THE RETURNED & SERVICES LEAGUE
OF AUSTRALIA LIMITED

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IN 1916

From: Rear Admiral Ken Doolan AO RAN (Retd)
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Inquiry into Palliative Care in Australia

The Returned & Services League of Australia would like to thank the Senate Community Affairs References Committee for the opportunity to provide written submission to the Inquiry into Palliative Care in Australia.

We invite careful consideration to this submission.

Yours sincerely,

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Returned & Services League of Australia

Submission to the Inquiry into Palliative Care in Australia
March 2012

Contents of Submission:

Summary

While veterans are not listed on the Inquiry terms of reference, this report focuses on highlighting the unique needs of the ex-service population and why there must be more awareness raised about their health and cultural needs particularly around end of life.

Australian veteran health studies confirm increased risks of chronic disease, many as a result of alcohol and cigarette abuse over many years. Incidence of cancer is also increased in some veteran cohorts. Likewise studies in relation to the mental health of veterans and their dependants indicate elevated rates of mental health conditions such as anxiety, depression, and post traumatic stress disorder. The results of veteran physical and mental health studies are similar internationally confirming that being a member of the armed services has definite impact on life's journey. Although the veteran population is declining due to the ageing of the World War II cohort, these physical and mental health conditions are already being diagnosed in our younger cohorts.

While limited research has been undertaken in Australia regarding veterans and end of life, there is much that we are learning from the United States, especially in relation to the older veteran cohorts and the re-emergence of mental health conditions. While the National Palliative Care Strategy has listed those with post traumatic stress disorder as requiring a different approach to care, there is no data collected in Australian health or aged care services to determine the extent of these mental health challenges at end of life, nor are there any programs developed to ensure appropriate treatment/care at end of life.

Despite veterans gaining special needs status in aged care and the acknowledgement from the Department of Health and Ageing of potential unmet needs in relation to palliative care access, there is limited understanding by health related and aged care services of the ex-service community's needs. A significant component of the ex-service community's culture revolves around commemorating those who made the ultimate sacrifice and 'looking after your mate' or 'looking after your mate's family'. While visiting those who are aged, lonely or infirm is very important to the ex-service community, unfortunately this is often hindered by health and aged care policies.

In Australia there is evidence that the ex-service community has low access to palliative care services and higher rates of dying in hospitals. More research is required to examine and determine barriers; however a barrier we are aware of is the lack of identification of those from the ex-service community. Even where they are identified, predominantly due to the holding of a Department of Veterans' Affairs health card, there is a lack of acknowledgement of the individual veteran's service history or how this may impact on end of life. There is great potential to improve understanding of the individual by incorporating armed service history in the care planning and assessment processes.

Death is a normal component of the life cycle, yet neither the general public nor medical practitioners feel comfortable discussing it. A cultural shift to normalise these conversations is essential. Advance care planning is an excellent starting point for discussions, especially with individuals diagnosed with an incurable condition. There is much benefit raising awareness about, encouraging and supporting people to complete advance care directives. Studies have shown that advance care planning can improve comfort and dignity at end of life, as well as less stress and anxiety being experienced by the loved ones left behind.

With Australia's ageing population, resources will be stretched, especially in relation to health related service provision. All Australians deserve and have the right to equitable access to quality palliative care services, and it is essential that this be provided at a location of the individual's choice, be that in their own home, an aged care setting, or a hospice. With higher numbers of persons needing and utilising aged care supports and services, it will impact on the aged care industry. As such appropriate reforms to the industry are essential. These reforms will not only promote access and provision of quality palliative care, but also decrease the impact on acute health services and decrease cost implications for the health sector.

Recommendation Summary:

1. That awareness is raised within all health related and aged care sectors to the unique requirements of veterans, their spouses or widows/ers, and their dependants, to ensure appropriate care and response to their needs.
2. That all health related and aged care services identify members of the ex-service community.
3. That strategies to strengthen volunteer visitation from community groups be developed within all health related and aged care settings.
4. That the provision of quality palliative care for those with chronic illnesses, including veterans, be enhanced.
5. That ongoing research in relation to palliative care for all Australians, as well as veteran specific be supported by government.
6. That all Australians have access to education about death, dying and advance care planning. Awareness must be raised to the benefits of advance care directives, and advance care planning actively supported.
7. That all Australians be enabled to access quality palliative and end of life care when needed. Resources and services must be available to support people to die in the location of their choice.

The Returned & Services League of Australia

The Returned & Services League of Australia (RSL) was established in 1916 and is the oldest, largest and most representative ex-service organisation (ESO) in Australia. The RSL is a national organisation with a firm focus on veteran and ex-service community welfare. The RSL's mission is focused on the betterment of the whole ex-service community. This extends beyond those veterans and war widows/ers with entitlements through the Department of Veterans' Affairs (DVA); it includes all past and current serving members of the Australian Defence Force (ADF) and Allied Defence Forces, their spouse, widow/er, and their dependants.

The RSL is committed to ensuring that the ex-service community is enabled a quality of life, and to age and die with dignity supported in a location of their choice.

Introduction

The World Health Organisation's definition of palliative care is used worldwide:

> *Palliative care is an approach that improves the quality of life of patients and families facing the problem associated with a life threatening illness, through the prevention and relief of suffering by means of impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.*

End of life care is defined by Palliative Care Australia as:

> *End of life care is a form of palliative care that is appropriate when the resident is in his or her final days or weeks of life. End of life care requires that the care recipient's decisions are reviewed more frequently and that the goals of care are more sharply focused on the resident's physical, emotional and spiritual comfort needs, and support for the family.*

As such, the aim of palliative care is to provide the best possible quality of life for people approaching end of life and their families/carers. While prevention and management of pain and other symptoms is paramount, each person's view on what is quality of life is an individual journey. For many, especially our older population, choices towards the end of life are often managed by others, including where they die. If a major component of palliative care is to respect the needs and wishes of the individual, then more must be done to ensure the individual's wishes are known and respected, including where they prefer to die. It requires a cultural shift in how we discuss and approach the issue of death and dying.

It is estimated that more than 56 million people died worldwide in 2010 (*Central Intelligence Agency, World Fact Book*), predominantly in developing countries. In the same year here in Australia, 143,500 people died (*Australian Bureau of Statistics, Mortality Rates*). Yet despite dying being a normal component of the lifecycle, people are hesitant to discuss death or dying. With the advances of modern medicine and improvements in living standards, including public health measures and health promotion, life expectancy continues to increase. While an increase in life expectancy does not equate to living disease or disability free, there is an expectation that whatever affliction we suffer, it will be 'cured' by the medical profession. This societal expectation has not only placed mounting pressure on the health and aged care systems, especially with our ageing population, but also has a bearing on access to palliative care services, as palliative care is still predominantly seen by the general population as end of life care, i.e. only being applicable to those in the last few weeks or days of life. To counter this perception, there must be greater awareness around the services provided by palliative care, and access to these services. To support this awareness, there is a need to normalise conversations regarding death and dying. To this end, the completion of Advance Care Directives is an essential tool yet one that is often neglected due to the fear of discussion and made complicated by legislation.

While veterans are not listed on the terms of reference to this Inquiry, for the ex-service community, cultural identity, co-morbidities, alcohol consumption and mental health issues can culiminate in unique requirements, particularly at end of life. The effects of these problems are not well understood by generalist medical, health or care services. As such, the RSL would like to highlight the uniqueness of the ex-service community and why a raised awareness is requried, especially for the provision of holistic palliative and end of life care.

Section 1: The ex-service community

(i) Ageing of the Veteran Population:

The ageing of the population has increased significance to the RSL as the ex-service community is ageing quicker than the general population. According to DVA statistics, there were in excess of 348,900 persons receiving benefit through DVA as at June 2011, however this was a decrease of more than 12,000 veterans and war widows from the previous year. Likewise, statistics held in relation to those persons in receipt of medical treatment entitlement through DVA (treatment population) decreased by 12, 254 in the 12 months from September 2010 to September 2011. The number of deaths per year in the ex-service community is not of surprise considering the ageing of the ex-service population. As a result of the sheer numbers of personnel enlisted in World War II, a high percentage of the ex-service community are now in the higher age bracket. Of those in the DVA treatment population, 75% are aged 65 years and over, and 57% are aged 80 years and over. Over the next decade, the proportion of DVA clients over 90 years of age is expected to more than quadruple. While the only statistics of the ex-service community are in relation to those entitled to benefits through DVA, we can safely assume that the wider ex-service community are of similar age groups.

As can be expected, DVA projections show the continual decreasing of the veteran population, estimating a decrease of approximately 20,000 persons from their beneficiary numbers each year. As the ex-service population decreases our need for quality palliative care services that understand veteran needs becomes more important. For many veterans and their dependants, wartime experience has impacted on their life's journey. As the veteran and war widow/er age, their needs vary from complex medical support to the need for high levels of emotional and culturally specific support.

While the older ex-service cohort is shrinking, the requirement to meet the special needs of this group will continue to be needed for a significant period into the future. According to DVA statistics, as at 30 September 2011 there were 57,865 persons under the age of 65 on the DVA treatment population, 24,114 are under the age of 55 years, and this number is unfortunately continuing to increase year by year.

(ii) Veteran Health risks:

Health issues of the ex-service population continue to be well studied. Analysis of health related problems through the DVA treatment population shows that veterans have higher rates of disease risk factors due to smoking, alcohol consumption, and the effects of trauma. Veterans are more likely to suffer from diseases of the digestive, nervous, circulatory, and musculoskeletal systems. Recent research continues to conclude that they are more likely, compared to the general population, to develop cancer, suffer from arthritis, and suffer from chronic airways disease. Risk factors are also high for the development of Alzheimer's disease. While for an ageing population these chronic medical conditions can be expected, the onset of these chronic diseases occur at a younger age for the veteran population than the general population. Many veterans have multiple co-morbidities with the number increasing incrementally with age. According to DVA, the Australian veteran population has, on average, five or more chronic conditions and a higher use of medication than the general population.

Chronic disease is of major concern for our health system and palliative care services. In the 2009 final report, the National Health and Hospitals Reform Commission found that "*the needs of people living with chronic diseases, people with complex health and social problems, and older, increasingly frail people are less well met.*" (*NHHRC, a healthier future for all Australians*). This description certainly fits with the World War II and Korean War cohorts and frequently results in unplanned admissions, and re-admissions, to acute health facilities.

Ongoing studies of veteran groups both in Australia and internationally are showing that physical and/or mental health illnesses are continuing to be identified, with some effects becoming evident many years post involvement in the armed services. Studies in relation to the veterans of the Korean and Vietnam wars indicate that, for many, health and well-being have suffered as a direct result of service in the armed forces. Similarly studies of the veterans of more recent conflicts are also concluding that health and well-being issues, including mental health illnesses, are more prevalent within armed forces personnel; this is particularly highlighted as a result of the multiple deployments the current, or recently serving, personnel are involved in.

(iii) Veteran Mental Health

More than a quarter of the DVA treatment population have mental health illnesses, about half of which are accepted as being due to military service. Mental health problems include insomnia, anxiety, depression and post traumatic stress disorder (PTSD). Mental health problems were under-diagnosed in the World War II cohort; however we are now seeing the impact of war-related memories associated with the ageing process, such as grief, loss and accelerated dementia. The combination of PTSD with a dementia type illness is especially challenging for the person as well as for family and professional health staff, as PTSD can frequently have a negative effect on war related memories. Mental health illnesses such as PTSD are well documented in relation to veterans, and although treatment programs have been utilised, success has been varied; the impact of the ageing process or the necessity for end of life care will undoubtedly be a further challenge for these veterans with PTSD. Of further concern is the rising numbers of current or recently serving ADF personnel with mental health illnesses. The multiple deployments and diverse operations of our current or recently serving members of the ADF - from combat, post conflict stabilization and peacekeeping, to disaster relief - are feared to be having a cumulative effect, leading to PTSD, depression and anxiety disorders. Studies conducted in the United States (US) and the United Kingdom (UK) are raising similar concerns to the studies being conducted here in Australia. So again, due to the effects of service, mental health illnesses continue to plague the ex-service population from a young age. Furthermore, while mental health illnesses are sufficiently disabling on their own, many of these veterans, like the veteran cohorts before them, try to solve their own problems through alcohol and drugs.

Mental health issues do not just affect the veteran. Research indicates that the effects of PTSD can also impact on partners and children. The partners or caregivers of veterans who suffered PTSD have been shown to have higher levels of depression, anxiety, hostility, obsessive compulsive symptoms, and physical complaints.

Despite the knowledge that has been gathered through research over the past few decades in relation to PTSD, there has been minimal research undertaken in Australia to investigate the effects that PTSD can bear on end of life. In the National Palliative Care Strategy 2000, individuals with mental health illness, acute stress disorder (ASD) and PTSD, including veterans, were highlighted with specific needs in relation to the provision of palliative care. Despite this, there has been minimal education of the general medical, nursing and health services about PTSD or about veteran care. Furthermore, despite the 11 year duration since the implementation of the Strategy, there have not been any projects to address the needs of people with dying suffering a co-morbidity of PTSD, nor are there any statistics kept by any State Health Department relating to numbers of people with a co-morbidity of PTSD receiving palliative care.

(iv) Veteran Cultural Identity

Culture profoundly affects the way we feel about ourselves and gives purpose to our lives. As previously stated, veterans identify themselves as members of a distinctive cultural group, the basis of which stems from shared war time experiences. It is a culture that has been in existence for almost a century. Bonds of mateship were formed in times of danger, as such there is high importance placed on "looking after your mate" and "looking after your mate's family". Commemoration of those who did not return from conflict is a vital aspect of the ex-service community ethos. While age and infirmity can hinder participation in commemorative services, the desire and "need" to participate does not diminish. As such ESO's like the RSL spend much time ensuring that all from the ex-service community are enabled to attend some type of commemorative activity, which includes services being conducted at aged care facilities and hospices (where agreed) or providing transport to commemorative services for those living in the community.

Predominantly there is high membership of ESO's and other social groups. The importance of remaining connected and part of the ex-service "family" is of significant importance to the majority of veterans or their widows/ers. It is not uncommon for a veteran to be a member of several ESO's simultaneously, and each will play an important role in their lives. There is high importance placed on volunteering to provide welfare activities to the ex-service community. Since World War I, war widows have been supported by legatees, a voluntary activity provided by veterans to ensure the safety and welfare of the widows and children of those who did not return. However age and infirmity, and the shrinking of the World War II cohort is now impacting on the extent of these volunteer activities.

Despite the ageing process decreasing numbers of veteran volunteers, there is one activity that continues to be of high priority to fulfil, that of providing a friendly visitor to those living alone in the community, living in residential aged care, or in hospital. "A mate for a mate". Palliative care studies demonstrate the vital work of volunteers in palliative and end of life care; likewise for veterans the importance of a visit from another who has lived similar experiences cannot be under-estimated.

Studies in the US consistently find that when facing end of life, veterans have an overwhelming need to talk to someone who understands. This is not surprising considering that it is common for an individual to look back over their life when faced with a terminal condition. For veterans the end of life experience may trigger emotions and memories from war related memories or trauma, thus the importance of talking with someone who has an appreciation and understanding of certain experiences, those experiences known only to another who has experienced them. The need for older male veterans to receive visits from men of similar age and background was also highlighted in the Victorian veteran palliative care study. In the US, one Veterans' Affairs (VA) facility is undertaking a project titled 'no veteran dies alone'. While projects such as this can be supported in the US due to the greater numbers of returned servicemen and women, all VA hospices see the use of volunteers from the veteran community as essential to quality end of life care.

The National Palliative Care Strategy highlights the invaluable support provided by volunteers and community networks to the social and emotional aspects of those individuals receiving palliative care. Unfortunately, gaining information that there is a veteran receiving palliative or end of life care, unless informed by family members, is frequently hindered by hospital or aged care Privacy policies. The RSL and other ESO's respect the Privacy Act; however it again raises the issue of health professionals and admission/ assessment forms asking the right questions. The simple act of asking if the individual would like a visit from an ESO would not negate the Privacy Act yet would enable the individual to stay connected to and supported by the ex-service community.

The RSL regularly requests health and aged care facilities to raise the question, 'Are you a member of an ESO? Would you like a visitor from an ESO?'. While this particular question is for the benefit of the ex-service community, the type of question asked could also benefit many other individuals from special needs groups, especially those groups where connection to 'their' community is of high significance.

(i) Veterans: special needs group

Since 2001, veterans and the wider ex-service community have been recognised with 'special needs' status for aged care planning. The decision to grant special needs status was based on the rapid ageing of the veteran population, their unique cultural identity, and the sacrifices and hardships endured as a result of their service and their spouses' service. Achieving special needs status demonstrated Australia's debt of gratitude to the ex-service community, and continues to honour and respect those who served in the defence of our nation.

Despite this honour, there has been minimal awareness raised in the aged care sector of veterans' special needs, and there is also little knowledge of their unique needs in main stream health. In relation to the provision of quality palliative or end of life care, veterans and their spouses have been specifically noted with special needs in the National Palliative Care Strategy both in 2000 and in 2010, yet to date this has not achieved improved access to palliative care services nor improved end of life care for this group.

Access to specialist palliative care services may not always be necessary for all persons who are dying, however it is essential that every dying person be provided care that encompasses palliative care principles. These principles include comfort, pain and symptom management, promotion of dignity, involvement in decision making, and bereavement support for families/carers. That National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life (2010) states, "*there are unmet needs of many from defined population groups and those with specific conditions.*" This list of population groups with unmet needs includes veterans and their spouses. The uniqueness of the ex-service population is that it crosses other cultures and other special need groups. Thus by improving awareness and knowledge of veteran needs, these skills can also be utilised in caring for those with a similar background in other disadvantaged groups. For example:

- There are a great number of veterans, past and present who are from Aboriginal and Torres Strait Islanders' backgrounds;
- There are veterans who reside in rural and/or remote areas;
- The RSL is aware of many veterans who are financially and/or socially disadvantaged;
- Many of our allied veterans are from non-English speaking backgrounds, such as European countries, Ceylon, South Korea, South Vietnam;
- Following a DVA funded study, we know that we have a sizeable homeless veteran population;
- Many veterans suffer mental health issues and/or suffer with dementia;
- Many of our older veterans or their widows/ers live alone in the community; and
- There are a number of veterans from the LGBTI special needs group.

While each of these groups have their own unique needs, the experience of their time within the armed services will add a further dimension to their physical and mental health care needs, especially at end of life.

(vi) The Need for Identification

While raising awareness and improving knowledge of veteran specific needs is of paramount importance, it will not be successful unless procedures of identification are improved. The RSL is aware that many health facilities and aged care providers only identify veterans as a result of the DVA health card. There are many from the ex-service community who do not have DVA health entitlements. Some of this group may receive other benefits through DVA, such as pension entitlements, however there are others who have never approached DVA for entitlement. For another group, while DVA does cover health benefits, they do not carry a DVA health card. A further complication is that there are some who are silent about their past, although it has been noted that this silence changes toward the end of life. As this demonstrates, if health and aged care services only identify veterans and war widows/ers by a gold, white or orange DVA card, many from the ex-service community are not being identified and thus their needs not appropriately met.

In a small Victorian study it was noted that even where there is identification it is in relation to DVA entitlements not the individual: "*no veterans' files contained any reference to their service years, nor the primary conflict in which they had been involved. Given that end of life, individuals often reflect on their life experiences, this is arguably a significant omission.*"(*O'Connor, M. What are the palliative care needs of veterans being cared for at home? 2011*)

This lack of recognition to the lives led by individual veterans is significant. Without gaining this information it is impossible to integrate their unique history into planning holistic end of life care. To the ex-service population, where one served, in which branch of the armed forces, and rank are all of significant importance to their cultural identity. Studies have shown that it also has much bearing on health and well-being, with each conflict, together with combat exposure, rank and service branch having effect. For example:

The Australian Korean War Veterans' Health Study was commenced in 2004. At that time, approximately 57% of the original 17,872 veterans had already died. Of the surviving veterans, they reported high levels of psychological ill health, lower life satisfaction and poorer quality of life, excess medical conditions resulting in high levels of hospitalisation, and a lifetime pattern of alcohol and cigarette abuse. However, the findings of the Study also demonstrated some differences in this cohort.

- Combat exposure - veterans who experienced heavy combat were 15 times more likely to suffer PTSD, six times more likely to have anxiety or depression, and twice as likely to have a history of alcohol problems compared to those veterans who reported no combat exposure. This group also reported lower life satisfaction or poorer quality of life.
- Rank - those veterans of lower rank were much more likely to have poor health, PTSD, anxiety, depression, and history of alcohol problems. These findings were independent of effects of age or education.
- Service Branch - Army veterans reported the poorest life satisfaction. PTSD, anxiety, depression, and history of alcohol problems were most prevalent in Army veterans, less prevalent in Navy veterans, and least prevalent in Air Force veterans.

Studies have also reviewed these differences in veterans of the Vietnam War. While studies show that there are high rates of PTSD amongst the Vietnam veteran cohort, they also have elevated incidence of cancer rates. Along with alcoholic liver disease, Vietnam veterans have 15% higher rates of cancer as compared to the general population, including melanoma, Hodgkin's disease, chronic lymphoid leukaemia, cancers of the prostate, eye, head and neck, and lung. Yet each service branch showed differences in cancer presentations.

- Navy - Navy veterans had higher rates of mortality from lung cancer and melanoma, but lower rates of mortality from non-Hodgkin's lymphoma.
- Army - Army veterans had higher rates of head and neck cancer and eye cancer.

- Air Force - no significant difference noted in mortality from neoplasm's than the general population. (*Australian Vietnam Veterans Mortality and Cancer Incidence Studies, Overarching Executive Summary*)

To provide the best possible quality palliative or end of life care, there has to be an understanding of the life of the veteran. There is potential to influence the practices of health practitioners through incorporating the service history of veterans in health and aged care documentation. The lack of current information about the individual's war service, or that of a spouse, not only makes exploration of possible underlying health and mental health problems very difficult, but disregards their cultural identity. This has also been noted in the US:

> *The Department of Veterans' Affairs (VA) hospice units have learned a critical lesson in caring for dying veterans: a patient's military history is highly relevant to providing the most appropriate, personalized end-of-life care. Recognizing the unique needs of our nation's veterans who are facing a life-limiting illness is important in guiding veterans and their families toward a more peaceful ending. (Dignity for Veterans at End of Life, Health Matters Magazine)*

(vii) Research on Veteran End of Life

While there has been minimal research conducted in Australia in relation to veterans and end of life care, there has been much work on this topic undertaken in the US.

> *Veterans have unique, often unrecognized hospice needs that complicate the dying process. For example, military culture instills stoic values that might interfere with peaceful dying. A "fight to the bitter end" attitude complicates death, requiring skillful intervention from hospice clinicians. On a battlefield, death is the enemy and "surrender" is failure; yet much of hospice work focuses on "letting go" and "surrendering." Additionally, combat veterans' last experience with death may have been filled with horror, and helplessness on the battlefield. These associations may also interfere with a peaceful* death. (Grassman, *Veterans: An undeserved Population, 2007*)

Many of the US studies are indicating that PTSD or other mental health problems such as anxiety and depression are being frequently noted as World War II veterans face end of life. Furthermore, studies have shown that some veterans who had not previously had signs of PTSD may experience delayed onset at end of life as the dying experience may trigger emotions and memories from their service years. While there are members of the general population who also develop PTSD from traumatic experiences, a US study argues that military combat may be different than other traumas due to the probable repitition of the trauma, ie frequent danger to self and also seeing others harmed/killed. Some of the potential effects of PTSD at end of life can easily be misdiagnosed to be part of the dying process, such as constant irritability, difficulty sleeping and/or nightmares, mild paranoia, vivid hallucinations, and severe depression, thus treatment/management is not appropriately provided. In a US education presentation to hospice staff regarding veterans at end of life, the need to monitor for PTSD is highlighted:

- *"Threat to life can mimic the original trauma, and exacerbate previously mild symptoms.*
- *The normal process of life review can lead to intense anxiety, saddness, guilt, and anger.*

- *Avoidance as a coping mechanism may lead to poor medical adherence or poor communication with medical staff.*
- *Distrust in authority can lead to excessive questioning of provider's actions and refusal of care.*
- *Patients with PTSD may lack caregivers because of a history of social isolation and avoidance.*
- *Emotional numbing may create distance with loved ones."* (*O'Leary et al, The Unique Needs of Veterans at the End of Life, education presentation*)

The PTSD & End-Of-Life for Maine Veterans Fact Sheet (US), highlights that veterans receiving diagnosis of a terminal condition often want to:

- *Make sure their story has been heard.*
- *Put the traumatic events into some sort of perspective in their lives.*
- *Deal with the effects that PTSD has had on their lives, such as mending relationships, giving and accepting closeness and affection, and getting affairs in order.*

The US literature in relation to veterans and end of life, including issue of PTSD as a co-morbidity at end of life, is substantial. There is recent legislation enacted in the US that all VA health services must provide (either themselves or via contracted services) palliative care services and end of life care.

In Australia the research is limited. While the small studies that we have indicate low access to palliative care services, more significantly the studies indicate that veterans are not consistently identified by medical services. Where veterans are identified due to DVA health card, potential for a co-morbidity of PTSD is not monitored. As reported in the small Victorian study, "there *was no reference to any PTSD that may have been experienced by veterans and no correlation between their service years and the cause of death."* (*O'Connor, M. What are the palliative care needs of veterans being cared for at home? 2011*)

In 2011, DVA listed the need for research to be conducted in relation to veterans and access to palliative care services. The RSL certainly welcomes this research, providing that end of life needs are also captured, and that the results are utilised to develop appropriate resource and education material and information guides for the ex-service community. Best practice concepts should also be explored. This type of information is already available in the US and is raising awareness and knowledge of the unique needs of the ex-service community. The devlopment of information, guidelines or best practice modules could be provided to all health professionals, including medical practitioners and nursing staff, carers, veterans and their families to promote awareness and service provision.

(viii) Influences on Palliative Care Access and Choice in the Ex-Service Community

There are a number of influences that effect access to, and choice of palliative care services by the ex-service community. While some of the influences are DVA entitled veteran specific, others are the same as for the general population. The general influences range from lack of knowledge in relation to the role of palliative care services and/or their availability, to the complexity of determining access. While each State has exceptional palliative care services, access can be different region to region. For example, in some States or regions any health professional can refer a person to palliative care services, however in other regions, the only way to access is via referral from a medical practitioner. These differences hinder access to specialist palliative care support.

The more specific influences for the ex-service community are unique to veterans on the DVA treatment population. A veteran or war widow/er in receipt of a DVA health card, in particular the gold card, is able to access more support to remain in the community. This treatment population accesses more health care professionals than the general community, and has little difficulty obtaining prescribed medication and required equipment, home help and community nursing support. Furthermore, within the DVA community nursing program there is a palliative care pathway. As a result, this cohort potentially has less stress at end of life. However, despite the entitlements, very few veterans die at home. While there is a distinct lack of research here in Australia as to why this occurs, it could be due to the significant burden of co-morbidity, or it could be as a result of break downs in the caring relationship due to insufficient general community support to keep them at home.

What limited studies that have been conducted in Australia indicate that access to palliative care services is low. A study conducted in NSW and ACT between 2000 and 2001 found that 75% of veterans and war widows/ers died in general public hospitals, only 15% had access to palliative care. Of those who accessed palliative care, 9% were cared for in dedicated hospice or palliative care units. The study further identified that in the non-hospice patients, palliative care consultations were low, around 3% for males and considerably less for females. (*Ireland, A. Dying in hospital: Summary of presentation to medical advisors seminar. DVA NSW office, March 2003*)

The low levels of access could also be related to a lack of information, both about their prognosis and about the availability of services. A recent veteran and carer project in NSW in regard to advance care planning, identified that veterans had a perception that their medical practitioner would tell them when they needed to consider writing an advance care directive and when they would need to access palliative care. However, discussions with the medical practitioners during the study highlighted that they did not feel comfortable talking about these topics, nor did they feel comfortable raising it especially if there had been a long standing doctor-patient relationship. So the dilemma, the veterans believe their medical practitioner will make the referral when it is needed, yet the medical practitioners are not willing to have the discussion thus resulting in no referral to palliative care services (*Report to DVA, not yet published*).

This lack of real communication was also highlighted in the Victorian study. "*Two veterans indicated that they did not really understand their illness and 'nobody has explained anything to me properly'*." Unfortunately this study also indicated that it is not just medical practitioners that do not initiate discussions around the issue of dying. "*There was little evidence of nurses explaining future care or end of life care with families – rather this was the domain of counsellors and pastoral carers.*" (*O'Connor, M. What are the palliative care needs of veterans being cared for at home? 2011*) The provision of holistic, quality palliative care requires a multi-disciplinary approach inclusive of input from specialist services, not one where dying is only talked about by ancillary services such as counsellors, social workers and chaplains.

The importance of having full and honest information to ensure choice can be exercised was highlighted in the findings of a study of elderly veterans and war widows regarding treatment choices in life threatening illness.

> *Overall participants were more likely to choose palliative care than invasive treatments. Men, especially older men, were more likely than women to choose invasive treatments. The study indicated that participants want to exercise choice in their treatment but that they want this to be an informed choice. (Barr, et al. Treatment Choices in life threatening illness: Attitudes and preferences of elderly Australian Veterans and War Widows, 2002*)

It is easily identified that to influence access to palliative care services, the key requirement is knowledge. Knowledge of services and support available and how to access them, but just as importantly, knowledge of disease prognosis. DVA has recently established the Coordinated Veterans' Care (CVC) Program as a step to improve the general wellbeing and provision of health care to chronically ill veterans with health (gold card) entitlement. The program is designed to provide coordinated care by medical, nursing and allied health professionals for those chronically ill veterans residing in the community. This program has only just commenced, however it may provide a link to appropriate referral and access to palliative care services for these veterans. While only a small percentage of those entitled to DVA health benefits will be part of this program, it may also have the added benefit of improving health professionals' knowledge of veteran specific needs.

There is much more work required in terms of educating veterans, their families and/or their carers about palliative care and options available to them, which includes support to remain at home. This is as appropriate to the general population as it is to the ex-service population. Providing appropriate education may assist people to access palliative care services earlier and promote a more comfortable and dignified death in the location of their choice.

Recommendations in relation to the ex-service community:

1. That awareness is raised within all health related and aged care sectors to the unique requirements of veterans, their spouses or widows/ers, and their dependants, to ensure appropriate care and response to their needs:
    - Education programs should be developed for health professionals to provide understanding of the unique needs of veteran patients and to raise the profile of veteran patients in the health related and aged care sectors. These programs could be incorporated into orientation programs. This action would increase health knowledge of the ex-service community. Similar programs are already in existence at ex-service owned/managed aged care services and at the Austin Hospital's Repatriation Campus in Victoria.

2. That all health related and aged care services identify members of the ex-service community:

- Examine the barriers that inhibit knowledge of veteran status within acute and aged care settings.
- For the RSL advocates for the inclusion of a question that assists with the identification of individuals from the ex-service community on all health related and aged care admission forms. For example: *'Were you or your spouse a member of the Australian Defence Force or of an Allied Defence Force*?' If the response is to the affirm, more questions need to be raised in relation to where served and in which branch of the armed services. Further questions will come from these responses.

3. That strategies to strengthen volunteer visitation from community groups be developed within all health related and aged care settings. For many different groups, including the ex-service community, support to remain connected to 'their community' is essential. This is important not just in relation to those dying, as loneliness, boredom and isolation from their community also have adverse impacts on physical and mental health. To strengthen volunteer visitation from 'their community':
    - The RSL advocates for the inclusion of a question on all health related, especially palliative care services, and aged care admission and assessment forms specifically enquiring if the individual wishes visitation from community support groups, including ex-service organisations.

4. That the provision of quality palliative care for those with chronic illnesses, including veterans, be enhanced:
    - Promote the use of chronic disease management programs and care planning to better manage chronic or terminal conditions, thus decreasing hospital admissions and reducing health costs associated with chronic disease management.
    - Promote referrals to palliative care services in the early stages of terminal disease trajectory.
    - Strengthen connections between palliative care providers and local communities, including the veteran community, to assist with improving the understanding of available support services for people facing terminal conditions.
    - Medical and health professionals require further and ongoing education to normalise communication regarding death and dying.

5. That ongoing research in relation to palliative care for all Australians, as well as veteran specific must be supported by government. In relation to veteran specific:
    - Health and aged care services must collect and record data in relation to patients requiring palliative or end of life care who have a co-morbidity of PTSD.

- Once data collected, undertake research in relation to the effects of PTSD at end of life care and to identify best care responses to address.
- Research must be undertaken to examine barriers to veterans' access of to palliative care services.
- Research must be undertaken to examine barriers to veterans dying at 'home'.
- Research to be undertaken to inform veteran best practice modules; modules to be developed and disseminated to health, hospice and aged care facilities.

Section 2: Advanced Care Planning

Australian studies on advance care planning conclude that it improves end of life care and provides what families consider a better quality of death. The Respecting Patient Choices program, based at the Austin Hospital in Victoria have undertaken much work in promoting advance care planning both in the hospital and residential aged care settings. The concept revolves around planning, discussing and/or recording your preferences for future healthcare around end of life at a time when you are unable to make decisions or express your wishes.

As indicated by the Respecting Patient Choices program:

- About 85% of people will die after chronic illness, not sudden events.
- Almost 50% are not in a position to make decisions when near death.
- There is a significant chance that families will not know what the dying person's views or wishes are about end of life care.
- Medical staff will generally commence aggressive treatment if uncertain about a person's wishes.

With our ageing population and with it the rise in chronic diseases, advance care planning is a key component to providing quality aged, palliative and end of life care. All to frequently we see older, frail persons transfered from residential aged care to hospitals for treatment that is unwarranted, and for many unwanted, as a result of general practitioners, care staff and/or families not being aware of the person's wishes, or more simply due to the expectation of 'cure' for all ailments.

Advance care planning has been shown to have a positive effect on both the person dying and the surviving relatives. For the dying, it has been demonstrated that it improves ability to maintain both autonomy and dignity at end of life, and for the surviving relatives, they felt less burden thus decreasing rates of anxiety and depression post their loved one's death (*Respecting Patient Choices*). The undertaking of advance care planning in residential aged care has been shown to empower care staff and relatives to keep a person's wishes.

The importance of advance care planning and the connection to the provision of quality palliative care is discussed in the Productivity Commission Inquiry Report – Caring for Older Australians (2011). This report also acknowledged the completion of a National Framework for Advance Care Directives but added that there was a case for harmonisation of state and territory based legislation with regard powers of attorney and guardianship. The RSL supports the need for legislation and documentation regarding advance care planning and powers of attorney/guardianship to be nationally consistent.

While national consistency around these two areas is of vital importance, the success of advance care planning is dependent on people's willingness to discuss the subject of death and dying, ease of access to practical information, open dialogue regarding condition prognosis, and most importantly that each person's wishes are respected and carried out by all.

The Community Based Palliative Care Support for Veterans and their Carers project undertaken in NSW from 2009 to 2011 identified key issues and considerations that needed to be addressed in respect to advance care planning. They identified that veterans and their families were reluctant to talk about issues related to mortality, although were more likely to listen to other veterans. While many of the veterans and their families preferred to die at home, this was a challenge due to the lack of health related information on disease prognosis, and the lack of discussion on options available. They also identified that referrals to palliative care services came too late in the end of life journey (*report to DVA, unpublished*). As a result of this project, information resources have been developed to support veterans and their carers at end of life; resources include a DVD on Advance Care Planning and document to complete, a Guidebook 'supporting end of life care at home', and a simple 'palliative care pathway' summary sheet with important contact details. Strategies to promote Advance Care Planning within the veteran community, based on this project, are currently being rolled out across NSW; the RSL looks forward to a national roll out.

We need to normalise discussions on death and dying. As previously stated, the Veteran and Carer project in NSW identified that neither patients and their families nor the medical practitioners felt comfortable in discussing dying. Unfortunately in our society, having conversations about care at time of death is seen as a difficult issue. However to have the opportunity to die a proper and dignified death the community needs to be educated about the reality of death and dying, this includes medical, nursing and other health related professionals as well as the general public. There is a desperate need to raise community awareness of these topics.

The need to raise awareness and assist individuals to discuss advance care planning is not something that has just been identified. State governments currently fund a number of health services to undertake this role. The Department of Health and Ageing also provide funding for pilot projects, such as the Making Health Choices program currently being trialled in a small number of Victorian residential aged care facilities. The Department of Health and Ageing acknowledges that this is an important role in residential aged care and as such advance care planning is planned to be given focus in the new Accreditation Standards.

Recommendation:

6. That all Australians have access to education about death, dying and advance care planning. Awareness must be raised to the benefits of advance care directives, and advance care planning actively supported.
    - Normalise conversations regarding death and dying, including skilling and supporting medical practitioners with this role.

- Appropriate funding must be made available to increase community awareness and education on advance care planning.
- Ongoing education of all health and care professionals to ensure appropriately skilled to discuss advance care planning with patients.
- National consistency of legislation must be implemented to support advance care planning.
- The RSL would support advance care directives being included in the proposed electronic health records.

Section 3: Ageing Australian Population and Palliative Care

Similar to other developed countries, Australia's population is ageing. The statistics are well known. According to the intergenerational report (2010) the numbers of older people aged 65 to 84 years will more than double between 2010 and 2050. At the same time, the numbers of very old people, those aged 85 years and over, will more than quadruple. The ageing of the population has wide implications on health services, and funding thereof, particularly as ageing brings complications of chronic disease, especially dementia.

The Productivity Commission Inquiry Report - Caring for Older Australians (2011) provides great detail of the effects of an ageing population on medical, health and aged care services. While advances in medicine can improve management of some diseases, it cannot solve problems associated with living longer, such as dementia and age associated disabilities, nor can it prevent the fact that all persons will eventually die. As such, providing quality palliative care and end of life care is essential.

The ageing of the population will increase the demand for palliative care services, yet currently access to quality palliative care is dependant on the setting of where people live, which thus influences where people will die. As identified by the Productivity Commission:

> *There is a strong case for a greater role for residential and community providers to deliver excellent palliative care and end-of-life care. Not only is this likely to be less expensive than equivalent services delivered in a hospital, but more appropriate care can be provided in a home-like environment that best meets the desires of the dying.* (*Productivity Commission Inquiry Report - Caring for Older Australians, 2011*)

In residential aged care, death and dying is not uncommon, as such, both palliative and end of life care should be core business in this setting. Unfortunately, use of palliative care services or provision of quality care that encompasses palliative care principles is not the norm. Due to the ageing of the population, we have an increase in people with dementia. Dementia is a life limiting condition that requires quality end of life care over a longer period of time. Residential aged care facilities already have high percentages of residents with dementia, and this is predicted to continue to rise. Despite the introduction of the National Palliative Care Strategy in 2000, this did not increase the number of older persons being provided quality palliative or end of life care. While the National Palliative Care Strategy 2010 has been developed, without adequate funding and appropriate and ongoing education for all health professionals, including care staff, nursing staff, allied health professionals and general practitioners, implementation will be ad hoc.

The introduction of advance care planning and improving the quality of palliative care and end of life care in residential aged care, would prevent many unwarranted and costly transfers to acute hospitals, including transfers to intensive care units. For many older people, especially those with dementia, residential aged care will be their final home. Unfortunately, as stated in the National Palliative Care Strategy 2010, only 10% of deaths occur in residential aged care, with a huge 70% occurring in hospitals.

It is estimated that there are significant cost savings if quality palliative or end of life care is provided in the residential aged care setting. Currently it costs approximately $140 per day to provide palliative care in residential aged care, as compared to $600 per day in a hospital. This certainly demonstrates that urgent change is required, both from a financial perspective and also from a quality of life and dignified death perspective. Too many of our older generation are transferred from their home, whether own home or residential aged care, to a hospital where they are surrounded by strangers in a cold clinical environment. While it is more cost effective for people to "die in place" rather than be transferred to acute health facilities, there is much work to be done to ensure that this results in a comfortable and dignified death. A shortage of skilled staff, the lack of appropriate equipment, and the lack of appropriate aged care funding would all need to be addressed. Additionally all health professionals and carers must receive ongoing education on palliative and end of life care; furthermore, advance care planning has to become part of the admission assessment processes.

There are also barriers to receiving quality palliative care in the community. Barriers predominantly revolve around funding issues and health/aged care silos. In relation to funding, community aged care funding does not include any explicit provision for palliative care, in fact the assumption is that palliative care is provided through the health system. Due to the silos of our aged care system, for those who are in receipt of specialist palliative care services, they can be denied access to other support services through HACC or even denied access to community aged care packages.

These issues were also highlighted in the Productivity Commission Inquiry Report - Caring for Older Australians (2011). The Commission provided recommendations that covered improvements to palliative care services and end of life care, including choice, funding, access, education, and advance care planning. In particular:

- Recommendation 4.1 - that the aged care system *"be consumer directed, allowing older Australians to have choice and control over their lives and to die well"*.
- Recommendation 9.4 - the creation of a single integrated aged care system, based on care entitlements covering all aspects of care, including respite, reablement, home modification, care co-ordination, and palliative care; all Australians access services via 'the gateway'.
- Recommendation 10.3 – *"The Australian Government should endure that residential and community care providers receive appropriate funding for delivering palliative care and end-of-life care."*
- Recommendation10.4 – *"Providers of aged care services should have staff trained to be able to discuss and put in place advance care directives."*

The implementation of these recommendations would alter current barriers. If we are to examine influences on access and choice, accurate information and consistency of programs, which includes adequately skilled staff and sufficient funding to carry out the programs, have to be the most important.

<u>Recommendation:</u>

7. That all Australians be enabled to access quality palliative and end of life care when needed. Resources and services must be available to support people to die in the location of their choice.
    - Adequate and appropriate education relating to palliative care and end of life care must be provided to all health professionals, including being a component of all undergraduate health related education.
    - Palliative care Standards must be embedded in all health and care settings.
    - Governments must provide adequate funding for provision of palliative care in aged care settings, with emphasis on supporting choice of location to die.
    - The RSL supports the recommendations of the Productivity Commission in relation palliative care services; in particular the importance of choice, funding, access, education, and advance care planning (recommendations 4.1, 9.4, 10.3, and 10.4)

Conclusion

Despite dying being a normal component of the life cycle, death remains a taboo subject. The lack of discussion in relation to death and dying impacts on referrals and access to palliative care, and also impacts on ability to have choice over location of death; this is certainly evident in relation to the veteran community, although further research is required to determine why there is low access to palliative care or being supported to die at 'home'.

Veterans have been identified as having unique needs. Special needs status was gained in relation to Commonwealth funded aged care in 2001. Likewise the National Palliative Care Strategy in 2000 also recognised that they had unique and unmet needs in relation to palliative and end of life care. However, despite the recognition, awareness of veterans' special needs are very limited in health and aged care settings, and identification of this group is limited to those who hold a DVA health card. Awareness of their unique physical and mental health and cultural characteristics must be increased in the health and aged care sectors.

Awareness must also be raised in relation to the importance of advance care planning. Improvements in this area would prevent transfers from place of residence, whether own home or a residential aged care facility, to hospitals where aggressive treatment is often unwarranted and unwanted.

To influence improved access to, and use of quality palliative care, there needs to be consistency of service access and availability regardless of where people live. Information should be readily available and easily understood to assist the community to understand when and how to access palliative care. Without appropriate discussions and information about options available, individual's choices will always be limited.

Ensuring adequate funding for the provision of quality palliative care needs to be combined with the skilling of medical, health and nursing professionals and care staff.

Quality palliative care requires a multi-disciplinary approach inclusive of input from specialist services, not one where dying is viewed as the domain of ancillary services. Finally, there needs to be a cultural shift – society must accept that death and dying are normal components of the life cycle; death and dying need to be normalised in conversation.