



## **Information on making a submission to the Parliamentary Inquiry into Better Support for Carers June 2008**

A Federal Parliamentary Inquiry is underway that is looking into Support for Carers of people with chronic illness, disability or frailty. To see the full information on the inquiry, visit the House of Representatives Committee website:

<http://www.aph.gov.au/house/committee/fchy/carers/media.htm>

The House of Representatives Standing Committee on Family, Community, Housing and Youth is conducting the inquiry and is calling for written submissions until July 4 2008. Public hearings will also be conducted across the country.

### **There are the four key terms of reference for the inquiry:**

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action;
- 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.

MS Australia and State/Territory MS Societies will be making submissions along with a range of community and carer organisations. Individuals can also make a submission.

We encourage the families and carers of people with MS to make submissions about their experience of caring, what impact your caring role has on your life now and into the future, and the ideas, suggestions and recommendations you have to reduce the unreasonable burden of the role.

The Committee is looking for practical solutions to the issues raised by the carer movement over a long period, so it can make strong recommendations to the Government.

Your frontline experience will be valuable in letting the inquiry know exactly what is happening and what is needed in the area of MS and chronic illness.

## Making a submission

Parliamentary inquiries of this kind are influenced by personal experiences, perspectives and suggestions. Submissions do not have to be in any particular format – they can even be in the form of a letter.

It is very important that as well as telling as much of your own story as you feel comfortable disclosing, you make it clear what you think Government needs to do to make the role of carer more viable and sustainable, and to increase the range of choices available to carers – either personally or more generally.

If you want to make your submission confidential you need to make a specific request so it is not published on the Committee website, or to publish it as a confidential submission without your personal details.

It is also important to stick as much as possible to the terms of reference to make sure that your submission is within the limits of the inquiry's scope. The terms of reference of this inquiry do give you scope to make a range of points and recommendations.

In addressing the terms of reference you may like to consider the following questions as a guide when writing your submission:

- What is caring for a person with MS like and what impact does it have on your family?
- What support and assistance do carers need to stay in the workforce?
- If you are working, what makes it possible to mix with your caring role or what do you need to stay in your job or run your business? Have you had to reduce your working hours due to your caring responsibilities?
- What impact will your caring role have on your retirement savings?
- Does the current level of financial support to carers from Centrelink adequately meet the needs of families? Are there more or different welfare arrangements needed to better reflect the reality of caring for a person with MS?
- What barriers do you face in being a carer? What practical things would assist you to overcome these?
- How do you see the future for yourself and your family? What are your expectations of Government assistance/programs in the future?
- What are the important things you need from the health, education and community care system? How could the system better serve your family?
- What innovative ideas do you have to improve carer support for those looking after people with MS?

If you want to present personally as a witness at a public hearing of the Inquiry in your State/Territory, please make this clear in your submission.

You are advised to also contact the Committee Secretariat by phone following the closing date as a follow up as spaces are often at a premium. Please also advise your MS Society if you are seeking to appear at a hearing.

### **Formatting your submission:**

The following has been drawn from the Fact sheet 'How to make a Submission to a Parliamentary inquiry' on the House of Representatives website

<http://www.aph.gov.au/house/committee/documnts/howsub.htm>

A submission may be as short or as long as you like. It may contain facts, opinions, arguments or recommendations. It may cover all the points in the terms of reference or only some of them, depending on what interests you. Supporting documents may be attached.

There is no prescribed format. However, to make submissions most useful we suggest structuring the submission using the terms of reference. If the submission is longer than a few pages, please include a summary at the front.

Submissions may be in hard copy (written or printed) form, or can be made by email. Hand written submissions are acceptable, but care should be taken to ensure that they are legible and suitable for photocopying.

It is helpful if each hard copy submission is sent with an electronic version on disk or CD-ROM, preferably in Microsoft Word® or Portable Document Format (PDF). This assists committees with publishing submissions on the Parliament's website.

Make sure you sign the submission. E-mailed submissions must include your name, phone number and postal address for verification.

The Inquiry provides parliamentary privilege and will consider requests to respect confidentiality but they reserve the right to publish your submission.

Your submission must include: (1) your name; (2) a postal address for correspondence; and (3) a contact telephone number; and (4) your position (for example, facilitator, president) if you are making a submission on behalf of an organisation or carer support group.

### **More information and assistance**

If you need assistance with your submission, please call your local MS Society or the MS Australia Policy Team on 03 9845 2700.

### **Where to send your submission**

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  
E-mail: [fchy.reps@aph.gov.au](mailto:fchy.reps@aph.gov.au) Website: [www.aph.gov.au/fchy](http://www.aph.gov.au/fchy)  
Phone: 02 6277 4566

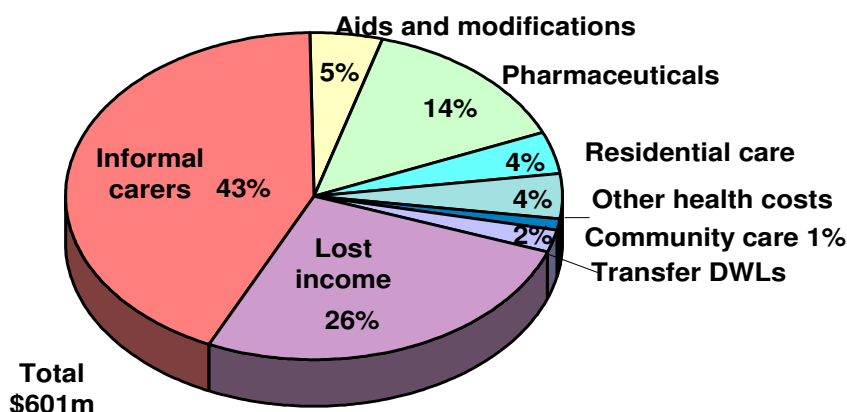
# FACT SHEET

## CARERS AND MS Economic and social impacts

### MULTIPLE SCLEROSIS CHANGES THE LIVES OF FAMILIES AND FRIENDS

- ✚ Informal care is often provided by family who, as a result of caring suffer from generally worse physical health, tiredness, stress, back/muscle problems, depression, anxiety, isolation and lack of respite.
- ✚ Many provide long hours of care because of the lack of other choices.
- ✚ In 2003, data from the ABS Survey for Disability Ageing and Carers showed that around **37.2%** of all primary carers felt they needed more support in their caring activities (ABS, 2004c).
- ✚ Most primary carers have lower rates of employment because of their caring duties, and as a consequence have lower average wages.
- ✚ Informal community care is provided by family and friends of the person with MS at no monetary cost. .
- ✚ Based on the statistics of the Australian MS Longitudinal Study (AMSLS), an average of 12.5 hours per week of informal care is required per person with MS.
- ✚ Carers are unable to spend that time in paid employment or in leisure activities
- ✚ Carers experience higher rates of depression than the average population

Figure 1-0: The Replacement costs of informal as a percentage of the total costs of MS.



**"70% of cases begin between 20 and 40 years of age, with the average age 30 years. The peak incidence occurs in the mid twenties, at a time when many people are buying their first home and starting a family."**

*The replacement cost of informal care provided to Australians with MS is over **\$258m.***

Source: Access Economics from AMSLS EIS data

Informal carers perform a range of task:

- daily living (personal care, meal preparation, transport),
- home and garden activities (household management, maintenance, managing household finances),
- care coordination
- child care.
- advocacy

### ***Carers need a range of support mechanisms***

- ✚ the existing disability, health and community care systems need to respond better to the needs of people with MS (including better timing, shorter waiting periods and better coordination) to reduce the care burden on families over the long term
- ✚ employment support programs are required to give greater employment continuity to carers who work and better incentives to employers;
- ✚ Full time carers need greater financial security and improved benefits
- ✚ Carers and people with MS need continuous access to services including aids and equipment, home and vehicle modifications, allied health and community care
- ✚ Home care and respite services for people with MS and similar neurological conditions need to be made available that are:
  - lifestyle friendly, flexible and age-appropriate;
  - are available over the long term course of the disease;
  - integrated with health services
  - offer appropriately trained staff.

**HOUSE OF REPRESENTATIVES Standing Committee on Family, Community, Housing and Youth**  
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fchy.reps@aph.gov.au Website: [www.aph.gov.au/fchy](http://www.aph.gov.au/fchy)

## ***MEDIA RELEASE***

*Issued: 14 May 2008*

*Chair: Annette Ellis MP Deputy Chair: Hon Judi Moylan MP*

# **Better Care for our Carers**

## ***New parliamentary inquiry announced***

The House of Representatives Family and Community Committee will conduct an inquiry to determine how to better meet the needs of carers who look after those with chronic illness, disability or frailty.

Committee Chair Annette Ellis welcomed the referral of this inquiry from the Minister for Families, Housing, Community Services and Indigenous Affairs Jenny Macklin. A 2003 Australian Bureau of Statistics survey found there were over 2.5 million carers in Australia, including more than 470,000 primary carers – people who provide the most care to a person needing support. The Australian Institute of Health and Welfare anticipates there will be more than 600,000 primary carers by 2013, with 70 per cent likely to be women.

In announcing the inquiry Ms Ellis said “Carers are often the hidden and unsung heroes who tirelessly look after family members and friends who cannot look after themselves. The demands placed on these carers often mean that they are exhausted, socially isolated and under extreme financial pressure, particularly as they are unable to access mainstream employment opportunities. Not surprisingly, carers have been found to have significantly worse physical health and psychological wellbeing than the general population.”

“The Committee embraces this opportunity to hear first-hand through a formal inquiry from carers about their day-to-day experiences and to learn more about the social, economic and physical costs of being a carer,” Ms Ellis said.

“A better understanding of the immediate and longer term challenges faced by carers will allow the Committee to make well-informed recommendations in the inquiry report on practical ways to improve and extend the support available for carers. While recently announced additional Federal funding for new supported accommodation facilities represents a step in the right direction, the Committee is keen to hear from those on the ground so that it can assess what more can be done to support the as yet unmet needs of carers.”

To better understand the challenges facing carers the Committee will inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- 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

The Committee invites interested organisations and individuals to make written submissions to the inquiry addressing the terms of reference by 4 July 2008. The Committee will report in early 2009.

**For media comment**, please contact the Committee Chair, Ms Annette Ellis, on (02) 6277 4372 (Parliament House) or (02) 6293 1344 (electorate office).

**For all other inquiries** please contact the Inquiry Secretary by phone on (02) 6277 4566 or by email [fchy.reps@aph.gov.au](mailto:fchy.reps@aph.gov.au) or visit the Committee's website: [www.aph.gov.au/fchy](http://www.aph.gov.au/fchy)