

**INQUIRY INTO THE EXERCISE OF THE FUNCTIONS OF
THE LIFETIME CARE AND SUPPORT AUTHORITY AND
LIFETIME CARE AND SUPPORT ADVISORY COUNCIL -
THIRD REVIEW**

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Carers NSW Submission to the Tenth Review of the exercise of the Motor Accidents Authority and Motor Accidents Council and third review of the Lifetime Care and Support Authority and Lifetime Care and Support Advisory Council

1. About Carers NSW and Carers

1.1 About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

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 caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by the community and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

1.2 Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW, there are estimated to be approximately 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Carers exist in all communities, including amongst Aboriginal communities, those of cultural and linguistically diverse backgrounds, amongst Gay, Lesbian, Bisexual, Transgender and Intersex communities, and throughout metropolitan, regional and rural NSW.

1.3 Submission format

This response addresses aspects of the functions of the Motor Accidents Authority (MAA) and the Lifetime Care and Support Authority (LCSA) in regard to how the MAA and LCSA support carers currently, and provides an overview of the relationship between health care provider, patient and carer, in order to identify how carers can be better supported in their caring role.

It is not the intention of Carers NSW to respond to all of the questions posed in the Review.

2. 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. Seventy-four per cent of the assistance required by Australians 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 fifteen years given government policy and the wishes of members of the community to be cared for at home.

The annual reports and websites of MAA and LCSA acknowledge the integral role families play in the treatment, rehabilitation and support of a person severely injured in a motor vehicle accident, stating that the family's involvement is actively encouraged in order to best assist the consumer to participate in their roles within their home and community. Carer NSW supports this proactive approach to the inclusion of carers in the support of a person with disability.

2.1 Use of the term carer

There has been confusion in the community services field and general community about who exactly is a carer. Often the term 'carer' is applied to paid staff in the residential, community care and child care sectors. It is also applied to people who choose to volunteer their time to assist a person in the community. As a result, the specific group of informal, unpaid carers is often not acknowledged. The annual reports of the MAA and LCSA use appropriate wording to describe the care provided by paid service workers, for example the term 'health professionals' is used to describe service professionals that work in the health care sector.

The annual reports of MAA and LCSA, as well as the websites use the term 'family' when referring to those involved in the support of a loved one. Carers NSW congratulates the MAA and LCSA in recognising the inclusion of the family in providing support to a loved one with catastrophic injuries.

Carers NSW believes it is also important for families to be aware of the role of informal caring they are taking on to support their family member. Due to the nature of the sudden acquired disability of the person requiring support, it is highly likely that many family carers will not have been carers before, or had time to prepare for the role of a carer, and will need to make rapid life decisions and changes.

For this reason it is important that families are assisted to identify as carers, to enable acknowledgement of their role and access to appropriate support. Carers NSW encourages the use of the terms 'carer' or 'family carer' rather than 'family member' when referring to family (or friends) that will take on a caring role of an individual. Identification with the term 'carer' is the first step in accessing appropriate support in their caring role.

2.2 Carer support information and access

The MAA and LCSA websites provide relevant information that is clear and easy to understand in regards to the LCSA scheme, application process, eligibility, and support.

One of the Key Result Areas in the MAA and LCSA annual report is for 'improved services available for injured people and their families'. It would be beneficial to provide information on carer specific support to assist family carers to both identify their role as a carer, and have access to information that will support them in their caring role.

Both websites need to have information to assist family carers to learn about and access appropriate services for their needs, different from those of the person for whom they care. Appropriate information could include access about services provided by Carers NSW and other carer support services, such as the Commonwealth Respite and Carelink Centres.

Carer support information is also important for people who have been deemed ineligible for the LCSA. There should be information available to assist carers to access other support services both for themselves and the person they are supporting. Carers NSW would welcome involvement in providing information about appropriate carer support services, including both support provided by Carers NSW and support provided by other services.

Another suggestion could be a specific booklet about what to expect in a caring role in caring for someone severely injured as a result of road accident or catastrophic injury. A general information booklet will assist families to understand and cope with a range of unfamiliar systems and what to expect in navigating the systems and support available.

It is evident family carers are an integral part of the care plan for the person catastrophically injured. Carers NSW believes the MAA and LCSA should include carer support programs as part of the Lifetime Care and Support Scheme for the lifetime of the caring role.

From August 2004 to December 2005 the MAA NSW funded Carers NSW to conduct the 'Carers Linked in Caring Project (CLIC) – A Support Program for Carers of People with Traumatic Brain or Spinal Cord Injury'. CLIC was designed to provide appropriate carer-specific information and support to carers of people with TBI or SCI who had been discharged from rehabilitation for at least one year. In this case, 'appropriate' support included information relevant to all carers, as well as specific types of information and support targeting the issues most commonly faced by carers of people with TBI or SCI. An evaluation of the project was conducted and included the following recommendations:

1. That the types of support offered to the carers of people with TBI or SCI in the CLIC project continue to be offered, and new models explored which go beyond emotional support to include psychotherapeutic programs
2. That services which primarily support people with TBI or SCI be funded to provide support to their carers as well, working in partnership with Carers NSW.

The evaluation demonstrates the CLIC pilot project was beneficial in supporting this specific group of carers. Carers NSW would welcome a partnership between the MAA, LCSA and Carers NSW to continue running the program on an ongoing basis.

2.4 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 Carer Recognition Bill 2010 currently before the NSW Parliament also recognises carers as partners in care, and formally acknowledges their right to be heard when we make policies, laws and regulations that affect them. It sets out the principles that should be followed by agencies when providing services to carers or persons they care for and ensures that carers' interests will be considered when agencies are considering legislative or policy proposals that will affect carers.

Carers have raised specific issues with Carers NSW in relation to the health and community care systems. 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 services to severely injured people of road accidents and their carers.

Feedback from carers indicates that there is a lack of understanding at all levels of the role of carers and impact of caring in a range of human service settings. In particular, carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning. Education to health professionals, service providers and Lifetime care coordinators regarding carer awareness is vital to ensure there is a clear understanding of the support needs of carers, how to work with them, and provide relevant information, resources and referrals that support individual carer needs.

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.

There is a need for inclusion of the carer, as appropriate, throughout the patient journey. 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. 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.

Carers also state that 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. Continuity of care can be improved through greater coordination across community care, acute care and residential care and between health, ageing, disability and other key sectors.

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).

Carers are often forced to accept considerable responsibilities in relation to the provision of care and support, yet provided with few rights or supports themselves. Family members should have choices about whether or not they begin, continue or cease their caring role. This choice must be enabled by the flexibility of support services involved in the scheme to adapt to changing carer and family situations.

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.

This is particularly significant for ageing parent carers. Given that young men under the age of 30 are most likely to be catastrophically injured in motor vehicle accidents, their parents will most likely provide their informal support. As these parents age, their support need will also change, with a need for not only ongoing respite care and other support services, but also planning for future accommodation and support needs of their adult child when they are no longer able or willing to provide care.

With regard to discharge planning from the health care sector to home, feedback from carers indicates there has not been support provided to them prior to discharge of their family member from hospital into their care. 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 the patient and/or carer and the carer's ability to provide ongoing care (ILCWA, 2006).

3. Conclusion

Carers NSW supports the functions of the MAA and LCSA in regard to supporting people with disability as a result of road trauma and their family carers.

This submission provides awareness of the role and support needs of carers, and issues carers have raised with us in undertaking their caring role. This submission provides the following recommendations to further assist carers in their caring role:

1. Use of the term 'carer' on the MAA and LCSA website to assist family members to identify their caring role
2. Availability of support services for carers on the MAA and LCSA websites
3. Continuation of the 'Carers linked in caring project (CLIC)' run in partnership with Carers NSW and the MAA NSW
4. Education to health professionals as part of the LCSA scheme regarding carers needs
5. Training for carers to support them in their caring role, particularly during the time of transition of the consumer for the health care setting to home, and also to prevent injury to the carer or the person requiring care.

Carers NSW appreciates the opportunity to comment on the review and welcomes further opportunities to partner with the MAA and LCSA in delivering support to carers of people with a disability who have been severely injured as a result of a motor vehicle accident.

For any further information please contact Maja Frölich, Multicultural Policy and Development Officer on 02 9280 4744 or majaf@carersnsw.asn.au.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Elena Katrakis', written in a cursive style.

Elena Katrakis
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