ADACAS
ADVOCACY

Dear Sir/Madam

RE: SENATE INQUIRY – CARE AND MANAGEMENT OF YOUNGER AND OLDER AUSTRALIANS LIVING WITH DEMENTIA AND BEHAVIOURAL AND PYSCHIATRIC SYMPTOMS OF DEMENTIA (BPSD)

The ACT Disability Aged Carer and Advocacy Service (ADACAS) provides advocacy to persons living in aged care facilities as well as those living in the community. ADACAS welcomes the inquiry by the Committee into the care and management of Australians living with dementia.

ADACAS is becoming increasingly concerned that the rights of elderly Australians are being eroded or ignored, and that this is particularly so for those living with dementia. It appears to ADACAS that once a diagnosis of dementia is made, decisions regarding every aspect of a person's life start being taken on their behalf – from where they live (and even who they share a room with), to what they eat, when they shower and who showers them, who they can socialise with, and where they go and at what time.

This appropriation of a person's right to make their own decisions is often done without any authority, or if authority is gained a blanket approach is applied even if a person still has the capacity to make decisions in some areas of their life. Often these decisions are wrapped in the mantel of 'duty of care' and without consultation with the person to whom they are being applied. While duty of care is obviously a legitimate obligation, ADACAS believes it is being too readily invoked and in many instances has become a means of managing behaviour, which is undermining peoples' basic human rights.

In 2010, the CEO of Hammond Care, Dr Stephen Judd, told the *8th Biennial International Conference on Dementia* that "the rights of citizens in Australia are being eroded by a protective disciplinary culture that denies them the basic freedoms of citizenship. At home we have the right to smoke, have pets, get fat and have sex if we want; but in aged care facilities we become captive in a controlled environment where we are 'protectively disciplined'. "He said that "aged care programs often conceive the elderly person as a subject to whom actions and ideas are applied, rather than as a person with an individual history, habits and beliefs and distinct likes and dislikes".

This largely reflects the experience of ADACAS advocates who are frequently engaged to help elderly people with dementia, both in residential aged care and the community, have their voices heard and to ensure that their rights are upheld. We have been involved in issues, for example:

- Where children or guardians have made financial decisions in relation to the person with dementia's assets which are contrary to what the person wants and has previously expressed;
- Where the management of aged care facilities have prevented the person with dementia from forming relationships of their choosing, often at the insistence of family members who have no legal authority to impose their wishes on their relative and to the great distress of the person involved;

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- Where staff and management of facilities have restricted a person's mobility through removing their motorised scooter for 'safety reasons', without having had any independent assessment of the person's ability to continue to use their scooter safely.

ADACAS acknowledges and understands that many aged care providers are finding it difficult to attract and retain skilled staff and that facilities are often under-staffed, with staff working long hours. It is our submission that notwithstanding resource limitations, facilities are obliged to uphold and respect the human rights of persons with dementia and to invest in comprehensive training for staff to understand how to communicate and understand people with dementia as individuals and to provide them with the time and space so that they are able to communicate and work effectively with them.

ADACAS advocates for individuals on the basis of their expressed wishes, whether or not they have dementia. It is our observation that rather than listening carefully to the person with dementia to ascertain what they want, the commonly adopted approach is one whereby the staff and management of aged care facilities, as well as the person's families and guardians, are increasingly resorting to imposing a 'best interest' approach to the resident, even quite early in the progress of the condition. This is where the person's wishes are not considered or taken into account; rather it is decided by someone else what that person's best interests are. It is our strongly held belief that although a person may suffer from dementia and although that dementia may make communication increasingly difficult, the person with dementia retains fundamental human rights that include inter alia the right to family, freedom of movement, the right to information, and freedom of expression. Although communication may often be difficult and problematic it is imperative that all concerned take the time and care to adopt a person centred approach whereby they listen and communicate with the person with dementia, in an effort to understand what their wants and needs are and, where possible, to act upon them.

ADACAS recognises that people with dementia may display their feelings and wishes through their behaviour when they lose the use of more traditional communication modes. It is beholden on those who care for them, to observe behaviours as an expression of the individuals need and attempt to discern what lies behind the behaviour, rather than respond to behaviours as non-compliance or 'naughtiness'. An alternative model which ensures that the express wishes of residents with dementia are respected and valued has been described by Julia Farr Purple Orange in their model of valued citizenship (Robbie Williams pers comms 2013). The model highlights the two very different approaches that can be adopted when dealing with issues of risk with regards to residents with dementia living in aged care facilities.

<u>Approach One: Problematized behaviours:</u>
Where a resident presents with a behaviour or issue that the facility or service identifies as a risk, this may trigger in the facility a 'duty of care' response. Often, the way that the person's behaviour is perceived by the management and staff of the facility is that of a "problem that needs to be managed". The facility will then focus on issues such as safety and security for the resident with dementia and other people. Consequently, the resident with dementia becomes increasingly isolated and excluded from society i.e. they are taken into a form of "custody" where they are deemed to be protected and thus become invisible to the community. Their thoughts, beliefs and input into the situation are dismissed or not incorporated in the response plan. They are no longer counted as having an important part to play in the process of their care and daily life. We submit that many aged care facilities take this approach more often than not when faced with residents who have dementia and are not compliant.

<u>Approach Two: Valued Citizenship:</u>
Where a resident with dementia presents with a behaviour or issue that the facility identifies as risky a duty of care response is also triggered. However, the staff and management of the facility using Valued Citizenship recognise that the person's right to an ordinary, valued life is the context of the

behaviours and therefore instead of seeking to 'manage a problem' they would, try to discover a solution that respects the individual and their right to an ordinary, valued life. The facility will then identify and implement enabling safeguards (as opposed to disabling security measures) while simultaneously seeking opportunities for the resident with dementia to flourish and grow towards achieving or sustaining a 'valued life'. The resident with dementia thus becomes included in the process towards achieving a valued life, is visible and part of the community.

Consider the example of a resident with dementia who seeks to use a motorised scooter to move around outside the facility and do his shopping independently. The Problematized Behaviours approach would view the scooter use as a "safety problem", and duty of care would result in a 'ban' on the use of the scooter, effectively denying him freedom of movement. The resident would not have any input into the issue, would no longer be able to move outside the facility, would stop being part of the community and consequently become 'invisible'. Furthermore, that resident might then exhibit other 'behavioural issues' (through sheer frustration) which trigger other 'protective disciplines' such as being moved to a more secure part of the facility, further reducing his freedoms.

If instead the facility were to respect the person's desire to use their scooter, explain and implement procedures or practices to enable him to stay safe and took into account his opinions on the matter so that he could remain safe but still use his scooter, then he would be encouraged to continue to live a valued life and remain visible and active in the community.

ADACAS supports the position of Dr Judd that the rights of Australians are being eroded by protective discipline in aged care facilities and recommends that the Senate call for major reform to the values, approach and policies of facilities and services provided to people with dementia to ensure that their rights as citizens can be upheld to the maximum extent possible and they are enabled to live valued and dignified lives.

If we can be of further assistance to the Inquiry please contact Ms Sonia Di Mezza

Thank you for the opportunity to participate in the inquiry.

Yours sincerely

Fiona May
CEO

30 April 2013