

Sub# 9



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Carers Queensland Inc.

**Submission to the
Health and Community Services Committee -
*Inquiry into palliative care services and home and
community care services in Queensland***

August 2012

Family carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged.

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with a disability, people who identify as culturally and linguistically diverse, indigenous Australians and those living in rural and remote Queensland provide care to a family member or friends on a daily basis. For some caring is a short term commitment whilst for others, it is a role that literally lasts a lifetime.

Carers Queensland Inc. is the peak body representing the diverse concerns, needs and interests of carers in Queensland. Carers Queensland believes that all carers regardless of their age, disability, sexuality, religion, socioeconomic status, geographical location or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment and education like other citizens of the State. Carers Queensland's vision is that caring is accepted as a shared community responsibility.

The Carers (Recognition) Act 2008 Carers Charter includes many of the above statements in the thirteen key principles.

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Inquiry into palliative care services and home and community care services in Queensland.

Date: August 2012

Author: Sarah Walbank, Policy and Research Officer

Approved by: Debra Cottrell, Chief Executive Officer
Carers Queensland Inc.
15 Abbott Street
Camp Hill 4152
Queensland
Phone: (07) 3900 8100
Website: www.carersqld.asn.au
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Introduction

Carers Queensland commends the Queensland Government on the timeliness and scope of this inquiry and welcomes the opportunity to provide meaningful input. We believe we are in a unique position to consult with, and advocate on behalf of, the 494,200¹ carers living in Queensland, many of whom who have, and continue, to play a pivotal role in the community care and palliative care sectors.

We aspire to provide an independent platform from which to advance the issues and concerns of carers and hope our knowledge and expertise in carer issues means that we are able to provide the State Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected and acted upon. Our ambition is to ensure that carers are recognised and included as active partners in the development of State social policy and services delivery practices.

We take this opportunity to provide the Queensland Government with responsible and cost effective recommendations which, if implemented, will better support the carers who play a vital support role in the community care and palliative care sectors across Queensland. Carers Queensland believes that a comprehensive system of services and programs of carer support is needed to sustain past achievements and meet the challenges of the future. These measures complement the government's commitment to carers through the Queensland Carer Action Plan 2011-2014 and the intentions of the Queensland Compact with the non-profit community services sector.

This submission has been informed by consultation with Queensland's carers, several government reviews, Australian and international research and the annual C3 (carer) Consultations.

Current Carer Demographics

Carers are, by and large, the main providers of care and support in the community and have been described by the National Health and Hospital Reform Commission as the 'invisible, unpaid workforce'² and a 'taken-for-granted resource', complementing and supporting formal community care^{3, 4} services. It has been estimated that carers provide 74%⁵ of the assistance required by people with disabilities and the frail aged and, as such, carers can be considered an integral component of the community care and palliative care sectors in Australia including Queensland.

Some Queensland statistics:⁶

- One in eight citizens identify as a carer
- One third of carers identify as a primary carer
- Two thirds of carers are women
- Carers are equally likely to live in a major city as in regional Queensland
- In 2009, there were 60,300 identified young carers between 15-24 years of age. The majority of these young carers are male

Of the 152, 800 primary carers in Queensland:

- 87.69% (134,000) co-reside with the person they care for
- 23,000 primary carers between the ages of 45 to 64 years provide 40 or more hours of care per week
- 8500 or 5.56% of all primary carers have been caring 25 years or more and of this group, 4,100 have been providing 40 or more hours of care per week
- 46.9% are a spouse or partner; 19% are a child and 23.7% are a parent

Nationally, carers provide 1.32 billion hours of care per year. Conservative national estimates suggest the replacement value of informal care is approximately \$40.9 billion per annum (equivalent to 3.2% of GDP and 60% of other formal health care). Carers provide on average 460 hours of care annually or 9 hours per week. However, the provision of care is not evenly distributed. Primary carers provide 54% or 714 million hours annually, despite representing only 19% of the citizens who identify as carers. The more severe a person's disability or illness, the greater the amount of time devoted to caring by the primary carer. Informal family care remains the lowest subsidised form of care provided in Australia.⁷

Research shows that many carers experience health, social, emotional, economic and employment disadvantages and are often marginalised in society^{8, 9}. To address these persistent inequalities carers are included in one of six social inclusion priorities in the Commonwealth Government's Social Inclusion Statement- A Stronger, Fairer Australia¹⁰ and have been identified as a group at risk of long term social exclusion in the Queensland Department of Communities 2009-2013 Strategic Plan.¹¹

Future demographics and demand for carers

Statistics indicate that the number of people willing or available to provide informal care in Australia is diminishing, although the hours of care provided and the contribution of in-kind support to the health and community care sectors is increasing proportional with the rise in the number of dependent people in the population.

The changing demographic profile of Australia means that an increasing proportion of carers are providing care to family members from different generations than previously. Known as 'sandwich carers', these individuals often provide care to an elderly parent and a spouse, child or grandchild(ren), dividing their time and energy across two different caring spectrums. Research conducted by the Mental Health Council of Australia indicates that 20.8% of carers of people with mental health problems care for more than one person.¹²

This trend poses a challenge to Australia, like other Western countries, that has an ageing population. In 2010, people 65 years and over constituted 13% of the population. By 2051, data projections suggest that as a proportion of the population older Australians will increase to between 26% and 28% or one in four of the population.¹³ Similarly, research conducted for the Disability Investment Group in 2009 predicts that there will be a rise in the number of people with severe or profound disabilities from 1.4 million in 2009 to 2.9 million in 2049. Healthy life expectancy is increasing but not at the same rate as life expectancy for everybody, suggesting that the demand for care in older age will increase.¹⁴

An urgent issue arising from this anticipated growth in numbers of people with severe and profound disabilities, people with dementia and older dependent people relates to the demand for both formal and informal care and how to meet the burgeoning costs against a diminishing taxpaying population. Research conducted for Carers UK suggests that one in three citizens expect to provide care and support to a family member or friend in their lifetime.¹⁵ There is no reason to expect the situation will be any different in Australia.

Submission Focus

Consultations with carers indicate a need for services that have as the core purpose and approach, a preventative focus; that is services that can and will work with carers and the person they support, to assist them to meet their current or future needs, whether it is for something as routine as respite care or the more difficult and challenging – such as palliative care.

If our community and allied health care sectors continue to focus primarily on prioritising assistance and resources for individuals and families in crisis, it will lead to an increasing demand for ‘crisis services’. People with emerging problems will (potentially) continue to be overlooked by the sector and left to manage their escalating problems as best they can until they can no longer cope and the crisis unfolds, creating a (potentially) perpetuating structure.

Preventative or early intervention services are underpinned by a commitment to social inclusion, working with and for carers as genuine partners, to meet the long term goals of both the carer and the person they support. Therefore, preventative or early intervention services have the potential to reduce the longer term demand for crisis responses and will see less people ‘fall through the cracks’, often a great personal costs. These strategies also have the potential to assist and support a greater percentage of the client population (carers and the people they support) than crisis services.

Overview

For many carers community care and palliative care services are the lifeline that enables them to continue with their caring commitments and responsibilities. Without the routine support and assistance of community care services many carers admit that they would have had to consider residential or nursing home options at a much earlier stage. Similarly, many carers have spoken of and have been humbled by, the wonderful assistance provided by community care services in the preparation for and after the devastating adverse weather events of the last three years.

Notwithstanding, many carers have, and continue to, experience difficulties in obtaining information about community based services, excessive delays in obtaining an assessment and even longer delays in securing culturally appropriate, flexible and timely services that meet the diversity of their needs.

Carers experiences of the palliative and community care sectors

The preference of people to live and die at home is compatible with the government's objective to shift health care from public hospitals and institutions to families and their communities. Research has indicated that 74% of Australians would prefer to die at home.¹⁶

In reality approximately only one-third of all people receiving end of life or palliative care services die at home¹⁷, although the vast majority of people with a disability or life limiting illness live in the community, often dependent on the support and assistance of family carers. The provision of community care and palliative care to people in their own homes would be impossible without the support of carers, many of whom are insufficiently prepared, supported or resourced for this complex, physically and emotionally challenging and sometimes prolonged role. The contribution of carers is often under-estimated by the health and community care sectors and individual practitioners.¹⁸

Caring for somebody with a disability, life limiting illness or nearing the end of their life can be a rewarding role, as many clients of Carers Queensland attest. Nonetheless caring can, and does, come at a significant cost to the individual carer and the community. Australian and international research highlights the financial, social, emotional, physical and psychological costs many carers incur with their caring responsibilities, particularly longer term carers or those providing many hours of support.¹⁹ Research conducted for Carers Australia²⁰ and the Australian Institute of Family Studies²¹ estimates that carers have the lowest collective wellbeing of the population; an average stress rating that is classified as moderate depression and experience a higher rate of mental health problems.

The provision of end of life care can exacerbate the stress already experienced by carers.²² Carers have repeatedly voiced concerns about unmet needs for information on appropriate services, enhanced communication, more flexible and responsive service provision and adequate recognition by, and support from, health and community care practitioners. This is supported by academic research which indicates that the greatest source of stress for carers, particularly those providing end of life care, includes an uncertainty about the treatments offered, lack of appropriate knowledge about the care of the individual, changing roles within the family, lack of affordable, accessible and regular transport, strained financial resources, physical restrictions, lack of social support and the fear of the future.²³ International research about end of life care indicates that 46% of carers experienced increased anxiety and 39% increased depression²⁴ and older spousal carers who experienced heightened stress with their caring responsibilities were 63% more likely to experience earlier mortality.²⁵

Carers are in a unique and ambiguous position, both practically and conceptually, in relation to service delivery. On one hand they are the pillars of the community care and palliative care sectors – providing innumerable hours of informal care and support; subsidising a system that can ill afford to meet the total need in the community. On the other hand, they also need support and assistance to deal with the challenging and sometimes harsh realities of their lives. Such support and assistance is available to professional practitioners through in-service training and supervision but is not readily available or forthcoming for carers. A carer in need of additional resources and support is regarded as a *potential client* and therefore dependent on highly rationed and means tested services, often unable to meet demand in a timely and proactive manner. As a result, carers continue to provide care, often at the expense of their own health and wellbeing.

As two carers highlighted:

*“I currently have a potentially terminal health condition, probably arising from the fact that I did not attend my GP early enough due to my caring and work roles”.*²⁶

*“Cannot spare time to have my health issues dealt with. Drama in organizing respite in two different facilities, (IF there was any available) and paying for it (since there is no money available from carer's respite) means I am unable to have surgery or address any (sic) big health issues”.*²⁷

Many carers feel abandoned and unheard by health and community care practitioners. As one carer whose husband has advanced dementia pointed out at a recent C3 Consultation, there has been little or no assistance from the family GP: *“The doctor asked me what's been going on and I said I am really tired. He sits there going BIG SMILES. Nothing.”*²⁸

Another carer of some 20 years pointed out she only heard about HACC services through ‘an accidental encounter’ with the hospital Occupational Therapist only in the last five years or so.²⁹

Carers can, and do, develop a strong sense of responsibility for the person they care for and support and over the course of their caring journey develop considerable expertise in understanding how the individual responds to their medical issues and treatments, what works well and what does not. Carers are often placed in the role of advocate by the treating practitioners yet carers feel they are not considered an integral component of the service delivery team³⁰, worthy of being consulted or communicated with.

As one carer stated:

"I was the primary carer for my mother for five years – up to her death. I have four university degrees and have been in this sector for 30 years and I thought I knew what carers experience. However, caring for my mother was the biggest lesson I have learnt. I refer to those years as the 'persona non-grata years' – I did the work but not once was I really consulted. The expectation from the health and allied health sectors was that I would do all the work – that's it, no discussion, no nothing. I did everything. Just before my mother died, the hospital social worker rang and accused me of the 'deliberate bed blocking' of an acute care bed. When I asked her if she had bothered to meet my mother; to ascertain for herself my mother's condition she adamantly admitted that she hadn't and that she didn't need to. My mother died the next day. It's sad that social workers are more concerned with meeting performance targets and applying policy than knowing and understanding the issues affecting carers and the people they support".³¹

Whilst current health and community care ideology acknowledges the contribution of carers and emphasises the involvement of carers in service assessment, planning and delivery, anecdotal evidence from carers suggests that reality is far removed from ideology and policy.³² As carers have repeatedly pointed out, service planning and delivery appears to be reactionary and usually in response to a crisis or imminent crisis, rather than planned with the carers and the person they are caring for.

A carer stated:

"Organising respite care is a dog's breakfast. Respite is over-priced for what you get..."³³

Another carer stated:

"[We] are too isolated from required oncology treatment or home visits, [and] as [the] carer [I have] spent too much time travelling to and from hospitals at late hours, at times sleeping in hospital with patient on cots. [I]n 2yrs we had been in 5 different hospitals. Waiting periods for ambulance transfers wasn't good for patient as well as quality of transfers were terribly painful for patient. My health as carer wasn't a priority, only caring for the needs of my mum emotionally and physically was. Community care services had too long a waiting list especially for those who were isolated and unreasonable red-tape with home assessing adjustments when patient was "in hospital" thus not allowing us to be ready with required equipment for when the patient returned home".³⁴

Some carers encounter additional marginalisation or disempowerment. Australian³⁵ and the UK³⁶ research into the experiences of people with chronic mental health problems and their carers highlight the stigmatisation and disparagement of carers by the very health professionals they seek advice and support from. Such stigmatised responses act as a 'social disability' which may result in lower self-esteem, loneliness and results in the poorer mental health of the carer.³⁷

As a carer in rural Queensland reflected:

*"If you have AIDS you don't belong. You don't admit to it. She [the palliative care service provider] would not come back to that house..... I'm carrying the stigma, he's passed away".*³⁸

Research has indicated that more than half of the spousal carers of gay men with AIDS experience suicidal ideation and these thoughts are associated with a perceived lack of social support, lack of social integration and 'caregiver burden'.³⁹ Research conducted by the Southern Cross University⁴⁰ into the experiences of LGBTI carers providing end of life care highlights the reluctance of some carers within the LGBTI community to access appropriate health care or support services due to the additional burden of stigma and the fear of discrimination and violence. The stigma and marginalisation can cause 'disenfranchised grief' for many LGBTI carers in response to the lack of recognition of, and respect for, their relationship with the person they cared for and supported.⁴¹ These issues continue to confront LGBTI carers in urban, rural and remote Queensland.

The relative scarcity of community care and palliative care resources in rural and remote regions means there are additional expectations placed on carers. Research has indicated that the needs of carers providing palliative care in rural and remote areas were three times more likely not to be met when compared with the patients' needs.⁴²

As one carer pointed out:

*My husband was granted respite in (name of town) for week. The only trouble was it would take me a day and a half to drive there and back, and another day and a half to collect him. The cost of the petrol and the drive..... It wasn't worth it – for me that is.*⁴³

A carer spoke of the lack of confidentiality that can occur in smaller communities:

*"I've been getting services for about 10 years now. I've had to battle for years to get home care and the yards, there is a perception that you are two healthy people at home and therefore you don't qualify. The assessment took a long time and there were lots of questions to be answered. After the assessment I went shopping at the supermarket and overheard the service provider talking with another person about my situation and details. My confidentiality was compromised. I received no apology. The people responsible for funding and services are all quite judgemental. The service providers seem to focus on the needs of my son but not us carers."*⁴⁴

As another carer in rural Queensland stated:

"I am prepared to take sub-optimal care because there is not a great choice of services".⁴⁵

For many carers the demands of their caring commitments exceed their personal capacity to give – either with time, finances, physical energy or psychologically. Many compromise in order to cope, financially and emotionally. Research conducted by Carers Queensland reveals 22% of survey respondents chose not to attend a medical appointment because of difficulties with transport services and the cost of fuel or fares.⁴⁶ These carers often carry chronic injuries which may, at a later date, impair their ability to continue caring or negatively affect their ability to sustain paid employment.

This lack of support for carers may occur, in part, because carers are seen as a free resource to supplement formal services.⁴⁷ The unrelenting nature of the caring role means that many carers 'burn out' from exhaustion, following which a crisis response is initiated. The continued expectation by others (including the health and community care sectors) that carers can and will continue to provide all the care and support necessary reinforces the perception that the locus of control is outside of their sphere of influence. For many carers this behaviour exacerbates their sense of marginalisation in society and is often evidenced in their own deteriorating physical and psychological health.

Caring for another individual is, for some carers, a short term responsibility. Yet, for other carers the responsibility may literally last a lifetime. Carers of people with dementia often face a decade or more of intensive caring responsibilities, often at a time when their own health and wellbeing is diminishing. Having regard for the anticipated rising prevalence of dementia in Australia⁴⁸ and the demand on a diminishing population of potential carers, the support of carers of people with dementia warrants specific consideration.

The impact of prolonged caring and diminishing health and wellbeing of the carer can lead to devastating consequences. Research into the homicide-suicide rate in older couples reveals that the 'act' is often associated with the changing (deteriorating) health status in the perpetrator, the victim or both and that up to 50% of homicide-suicides are committed by spousal carers, with approximately 20% of those caring for a spouse with dementia^{49, 50}.

Anecdotal evidence from the Carers Queensland Counselling Service suggests that suicidal and homicidal-suicidal ideation amongst carers is a real issue. Acknowledging this, Carers Queensland is currently supporting and actively assisting with national research examining the suicidal ideation rate of carers of a person with dementia. The results of the research will be developed into best practice systems and services and integrated into our business practices in a bid to better support carers prior to a potentially fatal crisis.

Preparing for the future

Restoring a carer's sense of control and an acknowledgment of their expertise is at the heart of building and maintaining resilience for carers. The implementation of truly person-centred planning and flexible service delivery will see carers as genuine partners in the delivery of community and palliative care and will restore control with the carer and the person they care for and support. In a recent survey of carers, nearly 90% of respondents indicated that they would be interested in participating in consumer directed care.⁵¹

In order to meet the future demand for community care and palliative care services in a cost effective manner it is vital that carer support services can, and do, provide a range of tailored programs to meet the needs of the carer (including their own health and wellbeing) and to assist them to engage effectively, and remain engaged, with the community care and palliative care sectors.

Recommendations:

1. That the Carers (Recognition) Act 2008 and the thirteen principles detailed in the accompanying Carers Charter be used as the foundation for further policy and strategy development with respect to palliative care and community care services in Queensland
2. That the Queensland Government works in partnership with the relevant representative organisations, NGOs and for-profit sectors to develop new models and systems that will not only meet, but embrace, the challenges of the future in a dynamic and responsive way
3. The social value of caring continues to be promoted through whole-of-government dialogue, policies, strategies and services
4. The introduction of the 'right of a carer to an assessment' underpinned by the principles of the Carers Charter and from which carer specific support services can be identified and agreed (separate to the assessment of the person with a disability and services identified and agreed)
5. That person-centred planning and service delivery is adopted as the norm by the palliative and community care service providers
6. The establishment of a holistic and integrated approach to assessment, service planning, delivery and review utilising practitioners from a range of health, allied health and community service areas located and working as a team rather than specialists in separate facilities with separate access policies and procedures

7. The development, implementation and funding of carer specific early interventions - such as information and advice, timely referral, training and education and locally provided, responsive respite care services
8. The introduction of portable entitlement vouchers that carers can use to purchase respite at a number/variety of facilities that suit their needs at the time (similar to the English 'respite voucher' systems)
9. Enhancement of advocacy support services to assist carers with representations with matters before the Adult Guardian and QCAT
10. The introduction of a new but complementary early intervention service to assist carers in 'preparing to care' following hospital discharge. This service would greatly assist those individuals new to the caring role following an acute or critical health episode or those preparing to enter the end of life' caring journey.

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