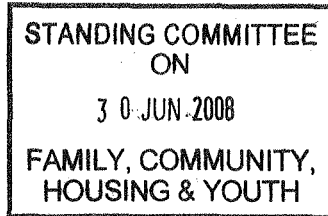


A.O.C. 8/7/08

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



26 June 2008

Dear Secretary,

Re: Submission regarding Better Support for Multiple Sclerosis (MS) Carers

As a full time carer of my wife, I would like to submit this document to you for your review as part of your inquiry into better support for carers. The submission details the following information below for you to gain an understanding of our personal situation and how I could be further assisted:-

- History of my wife's 42 year battle with MS
- Our current situation
- Caring for my wife and the impact on the family
- The cost of MS to the carer and family
- The problems I face being a full time carer
- Practical ideas that may overcome these barriers
- An innovative idea that would improve carer support

I hope that this will assist you to gain an insight into how we deal with issues on a daily basis as they arise and I have also provided some practical solutions that would assist myself and others in the same situation.

I eagerly await the outcome of this inquiry for carers. If you would like any further information or would like me to testify this submission, please do not hesitate to contact via the details provided below.

Kind regards

Ken

History of Val's Multiple Sclerosis (MS)

Val is a 63 year old woman who has had relapsing/remitting MS for a total of 42 years. Sadly, Val was diagnosed with MS three months before she was to be married to her loving husband Ken. Val was lucky to have two children of her own and also currently has two young grandsons.

Over a number of years, Val's deterioration with MS had been relatively slow and she has lead a fairly independent life. Having said that, Val has been through stages where she has gone blind in one eye for a couple of months, has experienced numbness sensations down either side of her body and had regularly been admitted to Austin Hospital for treatment by her Neurologist Peter when she experienced MS attacks. These attacks would occur two to three times per annum. Until recently, Val had never been wheelchair bound but on occasions had experienced difficulty walking. At this point, Val was not taking any other form of medication to alleviate or slow down the MS attacks.

Val's Current Situation

In December 1996 Val was advised by her Neurologist Peter to take Beterferon via an injection which she did every second day until November 2007. During this time Val had very few episodes until March 2007 when she had an attack which seemed to be the major turning point. Val started to deteriorate at a faster rate. By this, I mean it has been documented that her mental deterioration has significantly declined along with her physical ability to walk unaided. She now has a walking frame along with a wheel chair when necessary.

Val is now unable to do complete any tasks for example: cleaning, washing, ironing, cooking and any other basic household tasks. She has a marked lack of concentration, loss of planning abilities, instability and falling over on a regular basis, incontinence both bowel and bladder (she has a permanent catheter) and marked changes in her behaviour. As a full time carer, I do find our situation very sad, frustrating, difficult to handle and most of all very tiring. It is not so much physically tiring, it my mental tiredness that is hard to keep in balance.

Due to Val's requirements having a permanent catheter, she has the District Nurse attend our home every six weeks to renew the catheter. One particular nurse had observed the situation that we are in and asked were we getting any assistance which I answered no and how do I get it. She advised me that they have a specialist nurse who may be able to help gain access to services. This nurse contacted me and came to meet with us. She listened to our case and certainly advised me that I should be receiving plenty of assistance in caring for Val. Subsequent to our first meeting she has visited us on a number of occasions until she advised me that the period of time she had allocated to her to work on our case had lapsed but she would keep trying. This nurse did arrange for some in house help from our local council which included cleaning on fortnightly basis and showering Val three mornings a week which is proving to be really helpful.

Caring for Val - The Impact on Ken and the Family

I had to make the final decision to permanently retire from work when I was at the age of 64 in 2006. This decision was extremely difficult to make as it meant I lost my identity at work and independence to take up the role of full time carer for Val which was clearly not going to be an easy transition as you never know what the future holds.

My daughter Julia, (currently 34 years old) went backpacking when she was 22 years old and lived overseas for several years. On her return, she noted a significant deterioration in her mother's general state. Since returning to Melbourne, Julia has had many hurdles to climb in accepting her mother's deterioration due to MS and the marked changes that have occurred whilst she was overseas. For example, Julia noted that Val has had serious cognitive deterioration, memory loss, impulsiveness, deeper depression, change in behaviours and general confusion with daily life.

With Val's deterioration, sadly we now have a diminished circle of friends primarily due to the fact that going out is certainly a difficult task and overall one cannot expect continual help and support from these people. I have also found that over time, it is very hard for friends to really have a full and clear understanding of what happens with Val when the door is closed during or at the end of the day and there are only the two of us at home. If you looked at Val without her walking frame you would not think there

is anything wrong with her, she always puts on a brave face which can often give people the wrong impression about how bad her situation is.

I endeavour to do some activities during the week which include taking Val to see her grandchildren, going for a coffee and attending the cinema every couple of weeks. The cinema however can be good when she understands and enjoys the movie. If she is not enjoying the movie, Val will try to wonder off out of the cinema which can prove to be difficult in controlling her.

The Cost of MS to the Carer & Family

One may think that we are relatively lucky that I was able to work for the majority of Val's illness and as such, am now able to continue to provide for Val via my superannuation – a nest egg that would give us a liveable income. However, I do feel that in the case of the utility discounts (via State Government) we are discriminated against as neither have a pension card therefore are exempt. As an example, in summer running the air conditioning is an essential item for Val to assist in coping with her MS and equally having the heating running during winter due to her inability to move around readily. Apart from these items, the other entitlements we receive are the Companion card, Senior's card and Carers allowance.

Please be aware that I have managed on a single wage income for the majority of our married life and inability to access such discounts on essential items as above is frustrating on the part of the government, whether State or Federal. The current fortnightly carer's income and yearly grant is appreciated but in the overall scheme of things is a very cheap way out for the government.

Another hidden cost I have bared throughout the years is taking Val to her hospital appointments and being charged for parking my car in the car park. With Val's limited mobility, we are unable to park in the surrounding streets so we have no option but to use the pay car park. In the case of a once off visit, you don't mind that but when you are visiting her while she is admitted into hospital (Austin Hospital in Heidelberg) for a period of six weeks, it is extremely expensive. The cost is currently \$10.00 for up to three hours parking. If you have to go to the hospital twice a day, it can work out to be

\$16.00 for a total of 4 hours parking per day. For a carer, this hidden cost can amount to a large amount of money.

Another financial cost to us has been my superannuation. By this I mean that as a self funded superannuate, I was controlling my superannuation. However with Val's ongoing care, I felt I was at a point where I could not handle both control of my superannuation and cover the increasing demands of Val's condition. Therefore I had no choice but to make the decision to entrust my superannuation to what I felt was a well established organisation. Unfortunately this has proven to be a bad and costly decision. I do realise that the share market has been through a major crash. If I had not had the pressure and burden of Val's deterioration, this would have enabled me to make a clearer and more rational decision regarding my investments.

The Problems I Face Being a Full Time Carer

Up until the last couple of years I feel that between Val and I, we have managed her MS with periodical assistance from the Neurologist and General Practitioner. However, now two years later after retiring Val's MS has taken on a new decline. I have never been the type of person to ask for any assistance in the past as I could manage the situation but now that I need help, am finding it extremely hard to get any. The current problems I am facing are for example:

1. In 2007 Val had a case assessment completed by St Georges Hospital Aged Care Assessment section in Melbourne. Following that, we received a letter in June 2007 stating that Val had been authorised for the following:
 - High Residential Aged Care
 - High Residential Respite Care
 - EACH Packages (*Extended Aged Care at Home*)

This is where my confusion has really set in. As I did not have a clear understanding of what any of these packages meant, I have only accessed low level temporary respite care and funding via the MS Society. It was not explained to me that "Each" packages were available to me to assist me at home and I would receive a case manager through this service – I honestly thought it referred to the two options above. At the assessment last year, we are advised by the hospital that it

could take up to two years to have a case manager allocated to Val which as her carer is far too long to wait.

2. Val is unable to be left at home for any extended periods of time due to her impulsive behaviours which can/could be dangerous to herself and the house and her lack of physical mobility.
3. Our local GP regularly writes out scripts for Val's medication. She is currently taking five different types, one of them being Oxycontin. The GP must ring a Government department to get authorisation to issue this medication and until recently was only able to receive authorisation for a two week period. In our case, I have found it safer for us to have all of her medication made up into Webster packs by the chemist. As part of the conditions for Val to stay at temporary respite care, her medication must be in Webster packs. Apart from the inconvenience of fortnightly scripts, the cost of \$10.00 per script from our GP is also an additional cost to her everyday care.

Practical Ideas that May Overcome These Problems

1. Recently we have only had the one nurse really take an interest in our case and help me to move forward. The nurse has explained to myself and my daughter what the different packages meant, how we access them and who to speak to. It would have been extremely useful to have some sort of information pack provided to me when I received the high care approval letter indicating what I was entitled to. Then I would have had the knowledge to source a case manager and care services that Val needs. Instead we at the point of being quite critical in receiving further assistance.
2. Easier access and at shorter notice to daily respite care so that daily errands such as shopping and paying the weekly bills can be completed in the knowledge that Val is safe.
3. In reference to ordering Val's Oxycontin medication, only after many phone calls to the Government department, we are now able to access monthly prescriptions. It may be another factor for the Government department to take this type of case into consideration to make the approval process for medication more user friendly for carers.

An Innovative Idea that would Improve Carer Support

Being a full time carer, I have carefully thought about what achievable improvements could be made to make it easier for me and others in my position. For me personally, the process of gaining information and where to gain information/assistance needs to be a lot more transparent and a central point of reference. By this, I mean I would like to see a publication produced along the lines of 'The Foolproof Guide to being a Carer' which is specifically written for carers of any age and also published in various languages. As a guide, the publication content should cover the following topics:

1. What is Multiple Sclerosis
2. Different types of MS
3. How is MS diagnosed
4. How does MS effect the sufferer during day to day life (give actual examples of physical, mental and behavioural problems that have to be faced)
5. My role and responsibilities being carer (full time & part time)
6. What impact will being a carer have on my life
7. Role of immediate family members
8. Role of an MS Case Manager
9. Role of a General Practitioner (GP)
10. Role of MS Neurologist
11. This publication should contain all of the services provided by the MS Society (not everyone can gain access to the internet (eg: elderly people))
12. List of current and helpful websites on other support groups that carers can attend for carers that do have access to the internet.
13. Who can I talk to if I am having a melt down?
14. How does a carer gain access to government assistance and the process you should take?
15. How long does it take to get a case manager?
16. How often should an MS sufferer have neuropsychological assessments?
17. Where are these assessments performed?
18. What if I need a case manager sooner as the MS sufferer is deteriorating quite quickly?
19. Include some carer stories on how they deal with the MS sufferer and how they balance their life at the same time.

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20. How do you know when an MS sufferer should be placed in full time care?
21. How do immediate family members get support when they are finding the disease hard to deal with?
22. The following are processes that should be covered off within the publication:

- Who can I rely on to take responsibility for my case?
- How do I gain government assistance?
- What am I entitled to as a carer from the Government?
- Where do I go if I hit a brick wall eg – organisations won't return my calls?
- How do I go about getting the MS sufferer annual assessments and where do I go?
- What equipment may I need to have to assist the MS sufferer and how do I get these?
- What if the carer dies? What happens to the MS sufferer?
- Is there immediate respite care needed if required in this situation?
- Does anyone fund this type of emergency respite?
- How do I put a long term plan together for the MS sufferer if they should outlive me?

23. Another initiative I would put forward for consideration is to have some type of car park card that specifically allows carers to take the MS sufferer to their scheduled doctors appointments and allow carers to visit their family patient in hospital for free or at a heavily discounted rate. This would assist in easing the financial costs on myself and other carers.