Submission No. 167
(Inq into better support for carers)
A.O.C. 26/6/08

From: Nicolas
Sent: Tuesday, 10 June 2008
To: Committee, FCHY (REPS)
Subject: AC response:Submission

To the Committee Secretary

Please find below my submission

Re **Inquiry into Better Support for Carers**

Orientation: I am the sole, full time, carer for my wife who has dementia.
Both of us are retired.

My experience is about the lack of suitably **advertised, oriented and coordinated support** for me as a carer of a person who has been diagnosed, late 2003, with dementia or Alzheimer's. It has made my task so much more frustrating.

I was not told about my wife's diagnosis, but found out about it by opening the envelope containing the letter of referral. (I am not supposed to open such envelopes)
Also I was never told in a Medical Centre what help/support was available to me.
I was a volunteer with the *Galston Community Health and Resource Centre* and only through my continuous searching and reaching out, that I gradually found out about the various organizations and as to what I was entitled to
During this early period I experienced several breakdowns.
Help was just not made known to me from the start, or **advertised**.

I am a member of *Alzheimer's Australia NSW* and *Carers NSW Inc.*
I attended the 'Living With Memory Loss' program conducted by Alzheimer's NSW, Oct/Nov 2005. The follow up early in 2006 was unsuitable for me.
I did not fit in. Looking back on it now, the LWML program became an isolated event, while it should have been the beginning of a helpful relationship, it should have **oriented** me.

The Quarterly Newsletter of Alzheimer's Australia NSW *in touch* has no articles in it to support me as carer. When I spoke to the editor about this lack of support, he told me this was not the purpose of *in touch!*
The newsletter of Carers NSW, *CARERSNEWS*, April/May 2008, has an article *Assertiveness for carers*, page 13. I thought here is something that may be helpful
The article is totally unsuitable for me as a carer, it would be very wrong for me to act this way towards my wife.
The article appears to be straight out of textbooks and is not tuned for carers
I do not receive or experience any **coordinated support.**

According to a letter from the Prince of Wales Medical Research Institute this year, (2007 or 2008 ?), in Australia, 52,000 people will be newly diagnosed with Alzheimer's or other form of dementia. So how can their carers be supported?
With the aid of computers, the internet? The web site of Carers NSW appears to have some more for male carers. The book shop of Alzheimer's has few suitable books.

From my perspective, Alzheimer's Australia and Carers NSW appear to be busy
with lobbying and fundraising and lack fully experienced staff to help carers of my type.
Reading both their member's publications over the last few years, will confirm my observation.
Is it, because of this, that I was not pointed in the direction of supportive organizations?

I like to see both Alzheimer's Australia and Carers Australia better supported
by the Government so that they can more fully service their customers.
attract sufficient and suitably trained and experienced staff and as such become much better
recognized by the medical profession who will direct, newly detected carers, towards them.
This better funding of the two organizations will address the three problem areas of
what I called the lack of suitably advertised, oriented and coordinated support
for me as a carer.

Following my experience, I developed a ***Roadmap for Male Carers***
With the help of my daughter it is now also a website, but not linked
and as such, impossible to find.
I have submitted it, and other proposals, to Alzheimer's NSW
and also to Carers NSW. The aim is to incorporate my Roadmap
into their websites. So far I have not received a reply from either.
This reinforces my impression that they lack staff

I am Nicolas

inquirycares

ROAD MAP for MALE CARERS

Particularly for men whose partner has dementia.

May 2008

How to use the Road Map:
This road map is designed to be a step-by-step workout for you to gain an understanding about your situation and become a more relaxed and better carer.

Critically examine each of the headings. Does it appeal?
The headings are meant as prompts for you to get started. For example, consider the heading "Objectives". Can these be your objectives or do you need to formulate your own? Generally, we do not progress by copying somebody. We are individuals, unfortunately sometimes, and have to find our own way to come to terms with our own situation.

Now write your experience or observations for each heading.

Objectives.
To discover and express what is helpful for the carer of a person with dementia.

Frame of Reference.

This is written from a male perspective, a male who is living with his wife full time, whose wife has dementia and is diagnosed with Alzheimer's disease.

Limitations.

This represents very much my personal situation and learnings.
Various segments overlap.

First Realisation.

You suddenly find yourself to be a carer and you are totally unprepared and unqualified for this role. You are unlicensed but have no choice. You have lost control. You also come to realise that women appear to be more natural carers.

Have you lost your partner and or lover?

A partner is understood to be a person you do things together with, you are mutually supportive, discuss and plan, agree and disagree with. In a nutshell, a lover is a person you love and sleep with. With dementia you certainly have lost your partner. In addition you have lost the person you "love until death us do part". However, you have not lost your lover! She still wants to cuddle up with you and be embraced. "I will always love you" I hear again and again. Why did I find her so many times upset and crying because "you told me you do not love me anymore, you only care for me?" she says. For a long time this upset me very much, wondering where she got this from. Often she woke up and said this having dreamt it. It may all come from a time when I told her our relationship had changed, both of us being confused, but that I would care for her. Or, does she sense that the person she has become I no longer love?

You cannot argue or reason with a person that has dementia!

It is a very hard road to travel to this realisation and takes a long time to learn with many pitfalls. I learned that like the tactic of wrestlers of not going against the forces but finding ways to circumvent. My aim now is to avoid making things worse and causing tension. There is direct feedback enabling you to make amends. After a few minutes your partner may have forgotten so you can try again.

Validation Approach.

The principle underlying this approach is that all utterings and behaviour of the person with dementia are important, have meaning and are real to that person although they may be based on misinterpretation etc. Again the aim being to not cause tension and make it worse for both. I just failed to apply this method and caused distress. I should have achieved a reduction in anxiety and stress for both of us and the restoration of confidence in my partner. I said that she was wrong. She became distressed because I did not believe her. I reasoned against her. I was right but took the wrong approach! Next time better!

Fara Clowns of The Netherlands.

I saw a little of the Fara Clowns on the Dutch BVN TV. They made me realise that I have to put on an act. I took my situation very seriously, lost my sense of humour and found it hard to relax. Now I have found out what act I should put on, what works. This is a continuous learning process.
Growl at her and she will growl back, smile at her and she will smile back.

How are you?

Either of you may have health problems. Also you may find out when you are feeling down it may be very disturbing for your partner. I considered all available resources. Plenty is written about a healthy life style. The Internet is also a great resource for check ups.

Mourning and Alzheimer's disease.
It was once suggested to me that losing your partner to Alzheimer's was like mourning but that is never over. I did not relate to that. I was prompted to consider what I have experienced about mourning and what may be a common denominator with mourning. Those left behind in bereavement have to make many adjustments. As a carer, I have to make many adjustments too but not all of a sudden like in the case of the death of a close one. A carer has a long road ahead with many adjustments to make, a continuous process with many wake-up calls. With bereavement you do not get frustrated with the departed but as a carer you may be frustrated many times. The person is still there, although different. Unresolved conflicts of the past may become amplified or get in a groove with your partner. You may be blamed for things.

Shadowing.
A person with brain impairment loses many functions like, short-term memory, comprehension, reason, and planing and social skills. They live in a small world and become very dependent in a different way. They may reject people they knew from the past, stop social interaction and become totally dependent on you the carer. The result is they always want to be with you. Want to know where you are and do not want to lose sight of you. They follow you around. You may be accused of spending too much time with somebody, too much time with your computer or something else. They may start looking for you. On your return after a short absence you are met with the question "where were you"? This behaviour is called shadowing.

Impressions.
To others in the outside world or on the phone she appears to be all right, nothing wrong with her! Only an acute observer will notice she is on her best behaviour. You experience it all, her moods, her frustrations, her strained and unhappy face, her suspicions and questioning. But when at the next moment she interacts with somebody else, like in a shop, all is well, amazing! As a carer, you are on your own. Nobody knows what you experience with her.

More of the Same.
Same thing again and again. To you it may all be trivial, boring or not worth the attention. For example, how the clouds are not moving or how it is so still outside. Something wrongly remembered and repeatedly brought up. Like an old record stuck in a groove.

Let it all slide. Sometimes comment and acknowledge. Redirect the attention or change the subject. Explain when possible. Never argue or get her on the defensive. Realise that is her real world now!

When All Else Fails.
When you have had it!
Find a quiet place, do whatever!
Let it all go. Breathe it all out!
While breathing out feel your diaphragm coming up, also that little one designed for your discharge, feel it pull in! Beats painful haemorrhoids anytime!
With full breathing feel your tummy move.
Relax your tummy muscles, move your tummy.
Get some fresh air and get the circulation going again.
Go for a brisk walk and breathe freely.

When you can breathe out, you will breathe in.

Links.

Alzheimer's Australia
An organization for people living with dementia, their families and carers.
www.alzheimers.org.au
National Dementia Help line 1800 100 500

Carers Australia
An association for relatives and friends who are caring for people with a disability, mental health problem, chronic condition or who are frail aged.
www.carersaustralia.com.au
For carer information, support and counselling free call 1800 242 636