

ROC 21/7/08

Submission No. 983
(Inq into better support for carers)

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
AUSTRALIA

19th June 2008

Submission to the Inquiry into Better Support for Carers in Australia

Dear Secretary

On 19th June 2008 our group of 42 Family Carers held a **Carer Forum** at the Carers Centre (Carers WA) in Perth in order to discuss a submission we wish to make to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

While the individual feedback points might not reflect everybody's opinion, the Carer Forum Group agreed to include all input into the submission.

We appreciate the opportunity to provide your Committee with information on our feelings and issues that come with our caring role as well as our requests for strategies and action and we hope that these will be taken into consideration so that subsequently this process will lead to a better life for carers in Australia with appropriate support given to enable us to fully participate socially and economically in this society.

If you have any further questions in regard to our submission, please do not hesitate and contact our nominated chairperson for the Perth Carer Forum Group, Mrs Ann Jones, on

Yours faithfully

The Perth Carer Forum Group

(The signatures are included on the signed registration list under Appendix III)

The Perth Carers Forum Group

**Submission to the Inquiry into
Better Support for Carers in Australia**

June 2008

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Executive Summary

Introduction to the Perth Carer Forum Group

The Perth Carer Forum Group met on 19th June 2008 at the Carers Centre of Carers WA in Perth, in order to collate and submit a submission to the inquiry into better support for carers.

The group consists of 42 Carers of different ages, who are providing care for a family member or a friend with a disability, chronic illness, mental illness or who is frail aged. While some of the carers are providing full time care for their loved ones, others juggle part time care with paid work, volunteer work or studies, some are elderly and/or have their own health issues. We therefore believe that the input of the Perth Carer Forum Group is representative of a wide variety of Carers and their issues in the Perth Metro area.

The forum process was, to brainstorm around 4 tables, each representing one of the Committee's terms of reference, then for each person to appoint their 3 top priorities for each area before gathering as a plenum to further discuss and agree on those priority areas. The notes from the brainstorm sessions have been transcribed and are included in section following the Executive Summary.

The plenum then appointed a committee and a chairperson as their representatives. Their contact details as well as those of other group members are in Appendix I.

Recognition of Role and Contribution

Carers were overwhelming in their feedback on their role and contributions to the community and how this could be best recognised and supported by government, community services and society at large. The diversity of caring situations were highlighted – ranging from carers who have their own health issues, to care recipients with dual diagnoses, to ageing carers and those with multiple care recipients. In response to this, there was a resounding recommendation that a tailored, individualistic approach to assessment and service delivery would be the most beneficial avenue for supporting families, carers and care recipients in a holistic manner. This accounted for services such as respite and in home care, as well as information provision to carers at point of diagnosis. Correspondingly, the eligibility criteria for services, funding and other supports need to be relaxed or flexible enough to enable this inclusive process in recognition of the diversity of caring roles and needs, rather than a pigeon-hole system.

The financial duress experienced by carers contrasted strongly with feedback on how much family carers save the government. Carers know that they save the community care sector significant sums in return for meagre financial recompense in the form of Carers Payment and/ or Carers Allowance from Centrelink. Carers felt these financial supports were inadequate, especially given today's high cost of living and the impacts of the caring role on individuals. Carer Allowance, in particular, was noted as insufficient – "*only covers petrol*". The stringent eligibility criteria for these benefits were also a sticking point, with carers calling for more flexible guidelines.

In addition, the lack of recognition of carers' roles in society was found to be reflected in the following statement by a carer:

“As a carer you receive no respect, no benefits, no financial support, little practical support, often no or little respite, and no superannuation but are still expected to pay taxes.”

This led to a call for the government to reduce the income tax bracket for carers and to develop superannuation schemes for carers to ensure a solid financial future for carers.

The financial and career sacrifice of carers who had given up employment to undertake a caring role was also seen to be unrecognised, with carers recommending carer-friendly workplaces and appropriate financial support from government.

A flow on effect of the lack of recognition of carers' role and contributions to society is the low rate of pay for care workers who provide the bulk of assistance and respite services. This industry issue has resulted in a diminished work force of care workers, leading to a lack of support services for carers and recipients, further aggravating the negative impacts of a caring role. The high staff turnover in the community care industry has also culminated in poorly trained staff with little continuity of service provision – an additional concern for families, particularly those with high or specialised care needs. Carers felt that these workers should also be recognised for the work they do and be appropriately paid, trained and supported, so that they may better support families.

In relation to training and support, carers reported that they could be providing significant care in the line of nursing care, with very little training or skills. It is just assumed that they would have to somehow learn and undertake complex care tasks. Carers felt that the burden and strain placed on them needed to be recognised and that relevant, trained support should be provided to ensure that they are skilled and prepared for their caring role from the outset.

The stress of a caring role can also have a negative impact on various relationships, and a number of carers identified that marriages and other relationships often break down as a result. One solution that was suggested was a need for fully subsidised couple and marriage counselling to help stop the breakdown of carer relationships.

The capacity to plan for the future was a significant issue for many carers, who felt there were simply no avenues or support to effectively plan for their own future and those of their loved ones. This was especially the case for ageing carers of adult children with a disability, leading to serious concerns and stress. Carers identified the need for programs to provide in depth assistance and planning for the future for both the carer and the care recipient, with a call for government and support services to understand that if they support carers, the support ends up benefiting the care recipient also and vice versa.

Barriers to social and economic participation for carers

Carers reported to face lots of barriers in regard to obtaining support for themselves and the care recipient which impacts their lives in many ways.

Main findings pointed out the lack of service availability for carers and the care recipient, lack of time to access emotional support and financial stress. These and other aspects of caring can impact on relationships and marriages and as discussed at the forum often lead to a relationship/marriage breakdown. Carer Allowance and Carer Payment were found to be inadequate, not recognizing the demands of the caring role and putting Carers under financial strain. Carers who are also studying (to plan for a “life after caring”) found the costs of books etc prohibitive.

There was a strong perception that different departments and services are competing for the same limited funds and that health professionals are not listening to carers and not recognising the specific knowledge carers hold about the person they are looking after. The lack of clear, precise and consistent information available needs to be further addressed as an access issue. This and a lack of respite and accommodation facilities for people with high support needs as well as all the other above mentioned factors act as a barrier to social and economic participation for carers.

“Care recipients requiring full time care who have turned 18 years are ignored and the family left to care for them on a constant and continuous basis, with extremely limited post school options available.”

While this forum did not represent rural carers, feedback from a number of participants was that they have lived rurally and moved to the City to be able to access more services. Unfortunately many find that they still can’t get the help and assistance they need.

Practical Measures

Carers at the Forum nominated a number of practical measures that could greatly address the barriers they encounter and help them better participate in a social and economic context. By far the strongest recommendation was for increased respite services provided by trained, reliable care workers. The resulting time out from the caring role would greatly enable carers to engage in other activities of their choice. However, carers also had concerns for the quality of care provided in these services, suggesting that increasing the salaries of care workers and providing ongoing training for “Best Practice” models would significantly provide peace of mind and continuity of service provision.

There was recognition that some caring situations are too high care to be adequately contained in the home and that there are inadequate services for young people with high care needs. One carer recommendation to tackle this was to:

Provide a (State of art) facility which has high care respite for younger people (not with elderly), with trained care workers so carers can leave care recipients full time for two weeks, stress free knowing they are being properly cared for.

Other practical measures recommended reiterate previous suggestions of individualised, holistic assessments and financial support schemes for carers beyond Centrelink benefits, such as reducing tax for working carers and a comprehensive superannuation scheme for carers.

Strategies to assist carers to access the same range of opportunities and choices as the wider community

Outstanding in the group's search for strategies was the issue of future planning.

"We need a 'What if I drop dead?' booklet and someone to assist the carer in setting up an emergency and future plan"

Future planning requests were understood as a holistic approach to a highly complex issue. Earlier mentioned key issues such as lack of appropriate information and services, need for financial security for carer and care recipient, carers health and wellbeing, barriers to study and (paid) work and recognition of carers knowledge, their value and input to this society need all to be considered.

Carers also expressed strong concerns about Centrelink ways of dealing with and staff's view of carers:

"We need more privacy for interviews and change of attitude towards carers – we are not beggars"

The following key strategies were decided upon for specific recommendation to the Standing Committee:

- Carers in general and specifically those over 50 years old should be assisted by Government to set up a future plan/strategy and funding for the care recipient
- An independent non-government body as the primary support service for carers – a service who deals with carer payments and looks at individual assessment and support
- Carers to not just be on Centrelink pension – accreditation for carers and recognition as the specialist for the care recipient → will lift status of carers
- Access and support for flexible study options for carers and subsidised HECS
- Superannuation needed for Carers – more financial security
- Better coordination between different Departments
- Less money needs to be spent on bureaucracy and more on services
- "Respite vouchers" for carers – respite funding not being attached to guidelines and therefore more freedom and choice for carers
- Support strategy for young carers.

Feedback in Relation to Terms of Reference

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

Respite & Services

Issues:

- Carers who have their own health issues which require attention, can't access appropriate respite services to accommodate their needs.
- Carers often don't seek respite services as they can't find paid care workers. Care workers are paid too low, are not properly trained and the work they do is not recognised which leads to a lack of paid care workers and many leaving the field.
- Carers are sometimes asked to pay for their respite.

Recommendations:

- Respite services that cater for Carers who have their own health issues need to be developed.
- Increase the wages for paid care workers, recognise the work they do and properly train them

Assessments & Process

Issues:

- Carers need to seek and search for support – they aren't approached or offered support without them looking for it.
- Care recipients who have a dual diagnosis/ disability (e.g. mental & physical) 'fall through the gaps'.
- Carers who have multiple caring roles require multiple & varied support services.

Recommendations:

- Each Carer case should be assessed on an individual basis and the eligibility criteria should be more flexible.

Recognition & Having a Voice

Issues:

- Carers feel there is no recognition of the Carers' or recipients' rights.
- No adequate recognition of Carers' prior career & the salary they are sacrificing – before they became a Carer.

Recommendations:

- The burden and strain placed on Carers needs to be recognised and relevant, trained support provided.
- Employers need to recognise Carers in their workplace and provide support, flexibility and benefits to those employees.

Training

Issues:

- Carers are often unskilled, untrained and yet they are providing nursing care.

Recommendations:

- Provide full nursing and care training to Carers to ensure they are skilled and prepared for their caring role.

Financial

Issues:

- The Carer is taking a huge responsibility and 'burden' off the Government by being a family Carer – yet the Government acknowledges this with a very minimal payment for Carers.
- The Carers Allowance only covers petrol.
- As a Carer you receive no respect, no benefits, no financial support, little practical support, often no or little respite, and no superannuation but are still expected to pay taxes.
- A Carer who cares for 3 people can only receive one Carer Pension and two Carer Allowances, however if they cared for disabled children they could receive all Carer Allowances.

Recommendations:

- Government should assess the huge savings Carers provide them with and adequately pay them for this.
- The Carers Allowance needs to be increased to cover basic costs including transport costs.
- Government should reduce the income tax brackets for Carers.
- Government should develop superannuation schemes for Carers to help build a solid future for the Carer.

Accommodation

Issues:

- Carers who express big concerns over the recipient's health issues are advised to 'put them in a home' which just isn't an appropriate solution.

Recommendations:

- Adequate housing establishments need to be developed for those recipients who need constant care but are not old enough to be placed in an aged care home.

Emotional Support

Issues:

- Relationships and marriages often break down as result of the stress, demand and requirements of being a Carer.

Recommendations:

- There is a need for fully subsidised couple & marriage counselling to help stop the breakdown of Carer relationships.

Future Planning

Issues:

- Future of the care recipient as the Carer is ageing.
- Carers aren't able to adequately plan for their own future, causing much concern and stress for the Carer.
- The Government and Support Services need to understand that if they support Carers, the support ends up benefiting the care recipient also. Carers save the Government huge amounts of:
 - Resources
 - Facilities
 - Time
 - Money

Recommendations:

- In depth planning for the future of the Care Recipient
- In depth planning and assistance in planning the future of the Carer

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

Respite & Services

Issues:

- Government care plans are inadequate.
- Lack of sibling support & the impact of caring for a sibling.
- Impact of Caring role on siblings.
- Carers not receiving adequate support for the number of people they care for.
- Limited options for social or recreational time out.
- Lack of appropriate care options.
- Most people don't know where to get relevant information for themselves and Carers don't have the time to seek the services.
- Care recipients who are under 18 and require one on one, 24 hour a day care are 'ignored' once they turn 18 – leaving the family to cater for their constant Care. Post school options extremely limited.
- Respite guidelines non-inclusive of whole family needs.
- Lack of skilled staff.
- Time constraints are about the service not the family.
- Inflexibility of respite options.
- So much easier for a Carer to just stay home – causing exclusion & isolation.
- Many Carers want to keep their recipient at home but due to a lack of services, often can't.

- Many Carers who lived rurally have had to move to the city to access more services – but many find they still can't get the help and assistance they need.

Recommendations:

Emotional Support

Issues:

- Carers don't have time to access emotional support.
- Lack of availability of emotional support services and difficulties in finding support for each individual's needs.
- Relationships & Marriages breakdown due to the stress of caring.

Recommendations:

Assessments & Process

Issues:

- Different departments and services are competing for the same limited funds.
- There is no clear, precise and consistent information available – needs to be consistent across all boards.
- When a care recipient is diagnosed there is no support or information provided to the Carer.
- Professional services come from an insensitive approach.
- The detailed assessment forms to try to get assistance.
- Problems if a care recipient isn't able to sign or understand forms – the forms need to be more flexible.
- The stringent eligibility criteria to access support funding & services.

Recommendations:

Financial

Issues:

- High costs of specialists and treatments.
- Gaps between Medicare and private is an economic burden.
- Penalties for Carers who can't afford to have private health insurance.
- Centrelink's attitude to Carers – as if they are trying to 'scam' money from the system.
- Expense of continence aids – the cost of aids has increased across the board but the funding levels & payments haven't.
- Financial barriers of getting medication.
- Continual need to prove your eligibility to Centrelink.
- Centrelink is legislation driven, yet slow to respond to necessary changes.
- **Carers allowance is totally inadequate.**
- If a Carer is studying, no allowance for books etc.
- Carers feel they can't move interstate because the funds & services change from state to state
- Difficult for Carers to maintain their home and car due to lack of finances.

Recommendations:

Recognition and Having a Voice

Issues:

- Health professionals not listening to Carers. Carers can provide invaluable and important information.
- Loss of Carer entitlements after gaining employment.

Recommendations:

Accommodation

Issues:

- Unsuitable accommodation and housing options.
- Lack of respite & accommodation facilities for those with high support needs.

Recommendations:

Future Planning

Issues:

- Lack of understanding of a Caring Role by all levels of the community

Recommendations:

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

Respite & Services

Issues:

- Availability of respite services – no places available for high care recipients.
- No confidence in care workers as many are not trained or capable.
- No continuity – huge staff turnover.
- Shortage of skilled care workers.

Recommendations:

- INCREASE RESPITE and provide trained, reliable care workers.
- Increase salary of care worker – so industry appeals to more people and provide ongoing training for “Best Practice”.
- Provide a (state of art) facility which has high care respite for younger people (not with elderly), with trained care workers so Carers can leave care recipients full time for two weeks, stress free knowing they are being properly cared for.

Assessments & Process

Issues:

- Confusion over which package is most suitable.
- Assessments based on age not actual “needs”.
- Lack of information provided.
- Wait time for assessment can be up to one year – with no support.
- Local Area Coordinator (LAC) – too much workload.

Recommendations:

- **Assessments made on individual situations not one to suit all e.g. Carers with disabilities and level of needs required (not aged based).**
- Advice needs to be given on which package is most suitable for needs.
- Correct, up to date information needs to be given at point of diagnosis.
- A central information point – not spread through various agencies – that provides more information about what services are available to Carers with different needs.
- Bridging of full support during assessment wait periods.
- Decrease number of families listed with LAC so they can provide a better service.

Recognition

Issues:

- Carers with disabilities fall between the gaps

Recommendations:

Emotional Support

Issues:

- Carers have 30% higher divorce rate than non-carers.

Recommendations:

- More relationship counseling support

Financial

Issues:

- Better off if break family up and live apart – more funding available.
- Too many agencies competing for the same funds.
- Can't afford daily living expenses, medications and just the necessities.
- No money for holidays, normal things in life.
- Transport for disabled people too expensive.
- Expense issues when care recipient turns 18 years old.
- Inability to work because of care commitments leads to no superannuation for Carers.

Recommendations:

- “Pay me what you pay a care worker”.
- **Reduce tax for working Carers.**
- Vouchers for fuel, food and travel – Carer discounts.
- Assessment on needs not age.
- **Superannuation scheme for Carers.**

Accommodation

Issues:

- No suitable accommodation for mentally ill.
- Listed wheelchair accessible venues are NOT following standards.
- Lack of appropriate residential facilities – particularly for younger people with illness/disability.

Recommendations:

- Cluster homes, need to supply and distribute medications.
- Enforce legislation on disability access standards.
- Provide a (State of art) facility which has high care respite for younger people (not with elderly), with trained care workers so Carers can leave care recipients full time for two weeks, stress free knowing they are being properly cared for.

Future Planning

Issues:

- Real concerns about the care recipient’s future when Carer becomes too old.
- Future – what will happen when Carers become too old to care?

Recommendations:

- Long term care planning.

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

Respite & Services

Issues:

Recommendations:

- Helping a carer with visits of care recipient when care recipient is in hospital.
- “LAC” system for carers (similar support to Local Area Coordinators of Disability Services in WA however supporting all Carers not recipient)
- More appropriate services for elderly people.
- Respite Vouchers – respite funding not being attached to guidelines – more freedom of choice for carers.

- (Provide) support strategy to support young carers.
- Government providing funding for live-in carers.
- Local government needs to provide more services to carers.
- Spending less on bureaucracy and more on services.
- NGO's should have more (Government) support to support and facilitate carer issues.
- **Independent non-government body as primary support service for carers.**

One member of the forum expressed strongly the following view:

- “Homeless people or anybody looking for accommodation as potential care workers in return for accommodation.”

However this was an issue where a number of people of the forum vocally expressed their disagreement.

Assessments & Process

Issues:

- Forms (for ACAT, etc) too complicated and too many.
- Grandparents' needs - “Biggest enemy was government when I had to look after grandchildren”. Government system too bureaucratic to access.
- Too many government departments involved providing care services.

Recommendations:

- Simplify system – one independent/ non-government service in local area needed.
- Individual assessment for the Carer's situation with setting up of support strategies.
- Centrelink to form a more flexible, individual assessment.
- Centrelink – more privacy in interviews and staff attitudes towards carers needs to change. “We are not Beggars”.
- Assessments of care recipient not just based on first visit (in regard to in home and day care services).
- Help and assistance for filling in forms needed.
- (Lower) eligibility criteria for aged care.
- Simplified processes and coordination between departments needed in government.

Recognition & Having a Voice

Issues:

- Many Carers have illnesses themselves.
- Centrelink view of carers needs to change.

Recommendations:

- Recognition of Carers' contribution to support services.
- Recognition with certificate, exemptions from professional qualifications.
- Carers being consulted for service accreditation – “We know which services are good for our care recipient”.

- Separate body/ dept for Carers who deals with Carer Payments and looks at individual assessment and support.
- **Carers to not just be Carers on Centrelink pension – accreditation for Carers and recognition as the specialist for the care recipient → will lift status of carers**
- Caring role should be seen as employment.
- “Take Centrelink Out” - recognition and respect for carers – it’s a job and choice of employment (underpaid).

Emotional Support

Issues:

Recommendations:

- Better funding for support groups – recommendation.
- Mentoring support to help carers get through difficult times.

Financial

Issues:

Recommendations:

- Subsidy for health care to Carers.
- Health insurance for Carers (e.g. lifting, increased risk, etc).
- Superannuation needed for carers.
- Access and support for flexible study options for Carers and subsidised HECS.

Accommodation

Issues:

Recommendations:

- Government to act as a facilitator to transition in care.

Future Planning

Issues:

- **No future planning (from Government).**
- Who takes charge when the Carer can’t do it any longer? Constant stress/on your mind.

Recommendations:

- Access for Carers to specific care plans for carers.
- **Many Carers from 50+ should be assisted by government to set up a future plan/strategy and funding for the care recipient.**
- “What if I drop dead” booklet/ someone to assist the Carer in setting emergency & future plan up.
- Short and long term care plans needed.
- Strategy for ageing carers.