

## **Submission to the Parliamentary Inquiry into palliative care and home and community care services in Queensland**

**Submitted by “The Carers’ Group” Bulimba to Aaron Dillaway, MP, Member for Bulimba**

This submission is prepared by a group of people each of whom is responsible for the care of an aged or disabled family member. The group of about 15 meets monthly. Under the auspices of the Social Justice group of Sts Peter and Paul’s Parish, Bulimba, members from the parish and wider community offer support, friendship and advice to each other in their difficult roles as carers of loved ones in their homes. This submission includes what they see as the greatest problems they face as carers. It makes some suggestions about how these could be alleviated by Queensland State Government. It includes some comments on Section 4 and 8 of the Issue Paper but concentrates on Section 6. The personal experience of carers forms the basis of this submission. This group does not include people who live alone and require assistance

### 1. Services

Many of those caring for a loved one do not know what help is available and do not know how to access any help they are entitled to. Many do not know

- what help is available from governments?
- which government provides what help?
- if they are eligible
- what agencies provide what help?
- what do acronyms stand for?
- how are agencies accessed?

Those who are receiving some in-home help also have a number of questions

- Whom do I contact if I have a problem out of normal work hours e.g. a fall?
- How do I access respite care?
- Does a discharge plan after a hospital visit affect arrangements already in place?
- Where do I obtain permits e.g. parking, taxi etc
- How are these permits renewed?

Ongoing problems exist for many carers

- Application forms required for many services, both initially and for renewal, are complicated and duplicated by different agencies/ sections of government.
- Similarly, interviews to obtain (often vitally important) information are regularly required, often retrieving information that is already available from some other agency or government section. These are often time consuming, ill timed and emotionally draining for the carer.
- Many carers are confused about the procedures of service providers. These are different for each organisation.

- Many front line staff, particularly those from service providers, do not understand what their organisation can provide. Sometimes they are not given sufficient information about the specific needs of the client to provide appropriate care. They are unaware of the inconvenience and stress that ill-timed home visits cause to a carer. Each staff change requires the establishment of a new relationship of trust.
- Communication with Government Departments and service providers is often difficult
  - Clients are not always confident with modern technology e.g. computers, mobile phone, 'apps', text messaging.
  - Acronyms can be very confusing particularly for 'new' clients
  - There is a perception that some front line staff are 'ageist'

## 2. Social problems

As well as struggles with services and service providers, carers face huge social problems. They are swamped by "layers of worry" (Carer Group member). Not only are they watching a loved one suffer, but they are busy, dealing with many different medical, social, financial and government requirements often alone and lonely. "I felt that I was left on my own to deal with it" (Carer Group Member)

- They perceive that services have recently been cut, or soon will be.
- They are particularly concerned that social workers are not employed by private hospitals. In public hospitals, where they are employed, they are often overworked they do not see everyone who needs them.
- They dread decisions about committing a loved one to a nursing home or making decisions about medical treatment and life support
- They regret that many nursing home are located "out of town", a great distance for any visitor
- They suffer social isolation which grows as the time spent in caring grows

## 3. Financial concerns

The members of the group do not usually discuss personal financial worries and precise eligibility except as they are addressed in the section on services. However, there are two points that should be made.

- Members fear that services provided by the Queensland Department of Health may be cut. They doubt that the Queensland Government is aware of the needs of those caring in the home
- Means tests for eligibility for subsidies on medication, prostheses, medical equipment and some services e.g. home help and transport costs are perceived as unfair to some.

## Suggestions for change

The group has suggested changes to Government procedures to address significant unmet needs of carers

1. Coordination of the disparate services and providers.
  - Case manager. The most practical way in which carers feel that they can be helped is by the appointment of a 'case manager' to each caring partnership to demystify access criteria and services. This would allow the carer to contact ONE person when help is needed. Carers believe that this would greatly alleviate some of the anxieties that exist because of the fragmentation of services. Whatever this role is called, the carers need someone who knows them and their patient, is familiar with domiciliary service providers and assists in their access to them.
  - Coordination of departments. This is needed within the Queensland Government (Health, Transport, Community and Disability Services etc), and between state and federal governments (Ageing, Families, Taxation, Centrelink, Medicare etc). The group recommends there would be ONE form to include all required information instead of separate forms for each application. One form could be designed to include ALL required information so that ALL Government departments offering services and support could access that information. Presumably up-dates could be added without the trauma of re-applying when circumstances change. On-line health information (e-health) may assist in this.
  - Interviews should be limited. Carers are often subjected to 3 or 4 interviews when applying for services and support. They are interviewed regarding ACAT assessments, Parking permits, MASS applications, etc and they are interviewed again when the circumstances of the person for whom they are caring change. They suggest that this can surely be coordinated.
  - There should be active and ongoing liaison between hospitals and patient services, once again coordinated so that duplication does not become confusing
2. Distribution of information
  - One simple Booklet /Brochure should be available from and actively offered by GPs. These should include information about Government Support (both State and Federal) services, permits, concessions, allowances, support groups
  - Regular public awareness campaigns should be held about what is available and how it is accessed e.g. TV, radio, Public Transport, Hospital waiting rooms
  - Public awareness campaigns (perhaps 'name and shame') should be held so that disabled parking spaces are available for those who need them
3. Financial support
  - The most important financial support is the provision of appropriate Human Resources as mentioned in Section 1.
  - Electricity allowance should not be means tested for those with home oxygen, ventilators and other devices needing electricity to function in the home
  - Means tests applied to many allowances might be raised, particularly for couples.

The value of this Carers' Group lies mostly in the support and advice the carers give each other. 'I can say things here that I cannot always say to my best friends', said one group member. 'Seeing someone else doing it and surviving', said another. The fact that they see 'survival' as an aim gives some idea of the pressure and stress that these people live and function with. Yet they are a cheerful, warm and loving group, an inspiration to everyone who joins the meeting, and their requests for government assistance are considered and unassuming