

# COMMUNITY OPTIONS

## DEMENTIA RESPITE OPTIONS Albury & District

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4<sup>th</sup> July 2008

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

A.O.C. 15/7/08

**Submission No. 790**  
(Inq into better support for carers)

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community and Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because as the Coordinator of a Commonwealth funded program (Dept. Health & Ageing – NRCP program) I work exclusively with carers and people with a diagnosis of dementia who are living in the community. In my role which includes facilitating Carer Support Groups I am in a privileged position to hear many stories of the frustrations, stress, confusion, anger and guilt (just some examples of the feelings) that carers live with on a day to day basis.

In responding to the Committee's request for submissions I convened a focus group of 5 carers which was made up of 2 carers of a family member with dementia, a young carer caring for a parent with mental illness and frailty, an older carer caring for a very frail wife with a disability and complex medical problems and a mother caring for 2 adult and 2 younger children all of whom have disabilities.

Two of these carers have chosen to send the Committee their own letters which are included with this letter. However I have also attempted to summarise in point form comments made by all members of the Focus Group. These are as follows:

- At time of diagnosis 'inadequate dissemination of information' – not given any information about support services at '1<sup>st</sup> point of contact' which is usually GP/Specialist.
- All carers acknowledged that it is everyone's 'fundamental right' to have access to up to date, timely and relevant information so that informed choices can be made.
- 'Expertise of carers' not acknowledged by health professionals especially during hospital admissions and/or GP/Specialist visits. Comment by carer of 4 children with disability: "I have more knowledge that all the medical experts".
- Each caring situation is unique and very 'broad'. Therefore there are 'all forms of carers'.

- All carers are 'very different' – 'not all in same basket'. Therefore the needs of carers are very different – eg. student struggling to continue her studies and care for father.
- Caring is a 'full time job' - 'paid' approx. \$100 per fortnight.
- Broader community 'doesn't understand what a carer is' – lack of empathy. 'If it doesn't affect me I don't want to know about it' was the consensus of all carers in the focus group.
- Caring for a person is very isolating – can lose contact with community including family and friends.
- Very difficult to 'measure' and 'describe' the emotional toll of caring.
- Many disabilities are 'hidden' and not 'obvious' to the community – eg. Hearing/vision impairments, emotional 'disabilities' such as mental illness, conditions such as dementia
- 'No-one knows what is involved until you are a carer'.
- Carers are 'untrained' – only 'trained through circumstances'
- Young 19yr old carer did not know what her entitlements were – no one gave her information nor acknowledged her role as her father's carer. Felt lack of respect and acknowledgement (all carers identified this as an issue). This carer stated that 'it took a hospital admission (for her father) to be heard'.
- Young 19yr old carer 'found out about dementia and mental health' through her University studies.
- Assessments need to be 'holistic' taking into account not just the 'condition/disease' but all other aspects of what makes the person who they are and all other aspects of their life.
- Carer of the 4 children with disabilities stated that: "Knowledge is power" leading to a carer becoming 'empowered to make choices'.
- This carer especially felt that many specialist doctors keep the 'power to themselves' and consequently has not felt 'listened to'.
- Older carer caring for frail wife with disabilities stated that he is "doing OK and does have adequate support now". However this was not 'from the start' and he has 'learnt as he's gone along'.
- Community services play a 'vital role'.
- Lack of flexibility in service provision.
- Planned respite (in home and residential) 'very positive'.
- Longer respite breaks – eg a month. 63 days maximum residential respite allowed per year 'needs to be reviewed'.
- Not always 'confident in quality or consistency of respite care in residential facilities' – can lead to reluctance to use respite.
- Examples in a residential facility include 'time constraints for bathing' feeding etc'. 'Patient loses weight as staff don't have time to feed patient'.
- Caring doesn't cease when person goes into permanent care – caring role can 'increase' for reasons mentioned in previous point where family members attend twice a day to ensure wife does have a substantial meal.
- Mother/carer with 4 children with disability stated that she gets a weekend respite a month but 'sometimes it doesn't work'. This carer stated that 'it is 4.5yrs since she and her husband have had time together by themselves'.

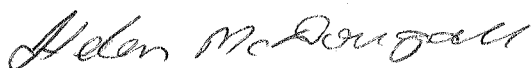
- 'Back up support' for carers to attend meetings either not available or carers don't know about it.
- 'Often takes a crisis to get action'
- Stresses of caring negative impact – eg. health, exams being missed.
- Financial hardships – eg. equipment/aids for person and for home, feeding formulas including Peg Feed bags, increased costs of power for CPAP (Sleep Apnoea) machines and electric wheelchairs, transport (disabled taxis, community transport), homecare services which may be subsidised but still attract a client contribution.
- Young carer who is a student needs to work but is unable to as caring for her father is a 'full time job' on top of her full time University studies. Has to pay for petrol ( to and from father's house), books, excursions etc.
- Lack of flexibility in service provision
- 'Bureaucratic system lacks flexibility in its response to people who are carers'.
- Carers of 4 children with disability 'would love to go back to work' – now unable to as 'one son's level of care has increased dramatically'. Husband now works 55 to 60hours per week. Therefore has 'no energy' to follow up on Centrelink queries etc.
- Centrelink 'messes people around' eg wrong forms sent out, rejected Carers Allowance all of which add to stress and which could be avoided.
- Younger carer would like 'emotional support in handling Dad's moods' as 'no one understands'. Would appreciate counselling but doesn't 'know where to go'.
- Would like a 'Peer Support / Younger Carers' program/support group'.

What all the carers would like the Committee to know is that 'you cannot measure the emotional strain and stress' and that the 'impact on people's lives is enormous'. All of these carers either live in Albury or in outlying areas which is also a disadvantage as often services such as those available to younger carers especially are not available in a regional centre such as Albury. Many services still appear to be 'citycentric'.

'Across the board' there is so much more that can be done to support carers generally. A good 'starting point' I believe is in more education for Medical practitioners and Practice Nurses. This education could be provided by the Divisions of General Practice with the emphasis on the need to acknowledge and respect the skills, knowledge and expertise that carers have about the people they are caring for.

Thank you very much for providing this opportunity to submit this letter on behalf of carers. Our hope is that the findings of this Committee will provide further impetus in attempting to understand and respond to the needs of all carers.

Yours sincerely,



**Helen McDougall**  
**Coordinator**  
**Dementia Respite Options – Albury.**

STANDING COMMITTEE  
ON  
10 JUL 2008  
FAMILY, COMMUNITY,  
HOUSING & YOUTH

Alishya Parss,

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

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because...

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More information is attached on a separate sheet

**1. The role and contribution of carers in society**

As a carer, I feel that my role is...

Firstly, Being a parent to the person that should  
~~be~~ be taking ~~is~~ care of me. My role includes  
taking responsibility for his needs and wants.  
Secondly I am his daughter.

More information is attached on a separate sheet

**2. The barriers to social and economic participation for carers**

As a carer, I face the following problems ...

As a carer my father has depression and frontal  
lobe brain damage; these are not physical  
disabilities and doesn't really get recognised socially  
Emotionally it is harder to look after <sup>him</sup> as people  
don't perceive ~~it~~ the level of care I provide  
for what it really is, especially as a 19 year old.

More information is attached on a separate sheet

3. The practical measures required to better support carers

As a carer, I need help with ...

Emotional support and financially it is difficult to afford petrol to take him where he needs to go. As I am also a full-time Uni student it is hard to get time and money to help improve my father's quality of life. It's a catch 22; I would like to get a job

More information is attached on a separate sheet

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by ...

Increasing the carers allowance to financially support my father. Emotional support, as it academically affects my uni work.

More information is attached on a separate sheet

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

Yours sincerely

Signature

Print your name

ALI SHYA PURSS

Date

30<sup>th</sup> JUNE 2008

Postal Address

c/- Dementia Respite Options - P.O. Box 287

Contact Telephone Number

0260 513 983

ARBURY NSW  
2640

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to be and independent but because of financial difficulty I still live at home. Although I take on all the responsibilities of an independent such as paying bills,

2. con't

I have been looking after my father since the age of 12 years old after he retired from work due to a tripple by-pass surgery. I mainly looked after his finances. As the years passed and my father got worse I took on more of a parenting role. He has diabetes, heart disease, depression and frontal lobe brain damage as a result, his mobility is decreasing, due to a lack of cognition and understanding it is difficult to maintain my fathers diabetes as he doesn't comprehend why he is not allowed to eat certain foods. And due to the depression I'm never sure what mood he is going to be in whenever I see him which is on a daily basis. That makes it emotionally difficult for me as I am also a full time University Student studying Psychology. Academically I am not able to achieve my full potential and I almost always have to get extensions ~~at~~ on assignments because I put my fathers needs first. My friends ~~do not~~ would not understand what I do as not every 19 year old does what I do. Socially, it is hard to go out on weekends and as I used to be an active volunteer in my region in regards to red shield appeals, salvation army door knock appeals and blood donations I can no longer contribute to society as I ~~was~~ could before.

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Committee Secretary  
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Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because...

I CONSIDER THAT CARERS ARE UNDERVALUED, UNDERRESOURCED,  
AND OFTEN ISOLATED FROM MAINSTREAM SOCIETY.

More information is attached on a separate sheet

**1. The role and contribution of carers in society**

As a carer, I feel that my role is...

TO SUPPORT AND GUIDE AND ADVOCATE FOR A  
PERSON CLOSE TO ME WHO THEMSELVES HAVE LOST  
ABILITIES TO ~~XXXX~~ DO THIS.

More information is attached on a separate sheet

**2. The barriers to social and economic participation for carers**

As a carer, I face the following problems ...

KNOWLEDGE TO ACCESS GOVERNMENT AND SOCIETAL  
SUPPORT AGENCIES,  
SOURCING CLEAR ADVICE ON HOW TO CARRY OUT THE  
CARERS ROLE AND IDENTIFY PRECISELY THE AVAILABLE  
RESOURCES TO ME.

More information is attached on a separate sheet

3. The practical measures required to better support carers

As a carer, I need help with ...

TRAINING AND KNOWLEDGE TO FACILITATE MY CARER'S ROLE

MATERIAL SUPPORT TO FACILITATE MY CARER'S ROLE

More information is attached on a separate sheet

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by ...

FACILITATING TRANSFER OF KNOWLEDGE TO CARERS RE:

a) SKILLING OF CARERS TO CARRY OUT THEIR ROLE

b) CONTACTS TO PROVIDE ACCURATE ADVICE ON WHERE & WHEN

SUPPORT AGENCIES ARE AVAILABLE

c) FINANCIAL AND MATERIAL SUPPORT AVAILABILITY

More information is attached on a separate sheet

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

Yours sincerely

M. T. L.

Signature

Print your name

MARTIN THOMAS

Date

7. 6. 2008

Postal Address

185, SPRINGDALE ROAD, BETHUNGA, VIC 3691

Contact Telephone Number

02 60 264 562

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

I would like to draw the committee's attention to some of my concerns in regard to support for carers.

Background.

My wife was diagnosed with dementia in 1997. I live in the border area of NSW/VIC where Albury is the closest large town but I live on the Victorian side of the border in the shire of Towong. I live in a relatively remote location. I cared for my wife at home until mid 2004. She was then put into permanent care in Albury and now lives at an Albury nursing home.

I am submitting a list of areas I feel that governments need to address with regard to carers.

1. My wife was diagnosed with dementia through a series of doctors in Albury, a GP and two specialists. At the time of diagnosis, although warned that times would become difficult for me I was not provided with any contact points to agencies or other support except to suggest I may want to join a dementia support group. I think it important that either the specialist doctors or the GP should provide a list of agency contacts that allows a carer to access advice early in the start of their role as a carer.
2. I was advised my wife was not safe to drive. To prevent her being isolated I had to give up full time work to care for her. I had no knowledge of either HACC support or Centrelink carer support. It was some two years before I felt I really needed outside support and I came to hear of HACC through telephoning local shires. Through one of the specialist doctors I heard of Centrelink carer payments. Up to this time I had to support my wife through short term contracts and part time work.  
I think it is necessary for carers to be advised from the time of a diagnosis what financial avenues are open to them.
3. Through shire officers I was advised of the existence of ACAT and my wife was eventually enrolled for assessment by them. Through the shire also I was told of day care venues and the possibility of respite at home. However, I found I could not use day care facilities in Albury (as we lived in Victoria). I had to transport my wife to day care in Towong until, eventually, my wife was given an ACAT funded package. I was then able to fund her travel to day care but the costs were so large that it consumed a large part of the budget and I was advised that it would limit my ability to get respite. So I went back to driving her myself. Later, I found there



were day care centres run by private organisations in Albury that I could have accessed and also that it was possible to use shire facilities in Wodonga. I consider that all packages in both HACC and ACAT need to be fully discussed with government officers in terms of the patient and carer's situation so as to maximise the benefits to both parties. Also a list of supporting organisations and the supports they provide.

4. I eventually joined support groups in both Victoria and NSW and through other carers I found that some had assessments where modifications to their homes to aid supporting their caring roles had been facilitated through government programs. I had carried out limited modifications at home myself but without such support. I suggest that the agencies giving in home or respite support should provide a **detailed list** of the supports available to a patient and carer so that they can fully discuss the options and access them.
5. Many carers, as myself, are put into the carer role unexpectedly yet have not the skills to carry out the role well. We are untrained. Counselling is useful but professional carers are given training skills to deal with the welfare of the patient while avoiding risk to themselves. Short courses in caring techniques and strategies for non-professional carers should be facilitated by government agencies - particularly to those carers recently thrown into the situation so that they can prepare for the future. Continuing counselling and advice in specialist areas such as behaviour management, heavy lifting, and incontinence management should be available as the need arises.
6. There is a tendency for specialist professionals to ignore the opinions and suggestions of home carers despite the close knowledge of the patient that they may bring. Also, among the general public there is often an assumption that the home carer is a lesser person than others because of their low income and the fact that they are not earning a wage. The difficulties faced by these carers is often ignored or misunderstood. Often agency officers supplying support have their own agendas and preformed opinions of what is most important for the patient or the home carer. This attitude continues when the patient goes into permanent care and the carer is no longer treated as a 'carer' but as a 'non-carer'.

Public education is needed to demonstrate the difficulties faced by carers, to show how economically important they are in reducing care costs, and how important it is for the welfare of the patient to remain at home. Agency officers need to be made aware that they are there in the interest of the patient and the carer and not in the interest of their agency other than to supply the support that is needed by both these clients.

7. Through my own experience and discussions with other carers I have formed the opinion that support agencies are often protective of themselves and unwilling to openly discuss their roles. Some agencies see the client not necessarily as someone



in need of support but rather as an avenue to obtain government funding. As such there appears to be a conflict of interest where the client is at a disadvantage.

I suggest that knowledge empowers the client and the better their knowledge the better they are able to maintain themselves. I do not see this as disadvantageous to governments but may be considered so to the management base of agencies seeking government funding. This is an area that needs to be addressed.

In my submission I make the following suggestions:

- That carers and patients be made aware of the available government sources of support as soon as possible as the need for a caring role is identified by the medical professionals. I believe this is best facilitated through the medical professionals as it is they that make the diagnosis.
- That government support agencies identify to clients non-government support agencies that can help them.
- That the various sources of support funds at different government levels be clearly identified to the patient and carer detailing the broad areas of support that they are intended to cover.
- Where assessment of a patient and/or carer's situation is being made that it is made clear to the clients of all supports that may be available to them and that there is full and frank discussion of the needs of the clients with the clients. When an assessment is made both client and agency officer need to sign off on the package proposed with reviews made when requested by the clients as well as at least an annual review of the patient/carer situation.
- That the carer is given a clear sense of the budget involved with a particular package at any government level and the flexibilities within them.
- That courses in carer techniques be made available to non-professional carers with support help for them to attend such courses.
- That there is dispute resolution available between agencies and clients and the clients are made fully aware of the avenues to do this.
- That public awareness campaigns of the importance of carers within society and economies is made.

My submission is about passing knowledge to the client/carer as quickly and efficiently as possible. Their needs should be uppermost and well managed agencies should see this. While this is true for governments it is important to observe that the need for a carer are first identified by the medical professionals. While they have a duty to respect clients privacy they also have a duty to pass the best advice and knowledge to their clients. I feel that the first failing to carers is at this level.

M. Thomas

STANDING COMMITTEE  
ON  
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HOUSING & YOUTH

M. The car