



# **Carers and the Health System**

## **Issue Paper**

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Issue Paper prepared by Carers NSW

## 1. Introduction

The Australian health and community care systems increasingly rely upon family, friends and neighbours who provide unpaid care and support to children and/or adults who have a disability, mental illness/disorder, chronic condition or who are frail aged. The creation of the Health Futures Planning Project offers a welcome opportunity to consider the relationship between these unpaid carers in NSW and the NSW public health care system in terms of key goals such as healthier people and quality health care.

**NSW Health's Future Planning Project is particularly timely given the increasing body of research evidence pointing to: i) the effect of carers being part of the health care team on patient outcomes; and ii) the effects of caring on the health and well-being of carers which, in turn, can have important repercussions.** Finally, this opportunity arises in a context where increasing emphasis is being placed on joining up models of care, particularly with regard to fostering co-operation between health and community care systems.

## 2. Major trends, challenges and future shaping forces

*Current Carer Situation in NSW:*

According to Australian Bureau of Statistics (ABS,2003a), in NSW there are:

- 748,000 carers
- 149,700 primary carers (primary carers are those who provide the most informal assistance in terms of health or supervision to a person with one or more disabilities)
- 46% of all carers are men whereas they comprise only 28% of primary carers
- the greatest proportion of carers are aged between 45 and 54
- 76% of all carers are of workforce age
- 55% of primary carers rely on a Government benefit or allowance as the principal source of income
- 40% of carers are caring for a partner, 29% for a child and 32% other

Each caring situation is unique. Some carers need to assist with the tasks of daily living, and are responsible for feeding, bathing, toileting, dressing wounds, administering medication, and managing incontinence, diabetes and other conditions. Others care for people who are fairly independent but need supervision or help with their finances and/or transport. Carers may also provide emotional support day in and day out for some of the most vulnerable and isolated members of society. Many carers spend substantial amounts of time on caring tasks; 45% of primary carers provide care for 40 hours or more per week. From the perspective of the public health system, some carers could be providing care for a short period following patient discharge from a serious operation; others might need to provide care following hospitalisation on a continuing basis for the foreseeable future; others may have been caring for the person requiring hospital treatment for years prior to hospitalisation and will continue thereafter; others provide ongoing care between admissions; still others provide care

for people requiring ongoing outpatient treatment or community health services, for example people with chronic mental illness.

Carers are a vital part of the health care support team. This is a fact which is increasingly acknowledged in international literature (Performance Improvement Advisor, 2004, p58), "Family members that care for patients at home can provide valuable information and feedback to health care professionals. Educating and training caregivers can increase compliance with discharge plans and prevent readmissions. During hospitalisations, caregivers can act as quality monitors, alerting staff to potential costly problems before they happen." That carers are a vital part of the health care support team is well acknowledged in hospital settings with regard to carers of children with chronic conditions or disabilities for example (Wilson, L and Harnett, E, 2005). It is a fact, however, which is less acknowledged within other areas of the hospital system and then often only in relation to discharge planning. International research indicates that carer inclusion can have benefits to patient quality of care (Droes, R, 2000; Kelly, M and Newstead, L, 2004) and can reduce readmission rates (Bridge, J and Barbe, R, 2004).

With proper support, information, training and education carers can become a more integral part of the health care team improving outcomes for patients and reducing health care costs. According to Brodarty et al (2003), when there is no carer or the carer is stressed, the likelihood of nursing home admission rises sharply. This study also showed that for carers of people with Alzheimers Disease carer interventions could improve outcomes for carers and patients.

While caring can provide considerable satisfaction and strengthen relationships, carers often feel exhausted, isolated and overwhelmed by their responsibilities. In a survey of carers conducted by Carers Association of Australia (2000) 58% reported that their physical health had been adversely affected, a third said that they had sustained a physical injury, and over half reported depression, anxiety, high levels of stress and other impacts on their mental health.

According to Women's Health Australia, (Lee, C and Porteous, J, 2002) carers are more likely to report overall health as 'fair' or 'poor' and more likely to report the following six symptoms: back pain, stiff or painful joints, constant tiredness, chest pain, indigestion/heartburn and breathing difficulty. Carers are also more likely to have been admitted to hospital in the past year.

Recent international studies (Lee, S et al, 2003; Schulz and Beach, 1999; Schulz et al, 1997; Kiecolt-Glaser J, 2003) have in various ways sought to quantify the effects of caring on carers' health and well-being. They provide further evidence to support the broad findings reached in population-based Australian research (Schofield H et al, 1998) that carers felt more overloaded, had lower life satisfaction and had poorer self-rated health than non-carers. Conclusions reached in the international studies suggest, subject to qualification, that carers have poorer immune system function, increased susceptibility to cardiovascular disease, slow wound healing time, increased incidence of degenerative diseases such as arthritis and a higher use of health care services.

These effects demonstrate two things. Firstly, that carers can become physically and emotionally exhausted influencing their capacity to care and the quality of care they

are able to offer. Secondly, that carers will often put their own health and well-being after that of the person they support. Yet there is a tendency for the health system to focus on the patient and overlook the carer's support and health needs.

With a median weekly income of just \$224 per week (compared to \$435 for non-carers) carers as a group is at great risk of being in poverty. Over half of all primary carers rely on a government payment as their principal source of income and almost a quarter are in the lowest income quintile in NSW (ABS, 2003a). There are numerous Australian studies that have also investigated the social impacts and health risks of carers as they can be forced to give up employment and forego community participation with increasing risk of social isolation (SPRC, 2004).

Appropriate support to carers can minimise the costs of caring to individual carers but also support the quality of life for the person being cared for.

### ***2.1 Major Trends***

The ageing of the Australian population is a demographic reality. According to the Productivity Commission (2005) the effects over the next 40 years will be pronounced. One quarter of the population will be aged 65 years or more by 2044-45, roughly double the present proportion of the population in that age cohort. The proportion of the oldest old (85 years and older) will increase even more, from 1.5 to 5 per cent over this period.

One of the implications of an ageing population is that there will be many more Australians requiring assistance because of disability (Giles et al, 2003). An important disability trend is the survival of many people with early onset disability into old age. According to the Australian Institute of Health and Welfare (AIHW 2000), this influences not only the longevity of the caring relationship, but also patterns of service use in health and community care.

Disease and injury projections for NSW over the next twenty years demonstrate that there will be some significant trends in the incidence and prevalence of certain conditions and diseases a number of which are related to the ageing of the population (NSW Health, 2005). Cancer (particularly lung cancer in women), diabetes (relating to obesity) and mental disorders including anxiety disorder, drug and alcohol dependence and major depression are all projected to rise in incidence and/or prevalence in NSW. Associated with ageing, the incidence of injury as a result of falls is projected to increase by 94%. The prevalence and incidence of cardiovascular disease is projected to remain fairly constant and chronic obstructive pulmonary disease is projected to decline, however, the prevalence of these conditions will remain significant. For many of these conditions assistance is required with a range of tasks including direct personal care and physical assistance, administration of medication, supervision or transport.

Carers provide the vast bulk of care. It has been estimated from figures in the AIHW (1999) report that carers provide 74% of the care needs of Australians while Home and Community Care services provide only 9%. Most people want to remain and be cared for in the community; that is, in their own homes (Productivity Commission, 2005). This is also current policy at all levels of government. By far the greatest proportion of care by hours and value is carried out by family carers.

There is considerable uncertainty about whether this can be maintained in the future. The ABS Social Trends (2002, 2003, 2004) has provided evidence of the changing composition of Australian families which has various implications for carers. These include:

- the low fertility rate
- the increase in lone person households
- the increase in the participation of women in the workforce
- high levels of geographical mobility

Both AIHW (2003) and the National Centre for Social and Economic Modelling (NATSEM), (2004), have considered the future supply of carers. The AIHW, examining the period 2003 to 2013 suggests that the ratio of carers to people with a severe or profound disability is likely to fall from 0.43 carers per 100 people with a disability in 2003 to 0.40 in 2013. This is not insubstantial and will increase as the population ages after 2013.

NATSEM in examining the period 2001 to 2031 finds that the potential total pool of carers will not rise as quickly as those likely to require care. It projects that in this period the number of older people likely to need assistance because of severe or profound disability is likely to increase by 160% whereas the number of people likely to provide care will only increase by 57%.

According to Carers NSW analysis (2005a) of the 2003 ABS Survey of Disability Ageing and Carers (2003b) for NSW key trends from 1998 to 2003 include:

- the number and proportion of older carers (75+) has increased
- there are more ageing carers who have recently begun caring
- the proportion of carers not in the labour force has increased from 61% to 64%
- the proportion of carers caring for 40 hours or more per week has increased
- the high proportion of people with mental and behavioural disorders who need assistance received neither formal nor family assistance.

There are implications for NSW Health. For example, the imperative to early discharge needs to be considered in terms of these trends. Similarly, with regard to the treatment of chronic illness there is a trend away from acute settings in favour of self care or community care without acknowledging that such care frequently falls onto families.

In short, there will be an ageing population overall and an increasingly aged carer population. It is likely too, given existing policy settings, that in the longer term there will be an increasing shortage of people available to care which raises the spectre of the demand for better formal support systems and closer examination of the relationship between formal and informal care.

## **2.2 Challenges**

According to the Productivity Commission (Productivity Commission, 2005), the current care mix, between residential and community care, is likely to remain similar over the next 10 to 15 years. The most likely scenario therefore is that carers will continue to provide substantial support to the health and community care systems over the next fifteen years given government policy and the wishes of members of the community to be cared for at home.

**The key overall challenge for NSW Government in general and NSW Health in particular is therefore to find appropriate ways of supporting family carers over the next fifteen years and onwards in light of the abovementioned trends and to reach all carer populations with this support. An important aspect of this challenge will also be to ensure that alternative care is available for those without carers or where people are no longer able or willing to care.**

*i. Supporting carers*

Carers NSW over the past twenty five years has identified the key components of carer support and the principles to guide effective carer support (Carers Support, 2003).

Key principles to guide effective carer support include:

- inclusion of carers at every stage of service planning and delivery
- flexibility of services
- maintaining quality of life and choices for carers and those they support
- supporting the total caring situation
- affordability of services
- responsive and accessible systems
- culturally appropriate approaches
- using innovative and/or IT based methods of delivery of support
- understanding the impact of caring responsibilities on the life stages of carers and those they support.

At a minimum most carers need:

- relevant information that is timely and accurate about the supports and assistance available to carers and those they support
- emotional support
- respite
- education and training
- services that are flexible and appropriate
- increased financial assistance.

Recent research emerging from the Carers NSW Mental Health Project (2001-2005) indicates that it is not sufficient merely to provide this support but the support must be tailored to individual carer needs, taking into account when and how carers need it. The report (Carers NSW, 2005b) focuses on the development of a theoretically and empirically based framework that can be used as a practical tool to ensure that carers of people with a mental illness/disorder receive appropriate information and support interventions depending upon their place in the caring journey, their life course/life stage, and their relationship to the person with a mental illness/disorder. There is now scope to examine the applicability of the framework beyond the area of mental health.

A key challenge for NSW Health is to develop a framework for carer support across the health sector in collaboration with other agencies. Key values underpinning support would include: equity, so that carers are supported regardless of the nature of the disability, illness/disorder or chronic condition of the person they support and that they will receive this support no matter where they live in NSW; and continuity of that support to maximise engagement and minimise the stress and anxiety of carers.

This framework would need to take into account the practice, service wisdom and research noted above but also some of the specific issues that carers raise with respect to the health system.

Specific issues that carers raise with respect to the health system:

First, the need for health professionals to understand the vital role of carers, what carers do and the impact caring can have. The complexity of the hospital system and community service systems means that there can be a lack of understanding about carers and awareness of the toll that caring can take. It can also lead to misunderstanding about the availability of support to carers.

Second, the need for inclusion of the carer, as appropriate, throughout the patient journey. The pressure within hospitals is toward clinical and technical health delivery which can mean that carers are viewed as extraneous to the process, notwithstanding that the non-hospital and health care for the patient will often reside with the family. Carers frequently do not receive the information, education and training that they need. At every level of the health system carers need to be identified and supported whether it is at the birth of a child, diagnosis of a condition, the end of life, or at any stage throughout.

Third, the need for a smooth transition between acute and community care is vital. Assumptions are too frequently made about a family member's ability and willingness to care. Carers often feel that the system moves too fast, especially in the first 36 hours after discharge. There is a gap between assessment and provision of services which causes stress to carers. Referrals can be made but services may not be available. This reflects a continued focus in strategic direction and budget allocation on acute rather than community care. Patients may not be linked back into the community adequately after discharge.

More broadly, the interface between the various sectors, health, disability, ageing and between community, residential and acute care needs to be better coordinated and developed into models of integrated care.

## **ii Reaching all carers**

As noted above, according to the ABS there are at least 748,000 carers in NSW although Carers NSW, using research carried out by the Social Policy Research Centre (SPRC, 2004) considers this to be an underestimate.

It is the case that many people carrying out caring duties may not identify as carers. This means that they are not known as carers to any agencies or services and therefore receive no "formal/documented" support in their caring role. The danger contained in this to NSW Government and NSW Health, given the commitment to healthier people in NSW, is clear in light of the known impacts of caring.

Given the previously noted trends certain specific groups will need particular attention in any carer support framework, notably carers from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander carers, male carers, young carers, remote carers and those with multiple caring responsibilities.

The number of carers from culturally and linguistically diverse backgrounds is already significant and is likely to increase in proportion over the next ten years. Services and support will need to be tailored accordingly, with due attention given to the diversity contained within this group. (Carers NSW and Multicultural Mental Health Australia, 2004)

Aboriginal and Torres Strait Islander carers as a group have some of the worst indicators of health. According to the ABS (2003) it is widely acknowledged that Aboriginal and Torres Strait Island people have substantially worse socio-economic and health indicators than the rest of the population. Higher hospitalisation rates require a family centred response from health services and one that is supportive not only of the patient but the whole care situation. There is also a higher rate of disability among the Aboriginal and Torres Strait Islander population.

Men currently comprise a significant proportion (46%) of all carers, although only 28% of primary carers. The growth in male carers is a significant trend and is likely to strengthen in tandem with the increasing longevity rates of men. The scenario of men caring for their spouses is likely to grow. The work of Ussher and Sandoval (Ussher and Sandoval, 2005) confirms that supportive interventions to cancer carers need to be tailored according to their gender.

There are currently 90,200 young carers under 25 in NSW, accounting for 4% of all people under 25 (ABS, 2003a). The increase in sole parent households (mostly single mothers) who comprised 15.4% of all Australian families in 2000, increases the likelihood of children and young people having significant caring responsibilities in families due to the absence of a partner, currently the greatest providers of care. According to the Carers Australia Young Carers Summit Report 2004, young carers need to feel recognised and acknowledged in the health system and assisted in finding services and being supported.

Access to health services is generally lower in rural and remote areas in Australia and about one third of carers in NSW live outside of capital cities. According to the AIHW (2005), there is a low prevalence of health professionals in regional, particularly remote, areas. It also found that in order to address this many clinicians work long hours and spend substantial amounts of time travelling. Where clinicians do not travel it is probable that carers will be required to provide transport.

The key overall challenge is therefore to develop a framework for carer support across NSW Health which takes particular heed of a range of population groups in light of demographic trends and/or social determinants of care. Underpinning this is the need to ensure that the best quality health care is delivered to patients and the health of carers in NSW is not undermined because of their caring role with consequences to both themselves and the public health system.

### ***2.3 Future Shaping Forces***

Many national studies (Intergenerational report, 2002; Economic Implications of an Ageing Australia, 2005) have been carried out with regard to the ageing of the population in particular, with a significant amount of attention given to implications for health costs. It is beyond the scope of this paper to reprise these discussions other than to note that the costs to NSW Health are clear.

According to NSW Treasury (2004):

- on average, an older person uses hospitals at four times the rate of a younger person
- it is estimated that, on any one day, some 51% of public health patients are over the age of 65 years.

Demographic change is taking place in a national and international environment in which consumers', patients' and carers' participation in health care is increasingly acknowledged. Graham Lister (2005, p4) writing from the perspective of 2025 imagines that, "(In 2025)[t]here has been a decline in family care for elderly relatives. While in 2005 informal care was some 8-10 times the level of paid care the increasing age of carers and changing family structures and attitudes has greatly reduced this ratio producing a major crisis in care staffing. In response, informal care was given more recognition, support and funding, and local voluntary groups formed to provide care developed in other forms of social engagement with health...In health and other issues concerning consumer and citizens rights there is a level of engagement that would have been very surprising 20 years before."

In NSW there exist fragments of support to carers throughout the health and community care systems which will need to be brought together to develop an overarching framework across Government, and particularly across health. For example, there is a NSW Government Carers Statement and within the health system there is a NSW Carers Program. Both are extremely limited in scope and application and funding base but do provide a basis for future discussion.

### **3. Analysis of options for future directions**

#### ***3.1 Recognition of carers***

Acknowledging the contribution of carers to the community, acute and residential care sectors is an important beginning point for carers.

Within NSW Health there can be a lack of understanding at all levels of the role of carers in a range of settings and the impact of caring on a carer's own health and wellbeing as well as that of the person they care for.

In particular, carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning.

**A NSW Health carer policy – flowing from a whole-of-government carer policy – would provide a basis for recognition and map out appropriate supports.**

#### ***3.2 Participation and representation of carers***

Carers and their representative bodies need to be meaningfully engaged by NSW Health at all levels with respect to issues that involve and impact on them.

For instance, carers and their representative bodies will need to participate in planning, service delivery, policy and decision-making.

To do this carers will need to be represented throughout NSW Health.

## **NSW Health needs to develop a Carer Participation and Representation policy that runs across the entire department.**

### ***3.3 Framework for carer support***

Central to the motivation for the development of a framework for carer support is the demonstrated need for carer inclusion, especially in care planning and discharge planning. Assumptions about a carer's capacity, confidence and willingness and indeed ability to provide care at home needs to be avoided. The carer's own physical and psychosocial health needs will need to be discussed and assessed. It cannot be assumed that the needs of carers are static and it should be recognised that these needs will change over time.

The principles included in the Royal Australian College of General Practitioners Guidelines (2000) are a useful starting point for care planning. The NSW Primary Care Reference Group (Graham et al, 2004) has further developed these guidelines with a view to maximising patient and carer participation in health assessments and care planning. Amongst others, patients should be actively encouraged to include a family member, carer or advocate prior to assessment or in the process of developing a care plan. As the above paper notes (Graham, 2004, p2), "Of overarching importance is that there should be good and regular communication not only between the general practitioner, the patient and the patient's carer/advocate but also between the general practitioner and other relevant service providers."

With regard to discharge planning, consideration will need to be given to information provision and education for carers. Carers cannot be expected to know what to do once the person they are expected to care for returns home. For example, a carer may not know how to lift properly. Failure to know this information may result in injury to patient and /or carer and the ability to provide care.

According to the Health Professionals Conference Report (Carers NSW, 2005c), inclusion could be furthered through pre-service and in-service education for health professionals on the following:

- understanding and acknowledging the role of carers
- promoting family conferencing in discharge planning
- listening to carers' needs, more open-ended questions and time
- partnership development
- appropriate and timely links to other services

It is important to acknowledge that information, training and policies do exist within the health care setting relating to care planning and discharge planning as noted above. However, there is no coherent framework of carer support that brings together these fragments of support and locates them within a vision of carer support incorporating the support carers need and how this will change over time. As noted in section 2.2.i above, a framework of carer support would need to be developed in terms of principles, values and minimum standards. Finally, according to Access Economics (Access Economics, 2003) carer support has demonstrable human and economic benefits.

**To deal with the issues of inclusion and support in a systematic way NSW Health will need to develop a Carer Support Framework.**

### **3.4 Interface Issues**

Continuity of care from acute to home settings is a key issue for carers. It can be improved through greater coordination across community care, acute care and residential care and between health, ageing, disability and other key sectors. The effects of greater integration will benefit carers in accessing a range of services, not least in accessing appropriate equipment and transport.

Recognition of the need to improve the interface between NSW departments has also been addressed by the Department of Disability, Ageing and Home Care in their planning for the future of the Home and Community Care Program. The minutes from the February 2005 HACC Statewide Stakeholder Planning Forum identify, as a medium term strategy, the need to "strengthen strategic partnerships with other agencies including NSW Health, WorkCover Authority, Office of Fair Trading, Ministry of Transport and the Australian Government Departments of Health and Ageing and Veterans' Affairs".

Continuity of care from acute to home settings is required in regard to assessment, responsive services, carer-friendly services, monitoring and review.

### **3.5 Workforce Issues**

In light of the Anti-Discrimination Amendment (Carers' Responsibilities) Bill 2000, part of the Anti-Discrimination Act 1977 (NSW), NSW Health should develop a policy for employees who are also carers. A study of working carers in the Greater Southern AHS by Roshier-Taks and Whyte (2005) highlights carer friendly work practices in NSW Health and the particular issues carers are faced with regarding the prevalence of part time and casual work amongst carers in the health workforce.

## **4 Recommendations**

- 4.1 The options identified above, namely a NSW Health Carer policy, a NSW Health Carer Participation and Representation policy and a NSW Health Carer Support Framework, are incorporated in the Futures Planning Process of NSW Health informed by current initiatives and existing information
- 4.2 The issues and concerns raised by carers and families are considered and integrated into the recommendations across all issue papers being developed for NSW Health
- 4.3 Improved NSW Health data collection which always includes carers and consumers and reporting to outcomes for both
- 4.4 Further research on best practice carer support and subsequent policy development
- 4.5 Education and training for health professionals in carer inclusion and support and for carers
- 4.6 A NSW Health Carer Policy for employees.

## **5 Discussion prompts**

- 5.1 If you agree that carers and families are a vital part of health care how can partnership with them be better achieved?
- 5.2 What are the steps that should be taken to build a framework of carer support?
- 5.3 How can better mechanisms for carer support be developed and integrated in NSW Health?
- 5.4 How can a better fit be established between the medical model of care on the one hand and the consumer and carer model on the other?

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