symptom happened, but was not very upsetting or troublesome
- Circle 3 Moderate- if the symptom was clearly noticeable, the veteran was bothered or upset by this symptom; or the veteran had to stop what he or she was doing, but only for a few minutes
- Circle 4 Severe - if the veteran was very upset by this symptom; the veteran had to stop what he or she was doing and took more than 10 minutes to calm down; or was upset enough for others to notice.
- Circle 1 if the symptom was not present at all, or 8 if you don't know.

Moderate and severe ratings should be given for symptoms that happen many times or for a symptom that happens only once or twice but is very upsetting.

*For each symptom, circle the number that best reflects the veteran's behavior.*

Symptom	Not at all	Mild	Moderate	Severe	Don't know
Jumpy or nervous	1	2	3	4	8
Upset by sudden noises	1	2	3	4	8
Upset by someone coming up from behind	1	2	3	4	8
Nightmares, agitated sleep, or trouble sleeping	1	2	3	4	8
Talking or thinking about terrible things that happened in the past	1	2	3	4	8
Watchful or worried about being safe	1	2	3	4	8
Irritated, angry, or aggressive	1	2	3	4	8
Distracted, preoccupied or off in his or her own world	1	2	3	4	8



## 12. Symptoms before dementia

Thinking about the veteran before he/she developed dementia, how would you rate his/her symptoms before he/she developed dementia?

For each symptom, circle the number that best reflects the veteran's behavior before dementia.

Symptom before dementia	Not at all	Mild	Moderate	Severe	Don't know
Jumpy or nervous	1	2	3	4	8
Upset by sudden noises	1	2	3	4	8
Upset by someone coming up from behind	1	2	3	4	8
Nightmares, agitated sleep, or trouble sleeping	1	2	3	4	8
Talking or thinking about terrible things that happened in the past	1	2	3	4	8
Watchful or worried about being safe	1	2	3	4	8
Irritated, angry, or aggressive	1	2	3	4	8
Distracted, preoccupied or off in his or her own world	1	2	3	4	8

### 13. PTSD Checklist – Military

Below is a list of problems and complaints that veterans sometimes have in response to stressful military experiences. Please read each one carefully, then circle one of the numbers to the right to indicate how much your veteran has been bothered by that problem in the past month.

Some of the questions below may be hard to answer as a carer of someone with dementia. Circle 8 for 'don't know' if you are unable to answer and move on to the next question.

Symptom	<i>Not at all</i>	<i>A little</i>	<i>Some-what</i>	<i>Very much</i>	<i>Extremely</i>	<i>Don't know</i>
1. Repeated, disturbing memories, thoughts or images of a stressful military experience?	1	2	3	4	5	8
2. Repeated, disturbing dreams of a stressful military experience?	1	2	3	4	5	8
3. Suddenly acting or feeling as if a stressful military experience were happening again (as if he was reliving it)	1	2	3	4	5	8
4. Feeling very upset when something reminded him of a stressful military experience?	1	2	3	4	5	8
5. Having physical reactions (eg heart pounding, trouble breathing, sweating) when something reminded him of a stressful military experience?	1	2	3	4	5	8
6. Avoiding thinking about or talking about a stressful military experience or avoiding having feelings related to it?	1	2	3	4	5	8
7. Avoiding activities or situations because they reminded him of a stressful military experience?	1	2	3	4	5	8

Symptom	<i>Not at all</i>	<i>A little</i>	<i>Some- what</i>	<i>Very much</i>	<i>Extremely</i>	<i>Don't know</i>
(continued)						
8. Trouble remembering important parts of a stressful military experience?	1	2	3	4	5	8
9. Loss of interest in activities that he used to enjoy?	1	2	3	4	5	8
10. Feeling distant or cut off from other people?	1	2	3	4	5	8
11. Feeling emotionally numb or being unable to have loving feelings for those close to him?	1	2	3	4	5	8
12. Feeling as if his future somehow will be cut short?	1	2	3	4	5	8
13. Trouble falling or staying asleep?	1	2	3	4	5	8
14. Feeling irritable or having angry outbursts?	1	2	3	4	5	8
15. Having difficulty concentrating?	1	2	3	4	5	8
16. Being õsuperalertõ or watchful or on guard?	1	2	3	4	5	8
17. Feeling jumpy or easily startled?	1	2	3	4	5	8

Any other comments?

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Thank you.

Please return your questionnaire in the envelope provided to:

*Dr Cecily Hunter*  
*Centre for Health Policy Programs and Economics*  
*The University of Melbourne*  
*Victoria 3010.*

## APPENDIX 7: Glossary of abbreviations

Abbreviation	Meaning
AD	Alzheimer's disease
AIHW	Australian Institute of Health and Welfare
BPSD	Behavioural and psychological symptoms of dementia
CMAI	Cohen-Mansfield Agitation Inventory
CACP	Community Aged Care Package
DSM-IV	Diagnostic and Statistical Manual Version 4
DVA	Department of Veterans' Affairs
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
MMSE	Mini Mental State Examination
NPI	Neuro Psychiatric Inventory
OARS	Older American Resources and Services instrumental dependency
PCL-M	PTSD checklist military version
PCL-P	PTSD checklist partner version
POW	Prisoner of war
PTSD	Post traumatic stress disorder
PTSS	Post traumatic Stress Screen
PTSS-CI-OV	Post traumatic Stress Screen for the Cognitively Impaired Observer Version

SES	Socio-economic status
TPI	Totally and permanently incapacitated
US	United States
VA	Veterans' Affairs (United States Department)