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Committee Secretary
Senate Standing Committees on Community Affairs
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Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

Aged Care Crisis welcomes the opportunity to respond to this Senate Inquiry on an issue which affects so many Australians.

Aged Care Crisis is an independent group of Australian citizens. Members of our group are engaged with the aged-care sector in a variety of ways – as health professionals, as consumers of services and as volunteers.

The web site www.agedcarecrisis.com seeks to provide a strong consumer voice to aged care. The by-line is '*where little voices can be heard*'. The site provides accessible information on many aspects of aged care, access to topical journal articles and an opportunity for site visitors to express their views and concerns.

We make the following comment.

1. More specialty-trained staff, skilled in the management of those individuals who have dementia or BPSD, are urgently needed within both the community and residential sectors. Our goal should be a team of doctors with an interest in aged care working under the supervision of a geriatrician - as well as skilled nurses, carers and case-managers. To be effective, this commitment to training must encompass continuing education and ongoing professional development.

2. The care of vulnerable people is a community responsibility. We draw attention to the current reliance on the market economy for the provision of care to a significant proportion of older Australians including those with dementia. This increasing dependence is creating serious problems within the sector. In particular, the pressures associated with cost cutting are driving many of those staff who seek to provide skilled, humanitarian and personal empathic care out of the sector.

The current level of ownership of aged care facilities by private equity groups, their short term focus on profitability, and the distance of their decision making processes from the coalface is a matter of grave concern.

3. Modern technology (such as alert buttons, home modifications) is an important resource that may assist in the care of people who have dementia and/or psychiatric disorders. However, the emerging research and development of robots to be used in a companionship role should be treated with much caution. People living with dementia and BPSD, whether living within the community or in residential care, require real relationships – not fake ones¹.
4. Most people wish to remain in their own home as they age². The fact that the number of people accessing home-care packages has increased significantly over the past two years³ is further evidence of this. Aged Care Crisis welcomes all measures that make this possible.
5. An effective and transparent complaints scheme would not only assist those who find their care arrangements lacking but would also provide much-needed accountability within the system – leading to long-term improvements. This reform is long overdue.
6. Access to clinical care and allied health professionals should be readily available to all individuals living with dementia or BPSD. When psychiatric medications are prescribed a program of careful monitoring should be in place.

Community care

7. The hours of support provided for those individuals receiving home-based care from Commonwealth packages (CACP, EACH and EACHD) is often insufficient to meet their needs - resulting in admission to residential care earlier than desired. The administrative processes, the practice of subcontracting services, and profit-taking at each level cuts into resources available to residents.

¹ The Independent - 2 April 2013: Dementia patients 'need relationships': <http://www.independent.co.uk/life-style/health-and-families/health-news/dementia-patients-need-relationships-8557488.html>

² The desire to 'age in place' (The Hoopla, 17 April, 2013): <http://thehoopla.com.au/desire-age-place/>

³ Aged Care packages in the community 2010-2011 - A statistical overview (September 2012): <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422942>

8. Quality assurance measures should be put in place for all in-home care. Currently there are few, if any, procedures, for assessing the quality of care received by recipients. All staff who supply that care should have met set minimum qualifications. The feedback that Aged Care Crisis is receiving suggests that the level of case-worker support to recipients is often inadequate.

Residential care

9. Older people in residential care homes across Australia, including those with dementia and BPSD, are at risk because there are no mandated staff/resident ratios in place. Many residential homes operate with dangerously low staff levels. Aged Care Crisis is aware of ratios as low as one staff member to 80 residents – and in some cases, none at all for significant periods of time⁴.

Staff are expected to do the impossible, they lose motivation and go elsewhere. This is particularly so when their employer is making large profits. The best trained and the most motivated are most frustrated and leave first.

Adequate staffing is the basis for the care and protection of all residents of aged-care homes. Those with dementia are more vulnerable than other residents.

10. There is a great need for additional residential care homes to provide the specialised support required for those older people living with psychiatric disorders. The shortage of these homes is dire.
11. The overdependence on psychiatric medications and physical restraints is directly related to the fact that staff/resident ratios in aged-care homes are very often dangerously low. Staff have little time to apply therapeutic activities or effective management techniques. Dementia specific-training is suboptimal. Skilled staff are often on call and not on site. As a consequence supervision and continuing education at the bedside are often non-existent. An excess of agency staff exacerbates staffing problems.
12. There is an over emphasis on documentation within residential care homes. A system has developed that depends more on what is written rather than what is actually done. This affects the ability of staff to adequately manage all residents – but especially to provide the care that those with challenging behaviour require.
13. A significant number of care homes now rely on having a registered nurse on call rather than on site. This is despite the fact that the level of care needed by residents is higher than ever before. One result of this is that medications are often distributed by personal care staff who have low levels of training. Another is that residents are often sent to hospital emergency departments when minor illnesses occur – as the home does not have skilled staff on hand to supervise their care.

⁴ 19 Dec 2012: Nursing home has no staff for 10.5 hours a day (Brisbane Times)
<http://www.brisbanetimes.com.au/queensland/nursing-home-has-no-staff-for-105-hours-a-day-20121218-2bl35.html>

14. The poor levels of the pain management and the lack of palliative care which exist in many residential care homes undoubtedly contribute to the behavioural problems of some residents who have dementia and BPSD. Again, the reduction in the numbers of registered nurses on site is one of the factors contributing to this situation.
15. There is a current shortage of general practitioners who visit aged-care homes. Those who do often do not have the time to devote to the management of those residents with dementia and BPSD.
16. A high priority should be placed on the design and physical environment of residential care homes. An appropriate environment is an important aspect of the good management of residents with dementia and/or psychiatric disorders. Aged Care Crisis is aware of the part that a creative and home-like environment plays in homes managed by organisations such as Hammond Care and Wintringham.

Related:

- Professor Sube Banerjee (YouTube): Dementia drugs have 'adverse, problematic' effects
<http://www.youtube.com/watch?v=I92HScBL3mM>
- 24 Apr 2013: Buttrose slams nursing home standards (ABC Radio, PM):
<http://www.abc.net.au/pm/content/2013/s3744672.htm>
- National President of Alzheimer's Australia, Ita Buttrose, launched phase three of the Fight Dementia Campaign at the National Press Club on 24 April 2013:
<http://campaign.fightdementia.org.au/ita-launches-the-fight-dementia-campaign-election-2013/>
<http://www.fightdementia.org.au/aged-care-reforms-vital-for-australias-future-says-ita.aspx>
- 15 Apr 2013: Dear Ita Buttrose (Aged Care Crisis): <http://www.agedcarecrisis.com/yoursay/4626-dear-ita-buttrose>
- 12 Apr 2013: Alzheimer's Australia urges the Government to protect human rights in nursing homes:
<http://www.fightdementia.org.au/alzheimers-australia-urges-the-government-to-protect-human-rights-in-nursing-homes.aspx>
- 11 Apr 2013: Hundreds of dementia assaults going unreported (ABC Lateline):
<http://www.abc.net.au/news/2013-04-11/nursing-home-dementia-assaults-going-unreported/4624374>
- 19 Dec 2012: Nursing home has no staff for 10.5 hours a day (Brisbane Times)
<http://www.brisbanetimes.com.au/queensland/nursing-home-has-no-staff-for-105-hours-a-day-20121218-2bl35.html>
- 8 Nov 2012: Continued rejection of aged care placement (Aged Care Crisis)
<http://www.agedcarecrisis.com/yoursay/4602-continued-rejection-of-aged-care-placement>
- 3 Sep 2012: In a system where drugs replace staff, no one can hear you scream: (SMH Opinion):
<http://www.smh.com.au/opinion/politics/in-a-system-where-drugs-replace-staff-no-one-can-hear-you-scream-20120902-2588z.html>
- 29 Aug 2012: Doctors could face prison over drug prescriptions (ABC Lateline)
<http://www.abc.net.au/lateline/content/2012/s3579035.htm>
- 17 Aug 2012: Premature deaths linked to drugs in nursing homes (ABC Lateline):
<http://www.abc.net.au/news/2012-08-17/dementia-patients-dying-as-anti-psychotic-drugs-over-prescribed/4204536>
- 16 Aug 2012: Families count cost of dementia drugs prescriptions (ABC Lateline):
<http://www.abc.net.au/lateline/content/2012/s3569736.htm>

Related (cont'd):

- 16 Aug 2012: Antipsychotic Medications and Dementia: Alzheimer's Australia position statement:
<http://www.fightdementia.org.au/antipsychotic-medications-and-dementia---alzheimers-australia-position-statement-.aspx>
- 1 Jul 2012: A tale of two nursing homes: Night and Day (Aged Care Crisis)
<http://www.agedcarecrisis.com/yoursay/4561-a-tale-of-two-nursing-homes-night-and-day>
- 10 May 2012: Locking up old people, throwing away the key (Aged Care Crisis)
<http://www.agedcarecrisis.com/the-column/4552-locking-up-old-people-throwing-away-the-key>
- 9 Apr 2012: Alzheimer's Australia damns dementia care (ABC Lateline):
<http://www.abc.net.au/lateline/content/2012/s3473622.htm>
- 30 Nov 2011: Elderly With Dementia Are Wrongly Given Antipsychotic Drugs, Inspectors Say
http://www.huffingtonpost.com/2011/12/01/elderly-dementia-antipsychotic-drugs_n_1123195.html
- 9 Aug 2011: Patient died after 'harsh' treatment (ABC):
<http://www.agedcarecrisis.com/news/4488-patient-died-after-harsh-treatment>
- 18 Jul 2011: Take a paracetamol instead of 'chemical cosh' to lessen effects of Alzheimer's, doctors tell dementia patients (Daily Mail):
<http://www.dailymail.co.uk/health/article-2016013/Dementia-Agitated-patients-need-painkillers-anti-psychotic-drugs.html>
- Dec 2009: Overuse of antipsychotic medication in elderly people with dementia? A view from general practice: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2873874/>
- 13 Nov 2009: Antipsychotic use in dementia (NHS):
<http://www.nhs.uk/news/2009/10October/Pages/Antipsychotic-use-in-dementia.aspx>

Aged Care Crisis has contributed to various inquiries, reviews and consultations - including the following:

- Productivity Commission Inquiry - Caring for Older Australians (September 2010)⁵
- Review of the Aged Care Complaints Investigation Scheme (October 2009)⁶
- Review of the Residential Aged Care Accreditation Process for Residential Aged Care homes (July 2009)⁷
- Inquiry into Aged Care Amendment (2008 Measures No. 2) Bill 2008⁸
- Aged Care Amendment (Security and Protection) Bill 2007⁹
- Inquiry into Older People and the Law (2006)¹⁰
- Elder Abuse Prevention Project (2005)
- Inquiry into Aged Care (June 2004)¹¹

Aged Care Crisis¹² has played a unique role in examining events and trends within the aged-care sector over the past decade. We have taken the time and effort to gather information¹³ for critical examination. We have published articles from the coalface¹⁴ and created a forum¹⁵ where participants can tell of their experiences and comment critically. We produce a periodic newsletter¹⁶.

We draw attention to the loss of human rights that so often occurs when individuals experience dementia and BPSD. We hope that the work of this Inquiry will assist in ensuring that those rights are maintained.

On behalf of **Aged Care Crisis**: Linda Sparrow.

⁵ Productivity Commission Inquiry - Caring for Older Australians
<http://www.pc.gov.au/projects/inquiry/aged-care>

⁶ Review of the Aged Care Complaints Investigation Scheme (October 2009):
www.health.gov.au/internet/main/publishing.nsf/Content/ageing-review-cis.htm

⁷ Review of the Residential Aged Care Accreditation Process for Residential Aged Care homes (July 2009):
www.health.gov.au/internet/main/publishing.nsf/Content/ageing-quality-accreditation-review-submissions.htm

⁸ Inquiry into Aged Care Amendment (2008 Measures No. 2) Bill 2008:
www.aph.gov.au/Senate/committee/clac_ctte/aged_care_amend_2008_measures_no2

⁹ Aged Care Amendment (Security and Protection) Bill 2007:
www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/aged_care_security_protect/

¹⁰ Inquiry into older people and the law (2006): www.aph.gov.au/house/committee/laca/olderpeople/index.htm

¹¹ Inquiry into aged care (June 2004): www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/aged_care04

¹² Aged Care Crisis Centre: www.agedcarecrisis.com

¹³ The Column: www.agedcarecrisis.com/the-column;
Legal Issues Column: <http://www.agedcarecrisis.com/legal-issues-column>

¹⁴ Your Stories: www.agedcarecrisis.com/your-articles

¹⁵ Letters and feedback: www.agedcarecrisis.com/yoursay

¹⁶ ACC Newsletter: www.agedcarecrisis.com/subscribe