

Submission

No 12

INQUIRY INTO THE OPERATION OF THE HEALTH CARE COMPLAINTS ACT 1993

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Joint NSW Parliamentary Committee
Health Care Complaints Commission
Parliament House
Macquarie St
Sydney NSW 2000

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Dear Committee,

Carers NSW welcomes the opportunity to make a submission into the NSW Joint Parliamentary Committee on the Operation of the Health Care Complaints Act 1993.

About Carers NSW

Carers NSW is an association for relatives and friends who are caring for people with a disability, mental health problem, chronic condition or who are frail aged. It is the peak organisation for carers in New South Wales.

Carers NSW is part of a national Network of Carer Associations and works collaboratively to lead change and action for carers. The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that all carers in NSW are recognised, valued and supported by their communities and by governments.

Who Carers NSW Represents

Carers NSW represents an estimated 748,000 carers across NSW (ABS, 2004).

A carer is someone who cares for a person with a disability, mental illness/disorder, chronic condition or who is frail aged. Carers can be parents, partners, brothers, sisters, sons, daughters, friends or children of any age. Carers may care for a few hours a week or every day. Carers are unpaid. They may receive income from a range of sources including wages or government pensions and benefits.

A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics (ABS, 2005) defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another

family member or formal services provide the majority of care (Carers Association of South Australia Inc, 2001).

Each caring situation is unique. Some carers assist the person they support with all their activities of daily living while others provide intermittent support. Their caring tasks can range from administering medication and dressing wounds to personal care tasks such as showering or supervision of daily activities. Carers also provide emotional support day in and day out to some of the most vulnerable, isolated members of our community and they often act as case managers; navigating service systems and organising appointments. Caring is the invisible work which enables people requiring support and care to live in the community, maintaining a good quality of life.

Carers are pivotal to both the community care and public health systems. In regard to the health system, some carers provide care for short, intensive periods of time following discharge from hospital. Others provide care intermittently for someone between hospital visits. There are carers who provide full-time care for many years to people requiring ongoing medical treatment and community support. Many carers care full-time, for the lifetime of the care recipient, for people with severe multiple disabilities. Carers are faced with anxiety over the fate of the person for whom they care after their own death.

The NSW Carers Action Plan 2007–2012

The Action Plan outlines a whole of government policy commitment to recognising and supporting carers over this five year period. It includes strategies to increase the respect and recognition of carers, reach out to family members who may not see themselves as carers, improve services to carers and the people they care for, encourage agencies to view carers as partners in care and support carers to combine work with caring.

Key Statistics on Caring in NSW

According to statistics on carers from the Australian Bureau of Statistics (ABS, 2004), in 2003:

- Approximately one-third of all carers in Australia live in NSW
- There were 748,000 carers in NSW (11 per cent of the population), 20 per cent of whom were primary carers
- 40 per cent of primary carers cared for a partner, 29 per cent for a child, 32 per cent for other (e.g. sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of primary carers were of workforce age although 45 per cent were not in the workforce
- The median gross personal income for a primary carer was \$224, other carers \$365 and non-carers \$435
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income

A report by the National Centre for Social and Economic Modelling (NATSEM, 2004) projects Australia faces a carer shortfall. It is estimated that by 2031 the number of

older people likely to need assistance because of severe or profound disability is likely to increase by 160 per cent whereas the number of people likely to provide care will only increase by 57 per cent.

Investment in carer support by government has been shown to give financial returns of 7:1 (Access Economics, 2003).

The physical, mental and emotional health and wellbeing of most carers was poor because of their caring responsibilities. As a result of caring over half of carers suffered a decline in physical health and two thirds felt their mental and emotional health had been affected by providing care (NATSEM, 2004).

The largest survey of carers' health and wellbeing was released in October 2007. The survey undertaken by Deakin University, Australian Unity and Carers Australia found the following:

- Carers have the lowest level of wellbeing of any group surveyed in the previous six years using the Personal Wellbeing Index measuring tool
- Sole parent carers had the lowest wellbeing of any carer
- The wellbeing of carers decreases linearly as the number of hours spent caring increases
- Carers are more likely than is normal to be experiencing chronic pain
- Carers are likely to have an injury and this is associated with reduced wellbeing
- Carers have an average rating on the depression scale that is classified as moderate depression, and over one third are classified as having severe or extremely severe depression (Deakin University, Australian Unity and Carers Australia, 2007).

Submission Format

It is not the intention of Carers NSW to respond to the specific three areas of the NSW Joint Parliamentary Committee on the Operation of the Health Care Complaints Act 1993 Inquiry but to outline the relationship between health care provider, patient and carer and provide an overview of issues for carers in regard to the health system and the health care complaints system in general. Carers NSW would appreciate the opportunity to address the Committee during the proposed public hearings in 2009.

Carers, the Australian Population and Health Care

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 people 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 20 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). This includes for example, cancer, diabetes and mental illness, all of which are projected to rise in incidence and/or prevalence in NSW. 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.

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. Seventy-four per cent of the assistance required by Australian's due to disability or illness is provided by informal carers. Every year carers provide over 1.2 billion hours of support (Access Economics, 2005).

According to the Productivity Commission (2005), the current care mix, between formal and informal 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 15 years given government policy and the wishes of members of the community to be cared for at home.

Carers as Partners in Care

The *NSW State Health Plan*, together with the *NSW Carers Action Plan 2007-2012* have placed a strong emphasis on 'carers as partners in care', identifying the integral role that carers and families play in supporting people with health needs, both while using formal services, and at home in the community. The *NSW Carers Action Plan 2007-2012* places specific emphasis on the acknowledgement that improving the quality of life and health and wellbeing of carers directly benefits the recipients of care (NSW Health, 2007).

The notion of carers as partners in care is increasingly acknowledged in international literature:

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 (Performance Improvement Advisor, 2004, p58).

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 (Wilson L and Harnett E, 2005). However, this 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).

The NSW Government has addressed the vital role of carers of people with mental health disorder or illness in the Mental Health Act 2007. The act acknowledges the role of carers as a partner in care and includes provisions relating to carers rights. In conjunction with the introduction and implementation of the act is training for health care professionals.

Carers and the Health System

This section provides an overview of specific issues that carers have raised with Carers NSW in relation to the health system. The information is relevant to provide awareness and understanding of issues that carers face, and should be used as a guide in the delivery of acute care services in NSW public hospitals. The issues raised also help to provide a picture of the specific needs of carers in relation to the health care complaints process.

There is a 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 impact of caring on their life choices and social, financial and health wellbeing. It can also lead to misunderstanding about the availability of support to carers. Carer's involvement is generally based on a deep and abiding personal commitment. Carers do not have the same resources, pay or training as health service providers and therefore should not be tasked with the same responsibilities.

Feedback from carers indicates that within NSW Health there is 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.

There is a 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.

In a 2005 Western Australian study with response by 1,619 carers the Centre for Independent Living Western Australia (CILWA, 2006) identified that carers experience a variety of problems such as injuries and heavy lifting, and overall deterioration of their physical and mental health after they commence their caring role.

The lack of specialist carer support and training was also identified. Data indicated:

Training and education

- Only 36 per cent of carers said they had received information or training on injury, avoidance or risk management
- 55 per cent of carers had never received such information or training and nine per cent were unsure
- Among those who did receive training or information, 29 per cent had acquired this knowledge through their own personal experience or training).

Injury and health and wellbeing

- 43 per cent of carers said they had been physically hurt or injured as a result of providing care
- 63 per cent reported that caring had a medium to very large impact on their physical health
- Carers reported a higher level of orthopaedic or spinal problems, cardiovascular problems and emotional or mental problems after they became a carer.

Specific needs such as the need for patient and carer to have access to adequate and appropriate information and communication mechanisms are vital for informed decision making. For people who do not have the capacity to understand and make an informed decision about their own health care needs, carers often take on this responsibility on an informal basis as advocates and substitute decision makers. Where the patient has capacity to make an informed decision, the carer is often an important contributor to assisting in providing information dissemination and communication between patient and health care provider.

Carers themselves often have needs within the health system that are different or additional to that of the patient. Research by Dow and McDonald (2007) illustrated the imbalance between expectations placed on family carers and the resources available to support them. They called this the 'invisible contract' that binds family members to carry out substantial care-work that was previously carried out by hospital staff. They found an expectation existed for the family members to accept a caring role with little consideration for their individual circumstances and listed examples where no consultation had occurred prior to arrangements for the transfer of care from the hospital to the home (Dow and McDonald, 2007).

The individual needs of the carer must be acknowledged and addressed to ensure adequate supports are in place when a patient leaves the hospital system to be cared for at home. This could include health worker training that addresses carer needs and contributions within the health care team; and discharge protocols that include and respect carer views and ensure follow-up supports are in place. 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.

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 (Carers NSW, 2005).

According to the Health Professionals Conference Report (Carers NSW, 2005b), 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

Young Carers

Carers NSW believe it is imperative to draw the attention of the Joint Parliamentary Committee on the Operation of the Health Care Complaints Act 1993 to the role of young carers in the NSW health system.

It is estimated there are currently 90,200 young carers in NSW (ABS, 2004). There is currently no available data of age breakdown of young carers in the 9-14 year age bracket. Carers NSW supports young carers as young as seven years old. There are 1,686 young carers on the Carers NSW database.

The *NSW Carers Action Plan 2007-2012* specifically refers to identifying and supporting 'hidden' carers'. Young carers have been identified within this group, including the need to support young carers directly, as well as supporting parents who need care in their parenting role to reduce inappropriate levels of caring by young carers.

Young carers may undertake tasks ranging from cooking, cleaning, being responsible for finances, minding siblings and supporting the person with an illness or disability. Supporting the individual may involve personal care such as showering, emotional support, or medical support such as administering medication.

Young carers identify that there is little understanding from service providers and in the community about the role of a young carer and therefore what their support needs are.

There needs to be a greater awareness of young carers and an understanding of the extent of the responsibilities they have. A survey of young carers conducted in the ACT (Moore, 2006) suggested that young carers and their families were not receiving supports because services did not respond to their need, they weren't of quality, they were not accessible and they were not well publicised. This meant that many young carers and their families did not know what they were entitled to or how to access supports.

Carers NSW recommends that Improved awareness of and training to community care service providers about young carers and their needs, in order for services to have a better understanding about how to support young carers, particularly in regional and rural areas is essential. Of particular importance is the acknowledgement and acceptance by health care providers that often young carers will be the main provider of care in the home when their parent is discharged from hospital, including providing medication and other health maintenance. Young carers will often be supporting a sole parent provide

this support to a sibling. This means that young carers need to be provided with appropriate information and training to enable them to undertake their caring role.

Carers and the Health Care Complaints Process

Carers have provided information that they often feel their knowledge and experience of the care recipient is not sufficiently acknowledged or used in health and care planning (Carers NSW, 2005). The role of the carer as a provider of information regarding a care recipient to health care providers must be acknowledged and utilised to enable health care providers to gain the most relevant information about a patient's care needs. The vital role of the carer also needs to be recognised in the relevant legislation, including that governing the right to complain through the Health Care Complaints Tribunal.

Carers require information to be provided in an accessible format so that channels of complaint and due process can be exercised more easily. The Health Care Complaint Act 1993 may be able to be produced in formats that are more easily accessed by carers across NSW. This may include providing visual aids such as flowcharts that document the various steps inherent in lodging a complaint.

Another issue of relevance to the accessibility of the health care complaints process is the vulnerability sometimes experienced by carers, especially those from disadvantaged backgrounds and those from culturally and linguistically diverse backgrounds.

People who reside in small communities may also find it difficult to lodge formal complaints when the system or person they are complaining about resides in their own small community. Similarly, carers and families frequently will not report inadequate care or mistreatment of family members or friends in residential care because of fear of reprisal by some residential care facility staff.

Recommendations

Carers NSW recommends that a review of the operation of the Health Care Complaints Act 1993 considers:

- The rights of the carer to act with or on behalf of the health service user including the right to complain through the Health Care Complaints Process
- The special needs of carers, who have their own requirements for information, education, communication and support
- That carers require access to support for their own issues which may arise from providing care
- The need for Improved awareness of young carers by health carer providers and training for them about young carers and their needs, in order for health care providers to have a better understanding about how to support young carers, particularly in regional and rural areas. This includes an understanding of and support for the role of young carers in case management and service coordination to meet young carers ongoing individual needs and those of their families

- That adequate mechanisms to prevent reprisal from health care providers exist to protect carers and other consumers who make a complaint to the Health Care Complaints Process from reprisal by health care providers
- That the Health Care Complaints Act 1993 is produced in formats that are more easily accessed by carers in NSW, such as:
 - The use of flowcharts that document the different steps inherent in logging a complaint
 - The use of non-intimidating images in fact sheets and other information tools that carers can relate to
 - The use of Plain English format
 - Ensuring the complaints process is simple, accessible and user friendly.

Conclusion

This submission has identified key issues for carers in regard to the health care system, and the integral relationship between health care provider, patient and carer. The inquiry provides an opportunity to recognise the role of the carer within the health system, and the information in this submission provides an overview of how carer recognition and carer support could be applied in practice to better meet the health care needs of both patient and carer.

The right to a fair and equitable complaints process is essential for all users of the NSW health care system.

Carers NSW acknowledges carers are increasingly being recognised as an essential part of the health care team and that their specific needs and rights require attention in all relevant legislation and inquiries.

Carers NSW appreciates the opportunity to comment on the inquiry and looks forward to the opportunity to provide more specific feedback during the proposed public hearings in 2009.

If you wish to discuss these comments further please contact:

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Yours sincerely



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