

Supplementary Submission No 9.1

(Inq into better support for carers)

MC 15/7/08

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
Submitted by email: fchy.reps@aph.gov.au

29 June 2008

Dear Secretary,

Inquiry into better support for carers

This follows my earlier submission dated 27 May 2008 and acknowledged by e-mail on 29 June.

Attached is a letter that I was prompted to write recently to John Franklin, Secretary of ARAFMI Illawarra (a branch of ARAFMI NSW Inc). Its purpose? That it would help him to explain the lives that carers like myself lead to the NSW Government bureaucracy. There are many like me; indeed, Mr Franklin is one.

We find – and this is sad – that some members of the department that has non-government organisations as its responsibility, and who are far from the scene and real events, need that explanation. The argument to which I refer in that letter is one raised by a senior member of the Department who objects to the fact that ARAFMI in discussion and literature mentions that carers suffer from *stress*, *shock* and *crisis*. No matter what the reality, the department does not like it. A hint that using such terms puts ARAFMI Illawarra's grant at risk.

It may be too late to enter this letter and to attach it to my earlier submission. Yet the members of your Committee may gain something from it, and may learn that it is not easy for valuable and active non-government organisations to deal with the department that funds them.

Please let me know if you need a signed copy of that letter.

Yours sincerely,

Peter

Attached: <20080627 to John – a Carer's Life.doc>
A Personal Submission – P. - May 2008

27 June 2008

Dear John,

Not having been able to attend today's meeting at the ARAFMI Illawarra office, it is not very clear to me what is the argument about stress and shock and crisis. And therefore I thought that I would explain my own state and that of my wife for whom I care at this time while she is in an episode of depression that started before Christmas 2006 with hospital admission and has – with a short break – continued to this day. It is not the first episode since the start of desperate depression and embarrassing and destructive mania fifty years ago; and if ever she recovers it will not be the last. Changes in medication – what may work and what does not – we are back to where we were in 1958.

After the two recent unsuccessful treatments in hospital (December 2006 and January 2007) with medication and ECT, our situation at this moment is worse by the day; and therefore I give the facts of my life as it is now while I surprise myself that I can carry on caring, helping, encouraging and guiding. But now I see no end to it.

If there is *one* of me, a carer for someone close, there are many others like me (and like us); and our individual stories form a mountain of despair and uncertainty and stress and shock that need understanding and succour (which ARAFMI *has* and *can give* in abundance).

I have written this account from the heart while I have a few moments on my own (and these are not many) without much attention to composition or sequence; but thoughts and emotions and anger as they come. Others will judge whether this is stress, shock or crisis.

The day dawns.

For me, it starts at 4 or 5 o'clock in the morning or earlier, thinking ahead to where our situation will lead us. It is depressing and discouraging; and thinking about it hurts. The future is uncertain. The first sound from beside me in the bed tells me what sort of day we will have: it is not hopeful. Mercifully I collect my thoughts for the better when my feet are on the ground and when my mind clears and I can be doing something.

I will get myself in order - wash and shave - so that I may look composed and tidy and in control of myself and of the situation, and be helpful and make breakfast.

By that time my wife will have risen and dressed herself. Then breakfast will be on the table and I will have laid out her morning medication. She does not stay at the table long. She takes her cup in silence and escapes to her chair in the sitting room while I wash up, make the beds, and do such other things as are necessary to keep a tidy home; and I will go to sit with her.

She needs me to be close to her and she needs my hugs because there will be tears of her uncertainty: "I can't remember anything", "I don't know what to do", what shall I do?". It is repetitive throughout the day as will be her need to hug me and find me close.

But soon she will silently withdraw to lie on her bed, minutes or hours; and for most of the day. And when she appears again, she needs my full attention.

At this moment, while I am writing this letter and away from her for a few minutes while she is awake, she is agitated and wants to be close to me. There is not much time in the day that I may sit and write as I do now.

Friends used to telephone; but less and less. There is not much to say since nothing changes. People in numbers put her in fear. We are isolated; an isolation that is self imposed. Those that telephone to give me advice what I should do (and sometime demand that I do it) are not welcome. Those who tell me often that I should get some help in the home mean well; but I know that a stranger appearing in the house (the very anticipation) will cause dramatic anxiety. I do not need that help. I am adept with brush and duster to keep the house in order; and with pot and pan.

She will answer the telephone and give the impression that "I'm not too bad"; just as I will speak on the phone in my other persona that shows some cheer in life.

There are now two persons in my body; and they are distinct. Perhaps it is to my advantage that I can - when the moment allows - think and speak as a normal person before I am called back to the other.

I must tend to everything. The garden is difficult because I am out of the house and she becomes anxious and looks for me.

I escape to do minimal shopping and return as quickly as I can. It is dangerous to leave her alone; and I do not again want to come home to find her unconscious and the cartons of her medication empty.

I take her out when she feels like it (and I will press her a little to do so) and we manage the anonymity of McDonalds. But even there, at a quiet time, the people are too many.

Time for lunch. I have to choose carefully what I prepare for meals because the latest medication has some risks associated with various foods. Packet soups are to be avoided as is much else that makes cooking simple. So I chop something fresh.

She appears in the sitting room; sits down, gets up, sits down, gets up and escapes to the bedroom; returns a few minutes later to start that sequence again.

She sits in her chair and there is a sudden cry; but I do not hear what she says and I am not supposed to hear.

TV is upsetting. That is no surprise, There is nothing that is pleasing.

Dinner is quickly upon me, and I take my time over it to cook something that pleases both of us; and she appreciates it, even if it is often hidden by the taste of curry.

Her need for my presence is constant. I must guide her very movements around the house and out of it. I must tactfully encourage her on some very intimate matters (and she does not mind this). She is not a good walker and is likely to stumble.

She is lost and out of control "please ring the police. I'm wicked" (it is a response to a serious episode in 2006 on which I will not dwell).

I take her to an exhibition at **artinport**, a new gallery in Port Kembla, for the opening of an exhibition by three people with disabilities, our son Robin amongst them. Many people who know us welcomed her; but her mind was not on it, and she told me afterwards that the crowd upset her. We went again a few days later during the day; but again she was not with it and sat down to wait for me.

I use to say (indeed I used to preach to others): "Tomorrow will be a better day". It's wearing a bit thin.

I am a carer, and have been for many years. So what do I need?

It is difficult to define. A clinical cure obviously; and we are lucky in our association with our psychiatrist to keep us afloat. But the cure is a long time coming and may never come; and I have accepted my situation.

No one can blame the mental health service for failures. The broken leg will mend; the broken mind may not. And eventually 'treatment in the community' means treatment at home.

I do not need courses on coping. I've been through it all, and I will be seen as arrogant as I have no interest in the vast array of courses and paper that appear endlessly. These do not help me and the many others like me.

I've learned much while with ARAFMI when I was able to be at Caring and Sharing meetings. The young man with babe-in-arms changing nappies at the meeting because his wife cannot cope. The distraught family whose son returns to the home to play havoc and destroy. The mother whose talented daughter's life has changed for ever. The father whose son will eventually take his own life. It goes on. There are many like me.

Strangely what may help in our isolation is what those that fund ARAFMI consider a luxury ("eyebrows were raised"). It is something that, in a mild and considerate way, accepts us as we are without judgement and comment; but with encouragement to socialise. But our isolation and our situation is incomprehensible to those not touched. No one but those who are in the midst of it can have that gut feeling, that taking of breath and of fear of where it may end.

Yours sincerely,

Peter