

'Invisible' carers come into focus

A summary of the National Health and Hospitals Reform Commission

Final Report 2009

We acknowledge the vital role of informal/family carers in supporting and caring for people with chronic conditions, mental disorders, disabilities and frailty.

We recommend that carers be supported through educational programs, information, mentoring, timely advice and, subject to the consent of those they care for, suitable engagement in health decisions and communications.

We also recommend improved access to respite care arrangements to assist carers sustain their role over time and that the health of carers should also be a priority of primary health care services dealing with people with chronic conditions. (Recommendation 14, NHHRC final report)

Background

On 25 February 2008, the Prime Minister and the Minister for Health and Ageing announced the establishment of the National Health and Hospitals Reform Commission (NHHRC) with a view to considering a reform of Australia's health system. On 3 April 2008 the NHHRC called for submissions regarding the future design of Australia's Health System with a view to producing a report that would provide advice to government based on input from the public. Following a process of meetings and consultation, the NHHRC produced an interim report on 16 February 2009 and its final report on 27 July 2009.

Carers Australia was actively involved in the consultation process through submissions, forums and meetings as part of our continued role in campaigning for acknowledgement of the role carers play in the health system and better health and wellbeing for carers across Australia. Caring can happen to anyone, anytime and without carers, the health system is not sustainable. It is essential that carers, and issues of relevance to them, be included in any planning for the future of Australia's health system.

The need to see carers as clients in the health system in their own right with strategies that will support their long-term health and wellbeing was also a focus of our engagement with the NHHRC. Our submission to the Committee's initial inquiry communicated the very clear message that decisions and policies made in relation to health should not be based on the assumption that carers can continue to provide unpaid care in the community without appropriate support.

The final report of the NHHRC reflects these important messages. It acknowledges many of the realities of the way in which care is provided in Australia by recognising and responding to the vital role of carers across several areas within the health sector, particularly in the aged care and mental health sectors, and in the management of chronic illnesses. It is a report that positions carers clearly on the health agenda.

A change of perspective

The report displays an overarching change in perspective on carer issues that is reflected throughout the document. Carers are given importance in the general discussion of health issues and solutions and particularly in the final recommendations. Significant changes can be seen when comparing the inquiry's initial design principles and final report. These changes suggest that the importance of carers within the health system became clear to the committee as the consultation process progressed. Importantly, the ongoing reliance on unpaid family carers to provide health care, functioning as the 'invisible workforce' of the health system, is clearly recognised within the report as unsustainable.

"We also rely heavily on unpaid primary carers (the 'invisible' health workforce) who may dwindle in the future as more people age and rely on family members to participate in the paid workforce."

The final report also includes an important change in broadening the definition of the health care system to encompass the aged care system, with a view to addressing the inequities and problems within aged care. This change of perspective also reflects the report's intention to promote a health system with a life course approach.

"A life course approach to improving health and wellness includes a strong emphasis on a healthy start to life, support for the whole spectrum of health needs during life including physical, mental and psychosocial, and appropriate care and support at the end of life."

The design principles

As an initial step in the consultation process, the NHHRC released the overarching design principles that would guide the future development of the health system. When comparing these initial design principles and the final report, there has been clear progress in terms of the Commission's consideration of the role of carers in the health system. The design principles in the final report involve several additional acknowledgements of the role of carers in supporting and advocating on behalf of others across all areas of the health sector.

Principle 1 of the report proposes a system that is "people and family-centered". This principle provides a clear inclusion of the role of carers in the principles underpinning the health system

"The direction of our health and aged care system, the provision of health and aged care services and our efforts to strengthen wellness and prevention must be shaped around the health needs of people, their families, carers and communities. A people focus reflects not only responsiveness to individual differences, abilities and preferences, but is grounded in the social and community context of people's lives and their ability to exercise choice.

This recognises the need to be responsive to factors such as cultural diversity (including Indigenous cultural traditions), people's 'lived experience' of illness and disability, and the broader social, educational and environmental settings that frame their lives and communities. Pathways of care, currently often complex and confusing, should be easy to navigate.

People should be given help, where necessary, to navigate the system including through reliable and evidence-based information and advice to help them make appropriate choices, in association with their families, carers and advocates. Care should be provided

in the most favourable environment: closer to home if possible, with a preference for less 'institutional' settings, recognising the need to support the important role of families and carers, and with an emphasis on supporting people to achieve their maximum health potential."

The need for a respectful, ethical system is outlined under principle 13

"Our health and aged care system must apply the highest ethical standards, and must recognise the worth and dignity of the whole person including their biological, emotional, physical, psychological, cultural, social and spiritual needs.

The humanity of care is integral, based upon the highly personal nature of health and aged care and the importance of trust and partnerships between patients, families, carers and health and aged care professionals. Care should be provided in a manner that does not support discrimination against any individual or group and, indeed, is organised to positively foster access and improved health outcomes for the most disadvantaged and marginalised in our society."

Mutual "respect and valuing of health and aged care workers by patients, families, carers and the community" is also seen to be requiring a 'significant focus'.

Principle 10 'Quality and Safety' states that "there should be effective systems of clinical governance, at all levels of the health and aged care system, to ensure continuous improvement in the quality and safety of services." As a key element of this goal, feedback from carers is noted to be "central to identifying quality and safety issues... and the solutions that need to be implemented."

Key recommendations

Recommendations are an essential part of the inquiry process, providing clear advice on future progress and changes to the health system. Importantly, they present government with the opportunity to consider, respond to and implement changes. The NHHRC has produced three recommendations that are particularly relevant to carers its final report.

These recommendations are encouraging in that they signal a substantial acknowledgement of carers in the health arena, and the possibility of future improvements that will benefit carers. Carers Australia will be working to ensure that these recommendations are met with an appropriate response by government and result in realistic improvements for carers within the health sector.

The role of carers in the health system

Recommendation 14

We acknowledge the vital role of informal/family carers in supporting and caring for people with chronic conditions, mental disorders, disabilities and frailty. We recommend that carers be supported through educational programs, information, mentoring, timely advice and, subject to the consent of those they care for, suitable engagement in health decisions and communications. We also recommend improved access to respite care arrangements to assist carers sustain their role over time and that the health of carers should also be a priority of primary health care services dealing with people with chronic conditions.

Of the 123 recommendations made by the report, this recommendation most directly identifies the overarching picture of carers within the health system. It highlights the inclusion of carers in future health planning, and puts forward concepts that suggest a shift in thinking for the health system in identifying the importance of carers and their relationship to those for whom they care. It also outlines practical measures that should be used to support carers and recommends that the health system needs to take an active role by working to assist carers to maintain their health and wellbeing.

Recommendation 14 is included as part of a series of recommendations under the heading 'Taking Responsibility'. They are framed as recommendations that require 'collective action to build good health and wellbeing'. Carers Australia believes that it is time for all sections of society, and particularly government, to take responsibility in supporting the good health and ongoing wellbeing of Australia's carers.

Consideration for those in rural and remote areas

Recommendation 67

We recommend that a patient travel and accommodation assistance scheme be funded at a level that takes better account of the out-of-pocket costs of patients and their families and facilitates timely treatment and care.

Recommendation 67 is included under the heading of "Facing Inequities: Delivering better health outcomes for remote and rural communities". It aims to address the inequities in health service delivery in rural and remote Australia, particularly the large cost borne by families in travelling long distances to access health services.

The total cost of the program is projected to be "\$85 million (at current levels of demand) – \$244 million (at 2.25 times current demand)" (p.270). Features of the scheme put forward by the NHHRC are modelled on research undertaken by PricewaterhouseCoopers in 2008 into a Patient Travel Assistance Scheme (PTAS). They include

- a subsidy of \$100 per night for both commercial and private accommodation
- rebate of 25 cents per kilometre for road travel
- co-payment of first night's accommodation (\$100) or first 100 km (\$25) for day trip for non-concession card holders.

Carers Australia has long been campaigning for more programs to support the ongoing costs of transport and accommodation for those in rural and remote parts of the country. This measure could be of real assistance to caring families who are financially disadvantaged by their inability to access health care close to home.

Caring and mental health

Recommendation 82

We acknowledge the important role of carers in supporting people living with mental disorders. We recommend that there must be more effective mechanisms for consumer and carer participation and feedback to shape programs and service delivery.

This recommendation reflects a central theme present in the design principles, suggesting that services must present carers with the ability to provide feedback on service delivery.

It also acknowledges that caring extends to multiple areas of the health sector and the essential role provided by those caring for people with mental illness.

Carers Australia believes that the role that carers play in supporting the mental health of the people they care for should be acknowledged in the health arena. Many of these carers advocate on behalf of individuals who are not able to represent their own views and their feedback regarding service delivery is invaluable. Listening to carers' experiences of service delivery in the mental health sector can only serve to improve the quality of mental health services and bring greater peace of mind to caring families engaging with these services.

Further important inclusions

Increased need for care

The report identifies that Australians are living longer and the proportion of older Australians is growing. It acknowledges that multiple population factors will contribute to an increased demand for care in future

“more people will be frail and seeking assistance from informal carers, yet they will be busier than ever earning a living to meet rising costs of living and their own retirement needs. For each older person in 2007, there were five working-age people, while in 2056 there will be fewer than three working-age people for every older person.”

Carers in the ‘service maze’

The report states that there are major challenges for patients, their carers and their families “in navigating through multiple providers of health and home care.”

It notes that in particular “people with genetic disorders such as cystic fibrosis and haemophilia, chronic conditions such as asthma and schizophrenia, frailty and dementia, or physical and intellectual disabilities require a varying range of health and social care.” and that this may increase the difficulty faced by these people and their carers in accessing the services they need.

“All Australians suffering from chronic illness require a range of health services delivered by a variety of health professionals across the spectrum of primary, secondary and tertiary health care. Navigation through the health system for a person with chronic disease is complex. People often fall between the ‘care gaps’ and ‘handovers’ between care givers.”

Self-management and partnerships with carers

The report views self-management to be a “cornerstone of reform” allowing people to take increased accountability for their own health.

“We must be active participants in our own good health, working in partnership with our health professionals, our carers and families. But this has to occur within the context of our social and economic circumstances and the communities in which we live. The aim has to be to encourage and support everyone to achieve their maximum health potential, regardless of their age or whether they have a chronic illness or a disability.”

Meeting health needs over the life course

Design principle 5, 'Comprehensiveness' outlines the need to have a system providing services that meet the different needs of people over the life course

"The health and aged care system should be able to meet the entire range of people's health needs over their life course. Meeting those needs requires a system to be built on a foundation of strong primary health care services with timely access to all other health and aged care services organised to promote continuity of care and good communication across the various health and aged care professionals."

This principle has a particular focus on increasing people's ability to receive aged care in the community and ensuring it is a viable option should they wish to do so

"A comprehensive health and aged care system ensures that care is available in a range of settings, with a focus on care in communities close to people and their families, so that caring, living with illness or disability, ageing and dying can all be 'in place'."

Care coordination for children with a disability

Recommendation 24 of the report addresses service delivery to children with a disability. It suggests

"where a child requires more intensive care for a disability or developmental concerns, a care coordinator, associated with a primary health care service, would be available to coordinate the range of services these families often need."

Mental health initiatives

The report also contains several recommendations to improve the situation for people with a mental illness and their carers including

- a "sustained national community awareness campaign" to increase mental health literacy and reduce the stigma attached to mental illness
- centres providing screening for mental disorders for all young Australians
- an Early Psychosis Prevention and Intervention Centre model
- more acute mental health outreach teams
- strategies for ensuring access to specialty mental health services for older Australians

Further, the NHHRC stress the importance of informing a patient's support network on discharge from services, in many cases this may mean their family carer.

"We recommend that health professionals should take all reasonable steps in the interests of patient recovery and public safety to ensure that when a person is discharged from a mental health service that: there is clarity as to where the person will be discharged; and someone appropriate at that location is informed."

Aged care initiatives

The report includes recommendations that support improvements in aged care that will assist clients and their families and carers. These support the NHHRC's inclusion of aged care as a significant part of Australia's future health plans

“The Commonwealth Government would assume full responsibility for public funding of aged care. This would include the Home and Community Care Program for older people and aged care assessment.”

“We recommend that advance care planning be funded and implemented nationally, commencing with all residential aged care services, and then being extended to other relevant groups in the population.”

Palliative care initiatives

Several recommendations specific to palliative care and end of life have been included in the report

“We recommend building the capacity and competence of primary health care services, including Comprehensive Primary Health Care Centres and Services, to provide generalist palliative care support for their dying patients. This will require greater educational support and improved collaboration and networking with specialist palliative care service providers.”

“We recommend strengthening access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on people living in residential aged care facilities.”

“We recommend that additional investment in specialist palliative care services be directed to support more availability of these services to people at home in the community.”

Improved access to dental care

Reports from carers suggest that there is an inability for many carers to pay for dental care as a result of costs associated with caring for a person with a disability or chronic condition. The report has put forward a proposal for more affordable dental care that could assist carers in this situation

“We recommend that all Australians should have universal access to preventive and restorative dental care, and dentures, regardless of people’s ability to pay. This should occur through the establishment of the ‘Denticare Australia’ scheme.”

Next steps

The government has until the end of the year to discuss options for the health system and to consider its response to the report. It is essential that the goals of the NHHRC report be considered and that the key recommendations to support carers are adopted by government. Carers Australia believes that this report signals new possibilities for the support and recognition of carers in Australia, particularly in their interactions with the health sector.

A Healthier Future for All Australians provides a clear starting-point for even greater recognition of the role of carers in the future of the health care system. Any improvement in health policy must be followed through in action that results in realistic improvements in people’s day-to-day experience of the health system. Carers Australia will continue to pursue the goals of greater support for carers, and to attain real change for carers in the health sector and beyond.