

4 July 2008

Ms Annette Ellis MP
Committee Chair
Inquiry into Better Care for Our Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
Parliament House
CANBERRA ACT 2600

Dear Ms Ellis

The Parkside Foundation wishes to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Care for Our Carers.

The Parkside Foundation is a non-profit organisation that provides personalised support in a wide range of settings for approximately two hundred people who are aged, people with dementia, people with a disability and their carers. The age of the organisation's clientele ranges from young adults to older people of retirement age.

The Parkside Foundation demonstrates its responsiveness to carer needs by continually adapting and expanding the range of services. The Parkside Foundation receives funding from the State Department of Health and Human Services, through Disability Services to provide community access services to 65 people with a disability, a wide range of services to people in receipt of individual funding packages, and HACC funded school holiday and weekend respite for carers of younger people with a disability.

The Parkside Foundation receives funding from the Department of Health and Ageing to provide: Community Aged Care Packages of Care, Respite for Carers in paid employment and of people with dementia. The Parkside Foundation is the lead agency in a NRCP funded consortium between five organisations, providing a range of respite options and support services to the carers of people with dementia.

The Parkside Foundation provides the following information for consideration through the Inquiry into better support for carers. The issues quotes and examples referred to in this document have been provided by carers who receive support through Parkside.

1. The role and contribution of carers in society and how this should be recognised.

The Parkside Foundation provides a range of support services to people with disabilities, people with dementia, older people, their carers and families. One of the major types of support provided by Parkside is the provision of respite services to primary carers.

Data from a recent ABS Survey of Disability, Ageing and Carers (2003) indicates that among primary carers caring for a partner or parent, the most common reasons that people felt for accepting caring responsibilities were that:

- it was what the care recipient would want, to be cared for by a person who has a relationship with them and is significant in their life;
- it was part of their responsibility to their family;
- they could provide better care than the other options available; and
- they have an emotional obligation to the person needing care

A sample of the support provided by carers include:

- "To care for my husband of almost 65 years, - He is 87 years old, is very frail and has dementia and rheumatoid arthritis. In attempting this task conscientiously and to the best of my ability I realise, and have to accept, that my identity is disintegrating and my future is being eroded. I am 76 years old and my present state of health lists the following: atrophic left kidney, chronic renal disease, ischemic heart disease, hypertension, atrial fibrillation, anaemia. It is my role and my choice to care for my husband as long as I can."
- "I care for my 87 year old mother; she has lived with my husband and our 3 children for 20years. In the past 18 months, she has declined in health." Care needs are increasing and therefore the carer is required to provide more extensive care over a broader range of tasks.
- "My elderly frail mother who has had a mild stroke. I wash and dress her as she can't use her left hand. I help her move from bed to chair as she cannot walk without assistance."

Being a full time carer is most often a 24 hour a day responsibility. In this unpaid role, the following tasks are typically provided:

- Shower, dress and do all necessary things.
- Personal, social and emotional support to a child who is in their mid 20's.
- 24 hour support for my 26 yr old daughter whilst keeping the household together as a single parent.

- I need to be there 24 hours a day, monitoring and caring for all her needs.
- Providing assistance with medical appointments, prepare breakfast and lunch, monitor medication taking, shopping, laundry, empty commode next morning, prepare meals, home help.
- Transport, homecare, emergency needs and travel assistance, and general home assistance.
- Bathing, medication, domestic chores, dressing, feeding, grooming, toileting, social outings, bedding, doctors, companionship, washing, pedicures, manicures, massages.

Many carers provide this role to more than one person. It is common in today's society for people to be caring for a parent as well as a son or daughter. This compounds the impact on the carer.

It must be acknowledged and understood that caring responsibilities become a normal part of the carer's life, with the caring role recognised as only one of many roles in which individuals are involved. The range of care specific services must be culturally sensitive, enhanced and expanded to help normalise the carer's lifestyle and minimise the demands of care giving.

2. The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

Demand for all community care services has risen dramatically in recent years and continues to increase. As people age, the majority of community care is provided informally by carers, often family members. The care provided by family and friends, coupled with formal services, is integral to sustaining the care situation and enabling people to live at home for as long as possible.

The barriers, issues and problems faced by carers include:

- "I am virtually placed under 'house arrest'. The result is social isolation. All daily activities outside the house have to be organised so that they coincide with the times that I have been able to arrange for a Support Worker to be with my husband. More problems arise when I want to attend a meeting or a lecture, or, as a member of Writers' group attend their meetings. Going to see a film or having a cup of coffee with a friend are no longer on my program."
- "Because my wife needs someone to be with her full time, I find it hard to have any personal time to pursue my own interests. I can only go shopping when we have a carer to look after her."

- "I am tied to looking after my mother and it restricts me to being able to work, to meet friends, to go out and on holiday, or to work for my husband. I can't visit family as easily."
- "Sleep deprivation, failure, money worries, and future day to day worries."
- "Not enough respite, not enough funding for holiday programmes as it cuts out at 25 years of age. I have no-one to look after my son in the holidays when the day support service is closed."
- Allocated respite hours are used to complete the household business, such as shopping, banking, bill paying, etc. Therefore, I don't have any respite hours left that I could use to spend time with my grandchildren.
- Health concerns and injuries to the carer, sustained whilst supporting the care recipient.
- Learning to appropriately manage challenging behaviour of the person being cared for.
- "My husband won't go out with anyone, so it is hard for me to go. I spend most of my time at home. To go out we need to get taxis."
- Time to be alone or with others who also care for a loved one.
- Trying to balance the responsibilities of running my own business and simultaneously caring for my mother.
- Having to work full time to support her, coming home tired and trying to understand her and meet her needs as they change.
- Having to reduce work hours to meet the caring requirements. This of course, reduces the financial income.

Whilst these issues may not appear to have a major impact if looked on singularly, they are nevertheless significant, and compound with other issues and obligations to make a person's capacity and willingness to care a complex issue.

Support from formal services is vitally important in sharing the care, overcoming some of the isolation that comes with caring and confinement to the home, relieving the carer of some of the workload and allowing the carer to participate in activities outside of the home as an independent individual. From the carer's perspective, formal services are a supplement not a substitute when constant care is needed.

Barriers to being able to fully participate in social activities are best summed up by carers, quoted as responding:

- "There is just no time for my life at the moment. I cannot participate in many social activities as I have an obligation to care."

- The person being cared for becomes dependent on the carer and often does not like them to leave. It is common to hear that if the carer does go out and leave them with someone else, they are 'penalised' upon their return, by either being ignored, an increase in challenging behaviour, or increased rate of incontinence. A carer then has to weigh up if the cost of going out exceeds the purpose or benefit.
- I am unable to leave my daughter at home alone. My social life is very restricted as I need to plan everything.
- There is no support for my son who is in his mid 20's after day support hours, which means I have to take him with me as he plays up on others.
- I have my daughter to care for and no one to have my daughter to enable me to have social activities or just a cuppa with a friend would be nice.
- I cannot leave her unattended as she cannot take herself to the toilet or walk by herself. If she tried she would fall and probably break something. I am tied to the house.
- I take her wherever I go.
- My mother does not let me go anywhere except the time I am working at the shop.
- My time for me is limited.
- Lack of funding for carers to be with my mum whilst I attend yoga or meet friends for coffee or taking my 14 yr old to courses, art classes, etc. It is difficult to enrol my daughter in activities held outside my mums care schedule.
- My wife will not leave the house and due to her circumstances I cannot have people come and visit.
- My husband needs company and friendship.

When consulting with carers, they have consistently expressed their need for help with:

- Housekeeping, grocery shopping and gardening.
- Occasional jobs like window cleaning and or spring cleaning, and the cleaning of gutters. This is especially important during fire danger periods.
- Access to a reliable in-house Diversional Therapy program.
- I need to know that there is immediate and quality respite available when I reach the point where I need a short break to prevent me from having a complete breakdown.
- More support to meet the care needs.

- Additional respite or support for my 27 year old daughter to attend social events without me. (This is support for her, not respite for me.)
- Mood swings, looking for group homes for my son and funding. Help with doctors, scripts, visits and medical charts.
- Looking into group homes for my daughter, and finding one that I feel she will be happy with and sharing with other people that she will get on with. This is very important to me.
- Someone to look after my mother's needs and keep her company while I work or socialise with family and friends or take part in community activities.
- Preparing meals and home help to release my burden and stress.
- Shopping and transport, general home assistance.
- Renovations to our bathroom and toilet.
- Safe secure housing suitable for mum's disability. I am not eligible for a transfer with housing due to income coming into the household.
- More time for me, so I can attend my own appointments, doctor, dentist, and visit family and friends.
- I cannot go out at night as my parents can't be left alone.

Services, such as regular respite, information and referral, counselling, domestic help, shopping, etc are highly valued by carers in maintaining their own wellbeing and sustaining their caring situation.

3. The practical measures required to better support carers, including key priorities for action.

Access to information - Carers need access to information about the diagnosis, sometimes this needs to be given to the carer and the care recipient at the time of diagnosis and then again at a later date, after the carer has had time to grasp and begin to understand the situation.

A carer highlighted their need to educate themselves about the advanced stages of dementia, either by attending courses or forums. Assistance is often needed to speak with government Departments and services. Knowing who to contact is so important, but often found out by trial and error or by word of mouth. There isn't a common point of accessing information or services.

"What rights and assistance is available to carers, as I do not know?"

Financial Impact - Many carers have a limited amount of money on which to live, with no capacity for increase. A majority of carers supported by The Parkside Foundation are reliant on Government pensions, benefits and allowances. Carers consistently comment that their income is not enough to pay for all the expenses, including the usual household expenses such as rent, mortgage, food, utilities, transport, medical, etc. In addition, carers and care recipients also have additional costs such as more frequent taxi costs, cost of support services, e.g. Hacc fees on a daily and weekly basis.

"Whilst Day Centre fees and support program costs are subsidised, the cost to us for the use of these services is \$132.50 per week. – 22% of our combined income."

"Our incomes (my wages and care recipient's aged pension of \$39 per fortnight) are considered separately for taxation, and yet treated as a single income for purposes of determining support or assistance."

It is well recognised that carers are managing their finances carefully, watching every dollar spent but still noticing an increase in financial commitments and stress. The reality for many carers is summed up as one carer wrote -"doing it hard, we go no where unless it is free or cheap."

Employment – Increased and more responsive services are needed for carers who are in the workforce or seeking to enter the workforce. Some carers have said that they have had to reduce their paid work hours, and have the flexibility in their job to be able to leave work and other appointments quickly to collect the care recipient from day care due to illness or falls. This can cause stress for both the employee and the employer.

Because of trying to balance work and home responsibilities, many carers have to accept lower payed jobs and work less hours a week. However they still have the same living and mortgage costs. A carer commented that it was difficult to continue running their own business, but that if they didn't work, then they couldn't provide the required income.

"Only temporary jobs were available to me during my first four years as a primary carer and so I held a series of short term positions throughout this period. I gradually increased y hours of work as I located support services."

Services – For Government, the services required may seem simplistic, but for carers, in the role of providing support day by day, often 24 hours a day, the needs seem insurmountable. Requests for what may seem basic services include:

- "Find activities for my son, who is in his mid 20's, to participate in. He is bored at home which ends in bad behaviour."

- "Care for my husband when I have appointments need time for myself."
- "Some help to allow me to look after my frail and elderly mother."
- "Assistance to find out where to start to look for group homes and what money would my daughter with a disability need to have?"
- "Help taking care of my mother who is suffering dementia."
- "Help cleaning the house."
- "Opportunities to mix with other carers and share ideas, being able to give strength to each other."

Balance other family needs and carer responsibilities - Carers are continually trying to balance caring and family needs. One carer said that they just wanted some help to meet their mother's needs; so that they could have some time and energy to be a mother and look after the other people in their family. Another carer said that her 14 year old daughter was missing out on lots of things because after providing full time care to another person, they don't have anytime left for her.

Stress - The Parkside Foundation put the question to carers "The things that cause me stress are...". The following responses highlight the continuing stress experienced by carers.

- Dealing with the future, worrying about what is coming and watching my loved one getting worse. Making sure that needs are met.
- Decline in care recipient's health and their unexpected falls etc, organising respite care whilst they are still in the acute stage until they rehabilitate and coping with family as well and working.
- Accommodation for people with a disability and trying to find the right accommodation with other people she would enjoy living with.
- Petrol prices running my son backwards and forwards, no group homes.
- Working full time. Giving the care needed to support my daughter with the best of care that I feel she needs.
- Knowing what will happen to my mother when she takes strangers into the home. (This occurs if I go out to work and leave her at home.)
- The state government and certain individuals within that department.
- Not having enough time to do everything.
- The demanding needs of my wife, whose needs are constant, on-going and give no flexibility.
- The future.
- Everything lately.

4. Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

Services need to be designed with enough flexibility to be able to retain carers in their role. This role is intensified during periods of illness of the carer, the person receiving care and or other family members.

Whilst all families can experience a crisis, the impact is intensified where there is a primary care role encompassing disability or illness. Carers are united in their concerns about the future years for themselves as well as the people they care for.

The Parkside Foundation put the question to carers "I worry about my future because ...". The following responses epitomise the feelings and worry that carers share about the future.

- I am alone as my life style does not allow me to meet anyone or belong to a club.
- I cannot afford to be ill as I worry a lot about who will look after my mum and my daughter.
- What will happen as I age or die?
- If I am ill, I wonder how long I will manage?
- The needs increase as my mother gets older.
- My mother is suffering dementia; she always takes a stranger into my house when we are working. I do not know what will happen.
- Where will my daughter end up? Group homes take lots of money to set up and who will pay for the establishment and ongoing support costs?
- If anything happened prematurely to my husband and I, what would be in place for my mother and her care?
- Now, as we approach our retirement, our plans to spend time together as a couple, travelling etc will be significantly affected by being tied to the house and looking after my mother.
- I don't know how it will end up and I don't want to burden the rest of the family with everything.
- This situation cannot continue as I am 83 yrs old.
- We all need a life.

The worry that carers continually experience is summed up by a carer who said "I have no idea how I will cope, I just take life day by day and try and do it right."

Society and service systems must provide more support, more respite and be more flexible and responsive to alleviate the increasing stressors in a carer's life.

"I think the Government can better help Carers by not losing sight of the greater picture of Caring for the disabled and for the elderly, and planning for future needs. There must be accommodation for those who can no longer be cared for in their own homes. I need to know that should the time come that I can no longer care for my husband that there is a place in a home for him close to where his loved ones live. Three of our five children live nearby which is of great benefit to us both. I like to be assured that I could stay the night with him if needed."

"I think the Government can better help Carers by looking after the 'Professional Carers' who work in the industry. An In-Home worker who works fulltime needs to work within a proper 'job structure'. Ie, paid an annual salary with usual annual leave and sick pay entitlements. I believe that this is not the case for many workers at the moment. Support Workers need to be paid according to their training and skills and the responsibilities of their job."

Increasing supply to match service demand - There is strong evidence to suggest that the current levels of formal services are not meeting demand. While the level of real funding has increased, so too has the demand indicated by waiting lists and minimal levels of service available. Hence funding is spread across more people and the level of real funding per client has been reduced.

Services need to be constructed and funding models developed, to allow families to live in the area of their choice. This includes the provision of a service model that better acknowledges and responds to rural and remote issues. There needs to be greater variety and better co-ordinated services. Services need to be made accountable for the quality of service provided.

Increasing income support - When carers are not able to work because of their caring commitments and they have no other means of financial support, they must depend on government income support. The Government needs to show a commitment to increasing the pensions, benefits and allowances for carers, elderly people and people with a disability.

"Provide working carers with a health care card. As a working carer, we assume the cost of living of our dependent partner, however unless the carer is in a high income bracket, the costs of disability plus costs of a couple living on a single income, with no means of earning additional income, all equates to financial stress."

Respite - The Government needs to allow more respite time per year without penalty. At present, most in-home support is classed as respite.

This gives a false impression of what is respite. Therefore support provided in the care recipient's home is just that – support, not respite.

Respite would be a few hours, every now and then, that would let a carer catch up with friends, go to a movie, sit and have a coffee, as others take for granted. Respite is not having three hours, on a particular day each week or fortnight with specific start and finish times, during which a carer must do the shopping, banking, buy the groceries, pay the bills, fill the prescriptions and maybe even go to the doctor themselves in an effort to stay healthy.

Respite needs increased funding, and additional innovative respite options need to be designed in recognition of carer needs, enabling services to increase capacity, be more flexible and responsive. Support to care recipients and carers need to be provided in a range of settings, including care in the home as well as in day centres.

The importance of carers to the effective functioning of Australia's care system will only increase as the population ages and demand for the provision of care in the community increases.

Transport - The Taxi Voucher Program offers support with restrictions on voucher usage for the care recipient. The residual cost remains high and the carer is excluded from using the vouchers, even if the travel they are undertaking is on behalf of the care recipient. Eg to a meeting, doctor's appointment or case meeting, or to and from visiting the care recipient in hospital.

Residential Options and Choices for people with a disability - Looking at the numbers of people with a disability that need support to enable them to live in a share house or group home when their parents can no longer cope. Carers and family structures should not have to breakdown or go into crisis to access supported residential options.

Support Groups – As an outcome of The Parkside Foundation's strategic planning process, the organisation has established carer support groups. These meetings can be formal or informal and are organised to provide information to carers, seek feedback and most importantly, provide carers with the opportunity to meet together and discuss common issues, share experiences and be understood by other people in a similar caring experience.

"Continuing the support available by funding foundations like Parkside and by making the stress of looking after a loved one less traumatic because of these foundations as their support is excellent."

Additionally, The Parkside Foundation has acknowledged the need of "giving the carer a break by organising 'something nice', a day out, a morning tea, a lunch, etc."

Carers have valued these opportunities and said how important it is that they are appreciated and that what they do is acknowledged. "Just someone to say they care and know what you are going through" helps.

With funding, this concept could be broadened to give the carer and the person they are caring for, an opportunity to go out, to do something pleasant together and even 'to be a couple'.

The establishment and formalisation of Carer Mentor Programs - Mentor Programs have many benefits and can work in parallel with existing support networks.

The Parkside Foundation provides a range of support services to people with disabilities, people with dementia, older people, their carers and families. One of the major types of support provided by Parkside is the provision of respite services to primary carers. Through the establishment of consultation processes with carers, we have identified a number of important issues that directly affect these carers in their role.

Common themes that emerge at most meetings centre on the complexity of the support systems available to carers and the lack of awareness of many carers about what is available and how to gain access.

Whilst there are initiatives to disseminate information, including Commonwealth Carelink Centres, it appears that other strategies are also required. When beginning their role as carers, they are often overwhelmed by the amount of information that is provided to them. The key issue is the provision of appropriate information at the time that the carer requires the service. "I was probably told about incontinence aids and subsidies over twelve months ago but I didn't need to know back then" said one carer at a recent Parkside Carer's forum.

The idea of using people who have ceased being primary carers as the mentors has many advantages. Carers often become socially isolated due to the long hours spent supporting the care recipient. When their caring role ceases, some people report that they have difficulty reconnecting with friends and society in general. By providing the opportunity to act as a mentor, the past carers not only get a chance to share their knowledge and skills but also have an opportunity to assume a role that provides a sense of purpose and achievement. On a very practical level, past carers are more likely to have time to commit to the program as opposed to current carers.

Thank you for taking the views of The Parkside Foundation and of the carer's that the organisation supports, into consideration as part of the Committee's Inquiry. I look forward to reading the report and reviewing any recommendations that are made to improve life for Carers in Australia.

As a representative of The Parkside Foundation, and of the carers and care recipients who receive support, I would be pleased to appear in person to further discuss these issues with the committee.

Yours sincerely

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