



DEFUSING A TICKING TIME BOMB

Improving the quality and delivery of home care in Australia

A DISCUSSION PAPER ON PRIORITIES FOR REFORM
MARCH 2014



Palliative
Care
Australia



The Pharmacy
Guild of Australia



The **sustainability of our health system** and the **health and wellbeing** of a large proportion of the Australian community are dependent on the extent to which **quality care can be administered in the home** to those with chronic illness, disability or high care needs following discharge from hospital or when approaching the end of life.



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1. EXECUTIVE SUMMARY: PARTNERS IN CARE

Caring for our ageing population will become one of the greatest challenges of this century unless system-wide reform in the provision of home care to a growing number of Australians is recognised and adopted as a priority by governments, policy makers, healthcare professionals and the community.

This is the conclusion of a panel of leading disability and aged care stakeholders who convened to address the growing care crisis in Australia. What emerged from the discussion was a picture of a system under immense pressure – a ‘ticking time bomb’ fuelled by demographic, social and economic change.

The number of people requiring aged care is expected to increase by 250% over the next 40 years, with around 3.5 million Australians using aged care services by 2050 (Productivity Commission 2011, Caring for Older Australians, Report no 53). The rising rates of age-related and other chronic illnesses will result not only in growing demand for more complex care services, but will also increase the burden on the country’s legion of carers – the individual family members and friends who provide unpaid care and support in the home environment.

As such, it is essential that home care reform is geared towards meeting the true needs of care recipients and their carers. Reform grounded in the concept of Consumer Directed Care – where care recipients and their carers are provided greater choice and control over the design and delivery of care – will provide the greatest benefit to individuals and the broader community, and must be prioritised.

At its core, creating a better system of home care in Australia involves:

1. Improving access to home care;
2. Improving the quality of home care; and
3. Improving the wellbeing outcomes of individuals receiving home care.

Integral to creating a better system of home care are the following elements of reform:

- Improving the quality and range of support services available;
- Increasing awareness and education about access to support services;
- Ensuring carers are acknowledged and fully integrated as ‘partners in care’;
- Providing adequate education to carers delivering home health care;
- Reducing the financial, psychological, emotional and physical burden of providing care;
- Ensuring adequate professional training and continuing education on aged care issues for all Australian healthcare professionals and professional care workers; and
- Increasing collaboration and coordination in the delivery of care.

These issues must be addressed as a matter of urgency and require a whole-of-system approach. The sustainability of our health system and the health and wellbeing of a large proportion of the Australian community are dependent on the extent to which quality care can be administered in the home to those with chronic illness, disability or high care needs following discharge from hospital or when approaching the end of life.

2. BACKGROUND: THE CURRENT SITUATION

Australia's care system is coming under increasing pressure as a result of demographic, social and economic change. The number of people receiving aged care services is expected to increase by about 250% over the next 40 years.

An estimated 3.5 million people (10.3% of Australia's population) will require aged care services by 2050, with around 80 per cent of these services delivered in the home (Productivity Commission 2011, *Caring for Older Australians*, Report no 53).

While the rapidly ageing population has cast a spotlight on the need for improved aged care services, the delivery of home care is not limited to the elderly. Increasing numbers of people with chronic illnesses and disabilities of all ages require consistent and high quality care in the home.

The increasing prevalence of dementia, mental illness and other chronic illnesses is projected to result in growing demand for more complex care services. At the same time, a relative fall in the number of informal carers will lead to more pressure on the formal aged care system.

There are also calls for the aged care system to be more flexible and responsive, with older Australians wanting to remain in their own home for as long as possible, with more choice and control over the services they receive (Department of Health and Ageing 2012-13 Budget Portfolio Statement).

Treasury Department projections suggest there will be stronger growth in high-care residential and community places relative to low-care residential places (Intergenerational Report 2007). The number of high-care beds in the community will soon match those within residential institutions.

In the area of community care there is likely to be an increasing demand for services at the higher-end of the care spectrum to help

bridge a potentially widening gap between the level of care some older people will require, and the level of care that informal carers are capable of providing (Productivity Commission: *Trends in Aged Care Services* 2008).

There are an estimated 2.6 million carers providing unpaid care and support to family and friends with a disability or who are frail-aged in Australia (SDAC 2009). Collectively, these carers provide 1.32 billion hours of care annually. The annual replacement cost of this care is estimated to be \$40.9 billion (Access Economics 2010).

While caring can bring rewards and challenges, it can also come at significant cost to carers and their families. Many carers bear a largely hidden burden that is detrimental to their own wellbeing and can lead to 'burnout'. Providing care can have a negative impact on the health of carers and this impact increases with the number of hours spent caring. Carers experience higher rates of mental health problems (particularly anxiety and depression) and chronic diseases (such as diabetes, asthma, arthritis and cardiovascular disease) than the general population (AIHW, *Australia's Health* 2012). Despite this, a carer's primary focus often remains the needs of the person for whom they care, leaving them with less time and resources to attend to their own health and other needs.

Carer responsibilities can also lead to financial hardship due to the costs involved in providing care and the reduced opportunities to work and save. As more complex treatments and types of care are undertaken in the home, the financial burden on carers grows. As such, 50% of carers are on a low income, with 62% of primary carers in the two lowest income brackets (SDAC 2009).

3. RECOMMENDATIONS: MAPPING THE WAY FORWARD

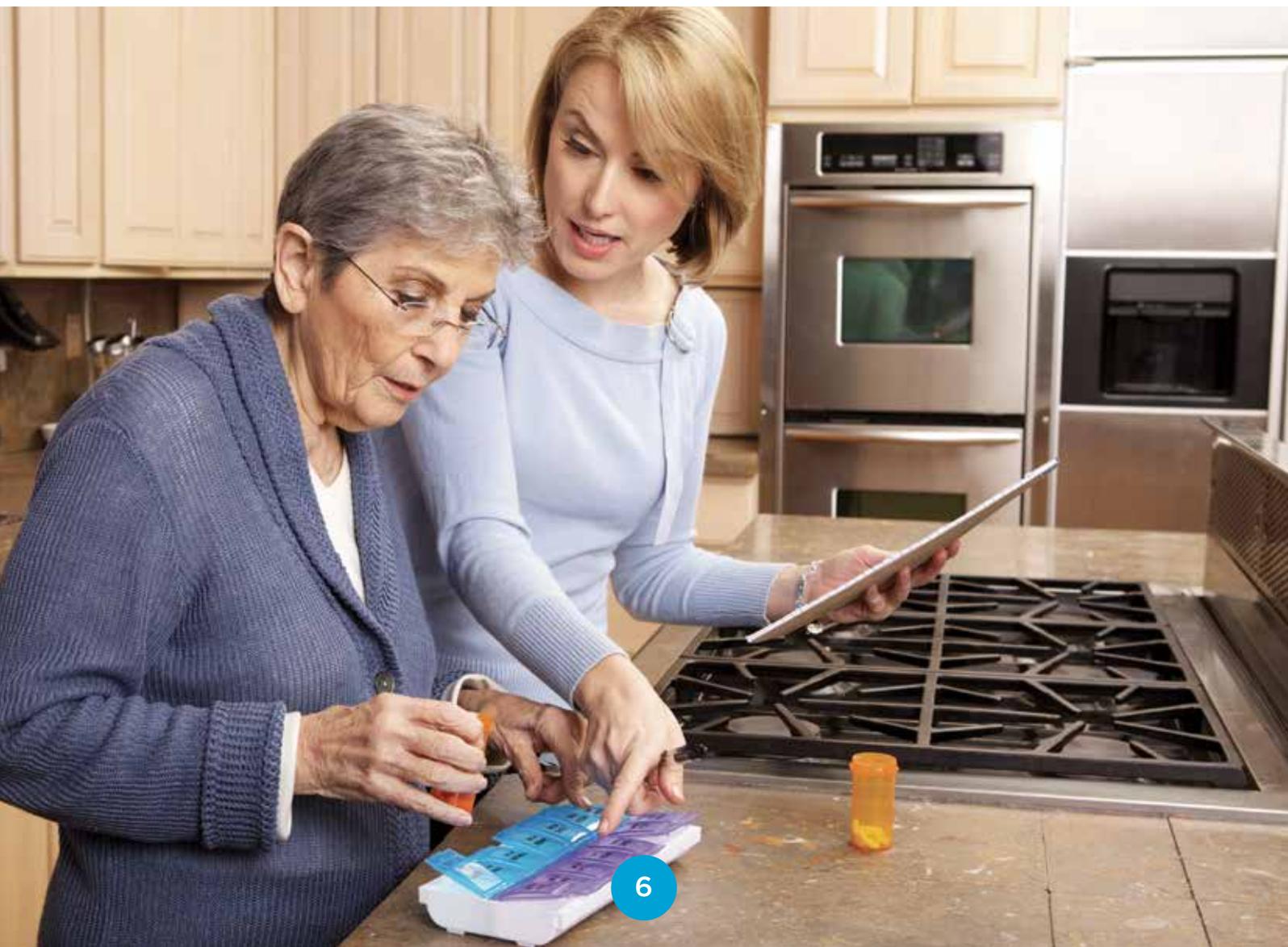
Integral to creating a better system of home care in Australia are the following elements of reform:

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- Ensuring adequate professional training and continuing education on aged care issues for all Australian healthcare professionals and professional care workers; and
- Increasing collaboration and coordination in the delivery of care.

Effective and sustainable home care reform requires a whole-of-system approach that involves the following key stakeholders operating as ‘partners in care’:

- Care recipients and carers;
- Professional care workers;
- Healthcare professionals; and
- Government.



3.1 Care recipients and carers

Significant improvements in home care could be achieved through the following care recipient and/or carer-directed initiatives:

3.1.1 Provide education and support to help untrained carers perform home healthcare

- Establish seminars through hospital outpatient clinics or carer support centres to educate carers on:
 - Medication requirements, including practical guidance on dosage and administration.
 - Wound prevention and management, including practical guidance on dressing, cleaning, and infection management.
 - End of life care.
- Provide consultations through hospital outpatient clinics or carer support.
- Where appropriate, provide Hospital in the Home services in the post-discharge period to enable carers to observe care requirements and learn how to meet these requirements (eg. wound management, medication administration, blood monitoring).
- Establish a comprehensive hospital discharge procedure to include condition specific education on the care recipient's needs so the carer is prepared to care for their specific medical requirements.

3.1.2 Improve knowledge of and access to care services and financial assistance

- Provide information that clearly explains the range of care services and financial assistance available, along with the process for obtaining access to these, at every stage of the care process, from assessment onwards.

- Ensure that information materials are tailored to accommodate for specific conditions (eg. dementia or continence), specific needs (eg. living in rural area or requiring high care) and specific backgrounds (eg. CALD – “culturally and linguistically diverse” groups speaking a language other than English or holding particular religious or cultural values) that may affect the delivery of care.
- Extend National Carer Strategy funding to include a national campaign to raise awareness of the range of care services and financial support available and to encourage care recipients and carers to seek assistance and support.

3.1.3 Increase support services for carers

- Work with respite facilities to increase capacity, boost staffing levels, improve facilities and introduce more flexible options (eg. long day care) so that respite services are more beneficial to, and taken up by, carers and care recipients.
- Include the regular assessment of carers' needs in the remit of case coordinators (refer to 3.3.3).
- Establish local carer support groups in each health district to allow a forum of discussion and a community for carers, easing the psychological impact of being a full-time carer.
- Increase the availability of bereavement care services for carers through carer support centres and other established networks.

3.2 Professional Care Workers

Significant improvements in home care could be achieved through the following initiatives for professional care workers:

3.2.1 Provide education and training to increase the skills of the professional carer workforce

- Establish national professional standards and mandatory provider-funded training and development requirements for care workers.
- Facilitate specialised training in particular areas in order to better meet the specific (eg. continence, dementia or end of life care) needs of care recipients.

3.2.2 Create a formalised process of collaboration with HCPs, overseen by a case coordinator (refer to 3.3.3).

3.3 Healthcare Professionals

Significant improvements in home care could be achieved through the following healthcare professional-directed initiatives:

3.3.1 Promote the valuable role of carers as 'Partners in Care'

- Encourage Colleges and professional organisations to design and implement HCP-directed programs which highlight the importance of carers within the system.
- Promote service models (in both the hospital and primary care settings) that acknowledge carers as 'Partners in Care' and address concerns about breaching patient confidentiality in dealings with carers.

3.3.2 Increase education and training in areas relevant to providing optimum home care

- Include in the formalised university curriculum of medical, nursing and allied health undergraduates sufficient training in areas of care specifically relevant to the ageing population (eg. palliative care, continence and wound management).
- Include in the Continuing Professional Development programs overseen by medical Colleges and professional organisations, education modules in areas of care specifically relevant to the ageing population (eg. palliative care, continence and wound management and the issue of home care and the care recipient's changing needs).
- Increase and extend the Commonwealth Aged Care Education and Training Incentive Program beyond 2014 to encourage a greater number of qualified nurses to undertake specialised aged care training.

3.3.3 Introduce case coordinators to foster collaboration and oversee the multi-disciplinary care of all care recipients

- Create a national network of case coordinators responsible for the ongoing assessment of the care and changing needs of the care recipient as well as addressing the support needs of the carer.
- Establish a formalised process, overseen by a case coordinator, for the development and review of an advance care plan for all care recipients.
- Increase collaboration, via case coordinators, between all medical and other care providers (discharge planner, GP, specialist[s], pharmacist, allied health professionals, social worker, professional care worker etc) and establish periodic case reviews to assess the home care recipient's needs.

3.3.4 Shift the acute setting focus from early discharge to thorough discharge planning

- Establish formalised processes whereby the discharge planner and designated case coordinator work together prior to hospital discharge.
- Include the carer in all discharge planning and decision-making.
- Ensure care recipients and carers are equipped with adequate knowledge of the condition(s) to be managed, the type of care required, details of the availability of support services and funding assistance and ways in which to access these, and are equipped with the medication, aids and/or healthcare products required.

3.3.5 Boost medication compliance through new and existing programs

- Incentivise, through Commonwealth and/or State and Territory programs, the introduction and maintenance of medicine home delivery services through community pharmacies.
- Encourage HCPs to inform carers and care recipients of the availability of pharmacy professional services and programs in order to improve the Quality Use of Medicines.

- Ensure clear Federal Ministerial responsibility for home care and aged care services.
- Ensure adequate funding and resourcing for the establishment of a framework that would allow a gradual shift away from informal to formal home care.
- Conduct national audits to assess the medical, support and financial needs of care recipients and carers and the degree to which these needs are currently being met. The results of these audits will guide priority reform areas.
- Ensure the system is equipped to address the needs of all people requiring home care, not just the frail-aged.

3.4.2 Increase the capacity of carers to be productive members of the workforce

- Raise employee and employer awareness of recent revisions to the Fair Work Act 2009 relating to the right of carers to request flexible working conditions and extended leave periods in their existing, paid jobs.
- Initiate a program to increase employment opportunities for carers within the public services sector.
- Promote the Care Aware Workplace program and establish an accreditation and acknowledgement process for businesses.

3.4 Government

Significant improvements in home care could be achieved through the following Government initiatives:

3.4.1 Introduce structural changes to improve the quality, coordination and delivery of home care in Australia

- Explore the opportunity of transferring the oversight and management of existing home and community care programs (services and funding) to the Commonwealth to ensure consistency and equity of access across the country.

3.4.3 Increase Government funding for services and initiatives that will deliver demonstrable benefits for care recipients and their carers

The national audit of the cost of care (refer to 3.4.1) will reveal additional areas for funding, but at a minimum the Government should:

- Extend the range of home care packages to better meet the needs of the individual care recipient and their carer.



- Expand the inclusion criteria for the National Disability Insurance Scheme to include other care recipients not initially eligible for support.
- Establish an ongoing National Equipment Library to provide subsidised access to equipment for, but not limited to, pressure relief, mobility, toileting, medication delivery, medication management (including dose administration aids) and respiratory assistance for all care recipients.
- Ensure that care packages and subsidy schemes are not mutually exclusive. Individuals requiring assistance should receive access to an appropriate care package as well as additional subsidies for which they may be eligible based on their condition and requirements.

3.4.4 Increase community awareness of the availability and accessibility of care services and financial assistance

- Undertake a sustained national awareness campaign on the availability of and process for securing care in order to increase

the health literacy of the community, dispel fears of premature institutionalisation and encourage individuals to seek care before they reach the point of hospital admission.

- Update and maintain the Aged Care Gateway to ensure that the most up-to-date information about care services is easily accessible to care recipients and carers.
- Include in the Aged Care Gateway details (including web links where possible) about how and where to source information on the full range of home care packages, allowances and other financial support offered to care recipients and carers.

Systematically implementing these recommendations will ensure that all stakeholders can work together, as partners in care, to improve the quality and delivery of home care in Australia.

4. ABOUT THE HOME HEALTHCARE FORUM

At the invitation of HARTMANN, representatives from a range of healthcare organisations took part in a Home Healthcare Forum in Canberra in early 2013.

The representatives met to discuss the broad topic of *'Reducing the burden of care by improving home services'* with a particular focus on home care after discharge from acute care.

Mr Russell de Burgh from the Ageing and Aged Care Division of the Commonwealth Department of Health and Ageing addressed the group, outlining key initiatives being implemented and assessed by the Government.

Participants were asked to address three primary considerations:

1. How to improve access to home care.
2. How to improve home-based care provided by community based carers.
3. How to improve health outcomes of those in the community post-discharge.

Forum participants included:

- Dr Yvonne Luxford - CEO, Palliative Care Australia
- Ms Ara Cresswell - CEO, Carers Australia
- Mr Barry Cahill - CEO, Continence Foundation Australia
- Ms Khin Win May - National Manager, Policy and Regulatory Affairs, Pharmacy Guild of Australia
- Ms Ann Marie Dunk - President, Australian Wound Management Association ACT
- Ms Jennifer Staniforth - After Hours Care Coordinator, Wendy's Home Services

The Home Healthcare Forum was independently facilitated. Representatives from HARTMANN were not involved in the discussion or the White Paper development.

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