

Gippsland Carers Breaking the Silence on unpaid care in Australia

National Carers Week is held again this October, a fitting moment to pause and reflect on just who and what is an unpaid carer. The rise and rise of the Carer movement from the early 1990's is a reflection of a growing public awareness of the role played by family members as unpaid givers of vital support to people of all ages who have a disability, handicap or frailty.

Historically families have always accepted primary responsibility to care for relatives with dependent disabilities whatever the age at onset, however this fact is often lost on the general public who see and hear the vocal minority that are the service system or governments who push particular agenda's for political reasons.

In 2003 a Survey of Disability Ageing and Carers conducted by the ABS showed there were 3.9 million Australians (20% pop) who had a disability of some kind, with just over 1.2 million reported to have a severe or profound disability for which they always or sometimes needed help. It is not surprising therefore that over 2.6 million people reported they were Carers, with over 487,000 providing a full-time or primary Carer role.

Readers will be amazed to learn that Gippsland has over 48,000 persons with a disability or frailty and over 24,000 families providing a caring service to loved ones with dependencies. Of these, at least 12,300 are primary Carers working full time as unpaid care-givers. Most of this care is provided to a person living in the same household.

The worth or value of unpaid care is a matter of some conjecture, with the latest paper by Access Economics released in October 2010 putting the replacement value at \$40.9Billion annually¹. If we only take into account the population of around 215,000 people with a severe or profound disability in Victoria, the accommodation replacement cost would come to over \$10.75billion based upon a per bed rate of just \$50,000 P/A. [the average cost of a group home bed is \$95,000 per year] This means all other carers are completely discounted by Access Economics modeling.

A host of public and private publications report that the funded disability and mental health support systems deliver accommodation services to, at best; less than 7% of all persons with dependent disabilities². Quite clearly this means that 93% of support is provided by informal or unpaid carers, the majority of whom (71%) are female family members³. The same is also true of frail aged care, but to a lesser degree, since the funded aged care system operates on a far more generous funding model than the disability or mental health sector models.

The pressures of changing social and family dynamics that exist today are causing ever increasing stresses upon informal care arrangements and the current trends towards women in the paid workforce are creating a dilemma for policy-makers. The current shift to so called 'community care' as a deliberate attempt to quell the demands of families forced to breaking point by minimalist support policy, are a reflection of the changing family dynamics and ageing population paradigms existing today.

Gippsland Carers Association was established in 1997 in response to a clear need by family carers of people with disabilities to have a voice in articulating unmet needs to receive increased support in their caring role, and access to options in alternate accommodation for the people in their care. Family Carers were supported in this endeavour by local community based groups who recognised that there were few funded accommodation or respite options available for Gippsland people with disabilities under the age of 65 years and even less for mental health.

Our Association is managed entirely by Carers for Carers and exists without any formal public funding to this very day, despite a number of Commonwealth reports that strongly recommend the public funding of family advocacy as a priority.

We welcome the support of the Gippsland community especially Latrobe City and Latrobe Community Health Respite Services. We are greatly in debt to the members of CIPAID for transferring their assets to us when they decided to wind-up their association. It was this generosity that has enabled our shop front lease in Morwell CBD for Carers Place to offer support to carers two days each week. We are now open every Tuesday and Wednesday for Carers and the public to drop-in and talk to us and obtain information and support about issues affecting their caring lives over a cuppa with peers.

Over the years our support has grown and our activities have spread, not only across the region and the state, but beyond to embrace a national push by caring families for recognition and a voice in influencing policy directions and funding decisions that effect our lives so dramatically.

In 1998, our Out of Home Respite Facility Project was conceived to highlight the issue of lack of access to holiday length out-of-home respite. In 1999, we were offered the gift of a building by Grace Bruce Homes for use as an 'out of home' respite service. The 12 bed facility had previously been utilised as an Aged Care hostel and had recently been refurbished. The facility, located at Dalkeith Park Traralgon in 23 acres of parkland offered 12 separate ensuite units and included laundry, kitchen, dining and staff accommodation far exceeding anything a group home could offer.

GCA Inc engaged in considerable discussion with the Victorian Government to encourage them to take up this offer. However, they continue to decline because the facility is deemed to be too large (i.e. 6 beds is considered to be the maximum acceptable) The out-come of this set of negotiations did, however result in a pilot project in 2003, funded by the Department of Human Services to provide holiday length respite. The pilot was independently evaluated and judged as having 100% client satisfaction with a recommendation that the model be funded. That is yet to occur.

In 2001, we produced a video entitled, Who Cares-Respite-The Future of Caring. The purpose was to continue to raise awareness regarding the need for increased facility-based respite options for families caring for people with disabilities. Video production was sponsored by Latrobe Valley Employment Services, and involved a broad number of parents and support groups across the Gippsland Region. The video was distributed to State and Local Governments, was shown at forums and events across the state and presented to a group of federal politicians (representing the Government and Opposition) in Canberra in March 2001. As a consequence of this visit, GCA was invited to participate in a 'roundtable' in Adelaide with the then Federal Minister for Community Services. At that meeting, a commitment was made to establish a national Steering Group, the National Family Carers Voice. However, a change of Minister resulted in the loss of that commitment, and yet again we wait for the support Carers so richly deserve.

GCA has written a multitude of submissions on matters relating to caring for disabled persons and their families and for funds to help run our Carers support centre/office and general support activities for the families of Gippsland. Most recent successful submissions include the Gippsland Bishops Family Foundation for a new digital photocopier on which to publish the Gippsland Carer newsletter sent out across Gippsland four times per year and a grant from the RE Ross Trust for our Capacity Building Project towards establishing a Regional Carers Support Network.

In 2003, as a result of participation in a number of National conferences, GCA became involved in a network of Carers, which has steadily grown via internet communications to include contacts in every state and territory. We gained national applause from carer networks for the introduction of 'Carer Long Service Awards' that recognise family Carers for their long years of unpaid service to people with disabilities and the nation.

Through the ABC 4 Corners TV program, in 2005 GCA became involved in a national campaign and rallies inviting politicians and people across Australia to 'Walk a Mile in My Shoes'. Thousands of pairs of shoes were placed on the lawns of federal parliament and the steps of state parliament across Australia in a co-ordinated national event. This was accompanied by significant media attention and meetings with Ministers and Shadow ministers, with commitments that are ongoing. The national rally has adopted the GCA 'long service strategy' and introduced a 'national carer register' now being rolled out across Australia.

GCA are pleased to act as 'auspice body' for the establishment of a National Carers Coalition (NCC) and participates in the set-up and maintenance of a national website for Carers at www.carers.net.au (currently under reconstruction). The NCC have set about the task of lobbying the Commonwealth to change the way that disability services and Carer support are delivered and funded.

Our submission to COAG in November 2006 sought reform of the Commonwealth, State and Territories Disability Agreement (CSTDA) raised issues of age discrimination, the absence of Citizenship rights and living choices for people with disabilities and the exploitation of family Carers for which we demanded action. We were successful in obtaining a Senate Inquiry into the operations and funding of the CSTDA and that inquiry was very condemning of the failures of the system .

The key to all our recommendations is our push for establishment of 'population based benchmark funding' which will put the funding of and choices in disability services into parity with the funding and choices of aged care services. We seek a national response to eliminate discrimination in living choices for disabled persons and the implementation of mutual obligation responses to family Carers who give so much and receive little in return.

Our attention is now focussed upon the Victorian state elections where our Policy recommendations are asking all candidates and political parties to embrace the need for funding of Regional Carer Support Networks, along with a commitment to recognise the crisis in supported accommodation services and a commit to funding support for the vital and irreplaceable role of family in caring for disabled citizens.

Caring families across the state are uniting in this endeavour to achieve changes with forums planned for 2011 (led by our example) planned to take place across the suburbs of Melbourne at this time. GCA will hold a Carers Forum in Gippsland on Wednesday November 3rd at Kernot Hall in Morwell. All Gippsland candidates are invited to attend and articulate their policies on Family Carers, Disability, Mental Health and related issues. We would welcome the support of all Gippslanders and Carer families everywhere in our struggle for a fairer deal.

For information on the Gippsland Carers Association and our activities phone our Carers Centre any Tuesday or Wednesday between 10am and 3pm on 5133 3343 or visit our website at www.gippslandcarers.org or by email to gippscarer@vic.australis.com.au or even by snail mail to PO Box 937, MOE 3825.

Jean L Tops

President

Gippsland Carers Association Inc.