

Submission No. 3

(Inq into better support for carers)

A.O.C. 28/5/08

Sent: Friday, 16 May 2008
To: Committee, FCHY (REPS)
Subject: Carers & Caring

The Secretary of the Committee,

Please find attached a couple of submission that might, or might not be, worthy of your consideration. I am a male carer looking after an adult female with both physical and psychiatric disabilities which leaves me little time to make submissions to a committee. I look forward to any reply.

Kindest Regards,

A COMMUNION OF THE SPIRIT

As I always do in writing an essay on carers and caring I make certain that all of us are talking about the same thing so it's important for me to ask here just who or what is a carer? As it happens the definition is relatively simple. A carer is: someone who provides unpaid care and support to family members or friends who have a chronic or acute condition, mental illness, disability or who are frail aged.

And who am I? I'm the primary carer for a friend who suffers from a nasty duopoly of psychiatric and medical issues either one of which would severely limit her physical mobility and as a consequence of this leaving our home becomes an almost practical impossibility. Both of us are mostly cloistered within the limits of the comfortable unit we've shared for the past eighteen years.

And given our ailments it's not surprising that departing our safe haven is a physical and psychiatric undertaking of monumental proportions. This is because not only the one I care for has limitations but I too have psychiatric issues that need to be catered for and one of those issues is my rampant agoraphobia which really does complicate the equation.

However, casting these issues aside it can be said that we are fully functioning members of our small "by invitation only" closeted community. As a carer I see it as one of my main duties to maintain that vital and vibrant interaction with others who fall within our chosen community wherever and whenever it's possible but in a general sense we are housebound.

And we sometimes need a wake up call to be reminded that being a carer requires a certain mind-set in order to cope successfully with what can be a complex calling that can gradually become more difficult with the natural passage of time. There are many carers who are at that point in their life where accumulating fatigue, or carers fatigue as the professionals call it, makes an already difficult undertaking even more challenging.

This is because carers have needs just as much as the one they care for. I've said it before and I'll say it again: carers need respite as much as those we care for need carers. But I see no immediate deliverance on the horizon for those worthy carers. As it stands at the moment I receive a fortnightly carers allowance and on a conservative twelve hour day that amounts to about 59 cents an hour. Which is, no matter which way we look at it, not a large amount of money. And how stupid am I? I performed the task of primary care giver for more than twelve years before I even became aware that there was such a thing as a carers allowance.

My fifty nine cents an hour is mostly absorbed in fuel for the motor car and medication. And even the so called safety net for pharmaceutical supplies is oftentimes ineffective in that not all the medication prescribed is covered by the Pharmaceutical Benefits Scheme and this can become problematic when one lives on a fixed income.

All the while the government saves billions of dollars a year by deliberately abuse by neglect those same carers and without these same carers the entire system, as it now

stands, could not continue to exist. It's a fair assumption that carers will continue to care unabated so what options, if any, are left? Carers anarchy? A good idea perhaps but carers are not in the position of strength whereby we can withdraw our services. We are surely not in a position whereby we can lodge a log of claims and expect to have it debated at any level of politics. There are an estimated 2.3 million carers, but it's not surprising that nobody has a definitive number of carers, but we lack a united front from which to press for improvements to our unchanging circumstances.

But carers are gradually becoming more and more vocal and activist in outlook and there are many fantastic agencies out there in our community who continue to act as our cry in the wilderness but we can't be certain at this stage which direction we are heading in. Perhaps our next step on this carer recovery journey will be to convince the politicians of all persuasions that we actually matter. Until we reach at least that small degree of recognition we can't even begin to lobby properly for the future wellbeing of our carers.

And it's not just a matter of throwing money at the problem because a full time carer doesn't have enough free time to spend it. Rather it's all about love and caring and compassion and empathy and affinity. Once these attributes are factored into the equation, it is clear that it is these same essential attributes that keep carers caring - often into their old age. But what's to be done about this unhappy circumstance of the calculated neglect of one of our most precious resources - which are the unpaid carers in our community?

There seems to be no immediate or apparent shortage of carers as such but with an aging pool of carers this could well change for the worst. I just hope and pray that this situation continues to incorporate those who're prepared and willing to make what is oftentimes an extraordinarily rewarding life's effort and to, perhaps sadly, assume the responsibility of caring for someone who needs caring for.

I can't even begin to understand the necessary fortitude when faced with that appalling and heart-wrenching question of who will look after the ones we care for when the carer can no longer cope with the high levels of care necessary for the continuing wellbeing of the ones they presently care for? What depths of despair must we reach before the practicalities of this unwelcome situation are properly addressed and carers and those they care for are elevated to the social status they deserve rather than being best described as the forgotten demographic?

But there can be no argument about the fact that it is the responsibility of those who can help themselves to help those who can't. It is our moral obligation to do so and is the key to ordinary people becoming primary carers in the first place. The need for a carer comes about in many tragic shapes and forms. The need might come about because of a road accident. Or an accident of birth but in the scheme of things the cause is of small importance. At the end of the day it is only the effect that matters to those special people who are chosen to be carers for someone who can't care for themselves. It's called a communion of the spirit with the ones we care for.

CARING FOR THE CARERS

Over time I've come to believe that carers are somehow especially chosen for their life's vocation and that we're chosen because we possess three specific and necessary attributes. These are a practically applicable compassion gently tempered with an inexhaustible font of love and a simple all encompassing patience.

It's hard to imagine that it was almost twenty years ago last month that I accidentally found myself in a crisis of compassion where I could either head off into the wilderness or accept the not insubstantial responsibility for a friend in desperate need. It wasn't as if I had a lot of options when I eventually chose to stay and do the "right thing". Whatever that was.

My own mental health issues consist of paranoid schizophrenia with agoraphobia and an attendant anxiety disorder while the one I care for sadly suffers from paranoid schizophrenia and the debilitating and near crippling condition of osteoarthritis in her right knee.

Whichever way I looked at it helping as best I could was the right thing to do and I've never had reason for regret but at that time, in my innocence and naivety I never really saw myself as being a carer in the long term. And the obvious inference to draw from this was that I knew next to nothing about being a carer but that didn't mean that I should be automatically excluded from taking up the challenge because it needed to be done and there was no one else to do it. And in one way or another I've been performing the role of carer ever since.

As you would rightly expect I oftentimes found myself completely out of my depth. We were both of us in a learning curve but somehow, whether by good luck or by good management, or a happy combination of the two we survived the initial psychiatric skirmishes.

I know now that as in all things in life there are degrees of illness and wellness that need to be carefully sanctioned and positioned so as to bring about the required positive outcomes. There are those with special needs, one so different from the other as to be effectively opposites. There are degrees of required care that are so varied as to be effectively opposites. And there are degrees of reciprocal interaction between carer and charge that are effectively opposites.

And accidental or otherwise it's this multi-layered interaction of a set of circumstances that is so rewarding for both the carer and the one being cared for as well. And that welcome interaction is why carers like me continue to care. So for better or for worse, by accident or coincidence I see a clear and present need to continue doing what I'm doing. All things considered I consider myself as very well compensated with a love honestly presented and freely accepted.

But caring does have a downturn. It can be exhausting and overwhelming if you're not constantly on the lookout for your own well being. And it's a well known and recognized fact that those most affected by accepting the position of carer simply

won't take due advantage of a well earned respite and this is for many different reasons. Not the least is that the carers mind-set is such that they can perform the task better than a temporary carer or agency or that any benefits are outweighed by the negatives or that the carer puts their own welfare last. The last of which is the most common reason why the noun respite is, for many carers, just another word in the dictionary.

When it comes about that you actually listen to those carers toiling at the coal face discouraging words like isolation, loneliness, hopelessness, helplessness, and frustration, are all in common usage. All of these words are used to some extent by all carers at some time in a sometimes vain effort to truly quantify and carefully define their own emotional and physical state of being. But the word that every carer is most familiar with is weariness. Virtually every carer I've come into contact with can relate directly to that word.

As luck would have it I've also had the good fortune to have been talking, in an informal manner, with some unpaid carers who, like me, care for people who can't care for themselves.

During one such chat it came about that one member of our circle had absolutely no idea that there was such a thing as a carers allowance or payment available from Centrelink. This poor woman had been performing the task of carer alone and unassisted for years and my heart really went out to her. Being the sceptic that I am I can see how such a situation might come about because Centrelink is remarkably reticent in advertising allowances and other facilities available to carers and they should bear at least some of the blame for such a regrettable oversight.

But not all is doom and gloom. As things often work out my own personal position of carer brings with it an entirely welcome appreciation at both my very best, and my very worst, efforts at being a full time carer. When that situation does come about it makes me feel good and provides some of the necessary wherewithal for me to face the dark unknowns that belong to a seldom predictable and a mostly uncertain tomorrow.

The whole of life commitment of being a full time carer doesn't just ask for the trilogy of compassion and love and patience – it demands it. But at the end of the day that's just what carers do. They care for their special charges in a special way under special circumstances with special unlooked for rewards.

This is not an altogether unexpected outcome given the prodigious amount of work and time and effort carers are prepared and willing to invest but mostly, when the proverbial push has become shove, it's all about that ten letter word commitment. Commitment to a another person in need truly is a special state of being.