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Submission No. 573

(Inq into better support for carers)

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Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
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CANBERRA ACT 2600

By email: fchy.reps@aph.gov.au

Dear Secretary

Submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers

Mill Park Schizophrenia Support Group ("the Group") wishes to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

The Group is submitting to the Inquiry because the role of carers in all communities is sadly overlooked, under-estimated and/or taken for granted. The fact that carers are usually family members caring for people they love makes the carer role difficult – we are expected to want to care because we love them but are given very little support or recognition until a crisis arises and we are forced to make ourselves heard.

We are also given no proper or formal "training". We are not nurses or personal care assistants but the jobs we do are the same. We learn by being thrown in at the deep end and then by our mistakes as we battle not only previously unknown illnesses but also the fact that our loved one is usually dramatically changed. This is the case whether we are dealing with aged care, physical disability care, mental illness care or Alzheimer's/dementia type care. We have to learn to accept this "new" person, to love this "new" person and to be their carer and friend as well. That's a huge amount to learn and no hands-on training is provided for this vital role.

1. The role and contribution of carers in society

As carers, we feel that our role is to ensure dignity and quality of life for the people we care for and for ourselves. We need to educate ourselves to learn about the illnesses/conditions of the people we care for. The people being cared for need to continue pursuing aspects of life they previously enjoyed, as much as their illnesses/conditions allow. Carers also need to be able to do this and to remain involved with employment, hobbies or interests in order to not lose ourselves in our caring roles.

2. The barriers to social and economic participation for carers

As carers, we face the following problems:

- Economically, carers often have to factor in loss of income from both the people they are caring for and themselves. Many carers who previously worked full time are forced to reduce their work hours or even resign. The consequent economic pressures placed on carers and their families is enormous and not appreciated or recognized.
- Obtaining carer allowances can also present various "nightmare" situations to many carers. Anyone who has attempted to apply for any assistance through CentreLink will know the hoops you are expected to jump through. If carers are lucky enough to meet the criteria set down by CentreLink, the benefits they receive are a pittance and are hardly worth applying for. As carers we need to maintain some quality of life for both ourselves and the people we care for. People who sit at home on unemployment benefits doing very little to help themselves or anyone else in the community receive allowances much easier than those seeking carer allowances. The benefits they receive are usually much more generous than any carer allowance. The feeling that "the system is letting them down" is common amongst carers.
- Having respite time is also a huge problem for carers. In order to have even a weekend off they need to arrange either in-home respite care or care in a respite facility. They need to feel comfortable about leaving the people they care for, otherwise any "time out" they have from caring is spent worrying how their loved ones are coping without them. It is for these reasons that many carers never bother to have any respite from their caring roles – it is sometimes just too difficult.
- Depression – the number of carers who develop depression or similar illnesses themselves as a result of the constant strains of caring is astounding. Most people in life will have at least one episode of depression. For many carers, it becomes a way of life attempting to juggle their caring roles and trying not to go "off the rails" themselves. Merely being diagnosed with depression and given medication is too little and most often too late. If carers and the roles they play in society were better recognized and more support provided they would no doubt cope much better. We need to learn ways of getting stronger to enable us to cope with our caring roles.
- There are associations such as Carers Victoria and CarerLinks North who provide invaluable support to carers. However, finding out about these associations often only happens when a crisis occurs. Details of these associations should be given to carers as a matter of course immediately an illness or condition which will require care is diagnosed.
- Information about different facilities such as support groups and activity centres or day care centres would be invaluable to carers, especially with newly diagnosed illnesses when everything seems to centre around the illness and the person with the illness.

3. The practical measures required to better support carers

As carers, we need help with:

- Learning about the illnesses/conditions we are dealing with. Immediate education is vital but this information is often difficult to obtain.
- Details of agencies, contacts or support groups where we live. Support groups can play an important part in both education and social aspects for carers and details should automatically be provided to any new carers so they don't feel lost and as though they are "doing it alone".
- Improving our awareness of self and who we are so we do not end up cut off from family and friends. This sometimes happens because we take on the carer role and forget about everything else or sometimes happens simply because of the intensity of new illnesses and their impact on carers. We need to learn to be aware of our own needs as well.
- Caring can completely take over our lives if we let it, and sometimes even if we don't let it. Only through experience and over time do we learn that it is okay to still want to go to work, socialize and do things just for ourselves. Carers need to know that it is completely normal to feel overwhelmed and that there is help if you know where to ask for it.
- Dealing with the guilt often felt when pursuing personal interests or hobbies is another hurdle for carers. People not in a caring role have no hesitation in pursuing such activities – it is okay for them to put themselves and their interests first. Carers do not enjoy the same luxuries.
- Transitional accommodation needs to be provided so that there is a different system to the one where people are moved from hospital and then home to untrained and often uneducated carers. If there was a "half way house" where people could go first it would assist them to learn to adjust to their illness and it would assist carers in learning more about the illness and putting measures in place at home which may be required, for example if caring for someone following a stroke then physical aids, hand rails etc may need to be installed to enable proper person care.
- Dual diagnosis facilities are extremely limited. Anyone who has dealt with mental illnesses will know that drug use and mental illnesses often go hand in hand. There are some facilities scattered across Melbourne but they are basically unknown to most carers. The situation used to be that if someone had a drug problem then they could receive help with that. However, if they also had a mental illness they were told that the drug facility could not assist them because they had a mental illness. The reverse was the situation with mental illness facilities – they said they were unable to treat drug problems. Many, many people were therefore "falling between the cracks". This situation is slowly improving but the facilities that are available need to be advertised and details given to carers who are dealing with people with drug abuse and mental illness issues.
- Respite opportunities and facilities. It is imperative that details of available respite services are provided to carers. Carers need to learn that it is okay to say "I've had enough and I need a break" but they need to know that respite for both themselves and the people they are caring for is available. Carers need to know how to access these respite services.

- Setting procedures in place so we are not constantly wondering what will happen to the people being cared for when their carers die or are no longer able to care for their loved ones. This is a huge concern to all carers and there are no easy answers. Many people being cared for suffer with multiple illnesses or disabilities and feeling comfortable about leaving them even for a short period of time is difficult. Imagine how this feels when you wonder who will be there for them when you are gone.

4. Strategies to assist carers to access opportunities and choices

We think the Government can better help carers by:

- Recognizing the important roles carers play in society and the community. Without carers our hospitals and rehabilitation centres would be overflowing. The Government also needs to recognize that carers need training. Learning personal care or communicating with someone who can no longer speak following a stroke are two examples. Likewise, dealing with someone during a psychosis can be frightening and dangerous. Some basic coping skills would help carers through many of these crisis situations. Nurses and personal care attendants receive training in these areas but carers are given no "formal" training. Even a free 2 hour course would help alleviate the feelings of helplessness often endured.
- The Government needs to recognize that carers are providing unpaid services both to the people with illnesses or conditions being cared for and to the community. Financial recognition of the "jobs" that carers do should be automatic. If Government looks at the cost of caring for someone in a hospital, nursing home or rehabilitation facility, it is very easy to see that the Government is getting an extremely good "deal" for often no cost – or very little cost if carers are able to obtain any allowances. If carers need to reduce work hours or give up work then financial assistance is vitally important to allow them some "normality" and quality of life.
- De-institutionalisation has meant that there are now very few places to go for activities and support. Places such as NEAMI are wonderful as they provide activities for people with illnesses and respite for carers.
- Similarly, there are not enough facilities for elderly people. Most places cater for younger people yet there are hundreds of elderly people in the community who are unable to access facilities because they either don't fit the relevant criteria. Transport to and from such facilities also needs to be addressed.
- Taking the time to "step into our shoes for a day" and see what it is like to live in the world of carers. The 24/7 aspects of caring are exhausting but unless people have lived or personally experienced this, it is difficult to understand or appreciate the many services carers provide within the community. We invite politicians to step into our shoes for a day, see how you feel after just one day and imagine having to spend every day of the rest of your life or the person you are caring for with no escape or respite. We don't think anyone would choose to wear such uncomfortable shoes.

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Mill Park Schizophrenia Support Group

June 2008

Thank you for taking the Group's views into consideration as part of the Committee's Inquiry. We look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely

MILL PARK SCHIZOPHRENIA SUPPORT GROUP

Signatures



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Date

30 June 2008

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