

Submission No. 1295

(better support for carers)

Acc 19/11/08

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## A Carer's Perspective

I was a full time carer for someone with major depression over a period of eleven years, before relinquishing her care so I could return to work. Issues relating to her care however are ongoing, and remain unresolved at the time of writing this report.

I have chosen to outline the entire situation in detail. I recognise that this makes it a very lengthy report, but I hope it will help to give meaning and context to my recommendations, and give the Committee, and the wider public, the opportunity to 'stand in the shoes' of a carer.

In Part One I outline the history and needs of the woman I care for, in Part Two, I make further observations about the reality of being a carer, and in Part Three make some recommendations for change.

### PART ONE

#### The story

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The lady whom I have cared for over the last 12 years is not a relative. I met her in 1996 when after a long and difficult marriage she suffered a breakdown and was admitted to a psychiatric hospital. She was 45 years of age. There she was given ECT (shock therapy) shortly after her admission, which resulted in an apparent brain injury, and severe and permanent deficits in her ability to function and enjoy her life as she had previously. In fact, she was unable to live alone or to manage her own affairs anymore, even though she had been an active and effective member of the community prior to her hospitalisation.

On discharge from hospital, she tried all accommodation options available to her over a period of about eight months, including living with her sons. However one by one each of these options failed, as no-one was available to give her the kind of support she needed to manage life with her new disability. She therefore needed a carer, and had nowhere to turn, and although I had only known her a few months, I was prepared to assist in her care.

I knew from the beginning that she had acquired a significant disability, although I probably wasn't aware that looking after her would mean that I wouldn't be able to continue to work full time.

It has been a frustration to us that we have never yet found a psychiatrist who would acknowledge that the radical changes in her may be caused by ECT, even though they coincided with her having the treatment. Nevertheless, some of the main effects that she and I have identified as resulting from ECT were that she:

- Had a perpetual headache for two years, even though she had never experienced headaches previously in her life. She has also had a headache most of the time for the 12 years since.
- Had been an avid reader but could no longer follow the story line of a book.
- Had played competition tennis for twenty years, and was competing up to the time of her hospitalisation, but after ECT she could no longer co-ordinate her serve. After a number of attempts to regain this skill she was forced to recognise that she wouldn't be able to play tennis any more.
- Used to sew regularly and make her own clothes. After ECT she commented to me that she 'couldn't look at a sewing machine now' – lacking the ability to concentrate, or to cope with anything detailed or fiddly, as she had in the past.
- Was unable to enter shopping centres or supermarkets because something had changed whereby the sound of the air-conditioning in those places had become intolerable. The noise of the motor seemed really loud to her, whereas she had never even heard it in the past, and we could only conclude that there must be something about the frequency of the motor that she now picked up on, as a result of changes in her brain.
- Struggles to initiate conversation except when with a few familiar people
- Whereas she had been highly sociable in the past, being the one who would propose and organise nights out for her place of work where she was leading hand, she was now unable to meet with even a couple of friends. If she did, during the get-together her headache would get worse, and then afterwards her head would spin and make funny noises for up to 24 hours. She would become exhausted and weak, and be unable to stand 'being in her own skin'. Her agitation would become intense and all she could do after getting home from a simple coffee with a friend was to go to bed with strong headache medication and some sedation, and sleep for 12-18 hours to recover. Generally by the evening of the following day she was beginning to feel alright again.

While in hospital she was put on the disability pension, as it was clear she would be unable to work.

She found it extremely difficult to adapt to all her new limitations and it actually took years for her to start to accept that she couldn't do the things she used to do. She experienced a strong sense of loss and ongoing depression from the devastating loss of freedom and enjoyment of life that she had always taken for granted.

Through trial and error we discovered that she was unable to wash or cook or help with household chores, or even to manage her day without help. She would seek help with decisions like what to wear, whether to have a shower first or breakfast first, or whether to close the window when it was raining. It was apparent that she needed a lot of detailed assistance if she was going to cope.

At some point I realised that what it boiled down to was that I couldn't expect her to do anything I wouldn't ask a five-year-old to do. I then recalled with interest an opinion expressed to me previously by a psychiatric nurse, who said that 'ECT dissolves adult defences', as it affects the frontal lobe where the treatment is applied.

She now needed to sleep a lot, as a result of the changes in her brain, the medication she was on to manage her depression, and the medications she was on to manage the side-effects of the primary medication.

She would become lonely and frightened if left alone, although she could manage a few hours, if necessary, as long as it was not after dark. Her tolerance did diminish over time, however, and ultimately she largely lost the ability to be left alone at all.

She and I did all we could to maximise her independence. We experimented together with trying to get her to do more, and it meant that over the first few years she had a number of hospitalisations as she went into deep depressions when overloaded with the responsibility of managing her own day. Over time we developed a clear understanding of what she could and couldn't do.

We discovered that all she could really do was to sit and watch television in short bursts. Her head and body would then feel overloaded and she would need to go and sleep. I would carefully monitor her many symptoms (headache, nausea, agitation, tiredness, weakness, 'brain sensations' and depression, among others) as they came and went throughout the day and night. I would then administer whatever of her prescribed PRN medication we agreed was needed. (PRN medication is medication the doctor has prescribed for her to take 'as needed', within the bounds of a set daily maximum.)

Most nights she would call me and we would be up at least once, sometimes several times. Because she needed to sleep a lot, it became difficult to sustain long periods of sleep at a time. We experimented with her staying awake more during the day, but it resulted in her suffering too much in terms of headache, agitation, over-tiredness etc. It proved better just to allow her to sleep as and when she needed to.

The highest gain in terms of her level of independence that we were able to secure, was that over a period of years she gradually became able to cope with the demand of getting her own lunch. A couple of years later she developed to where she could get her own breakfast as well.

For anyone who may read this and wonder whether she wasn't prepared to try hard enough, I can only say that she was more shocked and upset by the loss of all her life skills than anyone else. She could hardly even accept that it had happened. She would often comment to me about her terrible sense of sadness and loss that she could no longer be the person she used to be. She would say, 'I can't tell anybody what my head is like now', shaking her head in troubled disbelief. If she had been able to do anything about it, she would have done so without a doubt.

Furthermore, she is one of the most courageous people I think I have ever met, and she inspires me with the effort she puts in just to endure the many sufferings that have become part of her life.

Over the years she has spent countless hours sitting in my car waiting, while I did our shopping or paid bills or attended to things that needed doing. She had to come with me because she couldn't cope with being left at home alone, but she wasn't usually able to come in with me because it would over-stimulate her brain – with the consequences already described – and so she would regularly sit patiently in the car and wait: for an hour or two at times. In all those years I never heard her complain.

After the first few years when we discovered exactly what she needed to get by, we then had 8 solid years without any hospitalisations.

'Not having hospitalisations' doesn't mean everything was fine. It just meant that our situation never broke down to the point where she was at enough risk of self-harm that she had to go into a secure care environment. We monitored her mood every day as she and I worked together to manage the major depression that hung over her at all times.

When I first met her I was working full time. When that employment contract finished, I adjusted my schedule so I could support her during what was a period of traumatic adjustment to her new disability. I supported myself financially by creating various small business activities that fitted with her special needs, so that she could accompany me. I lived on the small earnings from this, and from my savings.

After three years of providing intensive support, I began to wonder whether, since we had established a solid routine for her day, I could return to work. My savings had dwindled, and I now needed a reasonable income to maintain the kind of lifestyle most people take for granted. I wondered whether she may be able to just keep to her routine in my absence during the day, and whether the luxury of having some spare spending money may make the 'sacrifice' of my absence something she could endure. Feeling that we were financially secure was also important for her stability.

Maybe she wouldn't like me being away, but she *could* cope with it.

Furthermore, I was 41 and I wasn't ready for my career to be over. I had been unexpectedly taken out of the workforce by my caring role, and I hated the thought that she might actually be ok on her own, but I was just worrying too much. I felt that I had more to give than for all my resources to be focussed on one person.

She agreed for me to try going to work. But then she is very compliant and would probably agree to anything she thought I wanted to do.

We tried it, but the aloneness got to her after a while. We weren't able to find any activities she could go out to that didn't overload her head. We had, after all, learnt that she coped best when being quietly 'minded' at home by one person. We battled on, but after some months I came home one day to find her lying, shaking and sweating, on the bed after having taken an overdose. She was admitted to intensive care and was there for several days.

When she recovered she told me she had heard a voice that told her to take the tablets. She had never been diagnosed with any kind of psychosis, but we were to learn that, on occasions, if she was exposed to too much stress, she could be troubled by feeling or hearing a suggestion that she do something self-destructive.

After this I realised that it wasn't overkill to think that she needed someone around her, and we simply couldn't find anyone who was available to do it other than me. As I had a fairly senior role, I was able to negotiate to work part-time from home, and we managed it that way for a while, but the writing was on the wall – I would have to leave work as soon as I could arrange to, and so I did.

Finding things you can do to earn money - either from home, or in a role where you can take someone with you – that fits in all ways with the demands of being a carer, is actually a very difficult thing to do. I happen to be a resourceful, multi-skilled person, and I found it impossible to earn an amount I could live on as a carer with a mortgage within the constraints of my caring role.

I tried a number of things over the years, but in general, even though I persevered for a long time on each, by the time I had set up the infrastructure and then covered operating costs, it ended up costing me more than I earned overall. Small business is challenging for anyone, and when you are trying to juggle being a carer, it is like operating with one hand tied behind your back. As a result, after eight years of struggling, I exhausted my financial reserves, reached a point where I couldn't continue to try to support myself, and had to go on the Carer's pension.

The pension paid me around \$325.00 a week and my mortgage was about \$240.00. It isn't difficult to see that it is untenable to try to cover all the costs of living on \$85.00 per week.

Over the three years that I struggled on the pension, I went steadily deeper into debt, placing bills such as food, water, electricity, fuel, car registration, car and building insurance, and all the other sundries of life on a credit card. I used cash advances from the credit card to pay the monthly minimum on the card, to avoid extra fees being applied and to maintain this temporary source of funding. I had never used or even kept credit cards previously.

I didn't shop for myself (apart from essentials such as basic food) for years, but despite all these privations, the situation was unsustainable and I knew it. I also knew, however, that this lady relied deeply on me to make her life ok. She had a child-like trust in me, and she had developed a great sense of security in my care. It broke my heart to think of having to tell her I couldn't continue to look after her. The only reason I was prepared to allow the frightening credit card situation to develop was that I didn't want to have to tell her that.

I knew there wouldn't be a care environment anywhere that could cater to all her special needs. I could hardly imagine what her suffering would be like when she was not protected from all the things that we knew messed her head up so badly.

I was hoping to find some kind of home-based business from which I could earn enough to support us both so I could stop living beyond my means and recover my situation. The cards were buying me time while I tried to do this.

However, when I had filled my second credit card up to the value of \$10,000, I knew I had to draw a line in the sand. I was not prepared to apply for a third card – to do that would be just to store up terrible trouble for both of us. We had run out of time. I began trying to think of what options there were for her care apart from me, knowing I needed to go out and get a solid job to try to recover my position. I was now 49 years of age, and worse than penniless – I was \$20,000 in debt on cards.

I told her that I was going to have to get a job and that we were going to have to find somewhere else for her to live, since she couldn't be alone. The news was, of course, frightening and bewildering for her, and it robbed her of her fundamental sense of safety in her world.

### **An alternative care arrangement**

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A friend helped me research the possibilities, and we found that there was nowhere other than an aged care facility where she could go. At 55 years, she was 10 years too young.

To get into such a facility, you have to have an 'ACAT assessment' (by the Aged Care Assessment Team). I approached ACAT and got a flat 'no' – she couldn't be considered because of her age.

The story of what I went through over the following four months of arguing with ACAT and jumping through the many hoops in order for them to consider this lady for assessment, is beyond the scope of this report (although I did document it at the time). It was a stressful, traumatic and inappropriate process, and it led me to conclude that the procedure of trying to obtain care for someone is probably deserving of an Enquiry itself. This document is available if required, and it makes interesting reading.

Finally, this lady was approved for an ACAT assessment, and since I had to return to work, and she would be without a carer, they eventually reluctantly agreed to her admission to one of their aged care hostels.

There were reasons why the location of some was much more suitable than others, and the one we most needed her to get into was full. We were offered the opportunity for her to go to another, brand new one, until a vacancy arose. It was 59 kms away from where we lived. We had to accept this interim arrangement because I had been to some job interviews and had been offered a job. I was due to start in a few weeks, and I needed those weeks to help her make the transition to care.

It turned out that she was in fact the very first resident in the new facility, and she was the only resident for about a fortnight. The shock of staying in a strange place away from me and being looked after by people she didn't know was bad enough, without the added dimension of being the only resident in a large four-storey complex – with a one-to-one nurse. It meant that I needed to stay with her all day every day until other residents started to arrive.

One-to-one may sound good, but it isn't for her, because of her special needs. We began to experience what we knew would probably happen; that you can't get people to understand that her head can't take lots of conversation. People naturally talk. By being alone with a carer, she couldn't avoid having to talk and listen and relate much more than she could cope with, and that was a big risk factor for her.

### **Centrelink**

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I had had to notify Centrelink that she had left my care and gone into an aged care hostel. I understood the rules said that they would cut my carers allowance as a result – reducing my income by \$90.00 a fortnight. It was a terrifying prospect. I was so far behind financially already, and was trying to avoid being forced into starting a third credit card.

I went and saw Centrelink and explained that this lady was in a hostel, and there were no other residents there, and I needed to be there every day until she could settle, or the whole thing may fail. I told the girl that I was now driving 120 kms a day and had all that extra fuel to pay for on top of my usual living expenses. I pointed out that life was more expensive now than when she was still in my care, and I already wasn't coping

financially before. I asked if I could be given special consideration in the light of the extra cost of fuel, and be allowed to keep the carers allowance, even though she had left my care. She said 'no'.

I pushed the issue and said surely there must be some discretion possible. She said she would go and ask someone else in the office, then came back and said there wasn't any discretion. The news was made harder to take by the fact that she didn't seem to care.

I left and was quite distressed. The pressures seemed too great to bear.

As any carer knows, especially if they are caring for someone with a mental illness, you need to appear calm to the person you care for. I could not let my lady know of the pressures I was under, or of the many trials I was facing from authorities on all sides. It was important that she didn't see my distress or learn of the countless obstacles I faced that threatened to prevent her from having an adequate care option. The need not to let any of this show requires you to be super-human.

### **Settling in the new place**

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I visited and stayed with her at her new hostel eight to ten hours a day every day for the first fortnight. She has such little tolerance for the unfamiliar that I knew I needed to be there creating familiarity until she could develop some sense of familiarity herself with her environment. New residents finally started to arrive, and one by one, each of them turned out to have dementia and to be unable to be any company for her.

I started staying fewer hours and then skipping a day here and there, as the day for my job to start was approaching. There needed to be a gradual process of reducing her need for me to be there. She was very co-operative with this process, showing the courage that is so characteristic of her.

I started work and she battled on on her own with me going there each night for tea and for the evening, so we were seeing each other. We had regular brief phone calls during the day to keep contact also. She tried hard to make it work, she tried to please the staff, and she tried hard to settle in, but after a number of weeks she fell into a deep depression, became at risk of self harm and had to be hospitalised.

I was then trying to juggle supporting her in an acute adult mental health ward, with trying to rise to the challenge of a new job, while also being somewhat rusty in relation to being back in the mainstream of life and the whole professional scene. Being a carer in an intense carer role is incredibly isolating. You can actually lose your social skills a bit. I also wanted to ensure I did justice to my employer in the important role I had taken on. I had a lot on my plate.

We muddled through, and after a few weeks in the mental health ward, a place came up at the aged care hostel we had initially wanted her to get into, which was good because she felt completely unable to return to the first hostel.

Concerned that she wasn't really ready for discharge from psychiatric care, I explained to the manager of the aged care facility that this lady was in hospital after not coping at the other hostel. I was told that unfortunately she would be unable to hold the room for her. Unless she took the position up within a few days she would give it to someone else. We couldn't afford to lose it, but I was also worried about getting off on the wrong foot by her trying to be there if she wasn't psychiatrically well enough.

As happened so often, she put in a huge effort and told me she'd be alright – she'd manage going there, even though she didn't feel completely stable in herself. I knew that she was quite worried about going to this second hostel because she had been so negatively affected by her first experience, but she rose to the occasion.

### **Centrelink again**

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The second hostel was only 40 kms from home, and it tied in a little with where I was working, so some of the pressure was relieved for me in terms of travel.

To go into a hostel, you need to pay four weeks rent in advance. Luckily for us (since neither of us had any money) because the first hostel was brand new, their accounting system wasn't set up and they didn't ask us for any rent for weeks. However when they did finally bill us, we had to pay three weeks arrears on her rent as well as four weeks in advance. To cover this we needed to find a massive \$2,500.

Despite all my other financial pressures, my first three fortnight's pays needed to go straight into paying her accommodation. She didn't have any money, and she wasn't going to be able to keep her place unless I came up with the money.

Because of all these financial difficulties, I had to leave it till the last moment I legally could, to inform Centrelink that I had started a job. I needed to delay for as long as possible losing what was left of my income support – the Carer's Pension (I had already lost the Carer's Allowance weeks before) so it could help to bridge my ongoing expenses until I received a pay. You are required to tell them not later than 14 days after starting a new job that you have done so. I left it till the 14<sup>th</sup> day and then notified them. I was chided for not telling them earlier, but I knew I hadn't had a choice. I was trying to stave off losing the house.

I explained to them that I would be spending all my pays for the next few weeks paying for this lady's accommodation bill, and that there were accumulated debts of my own to pay off after that. I then asked if they could allow me an exemption from having to repay the extra fortnight's pension I had received by not notifying them before I actually started work. They said that wouldn't be possible – I would have to repay it.

Sure enough, a little while later I received a bill from Centrelink demanding that I pay back the fortnight's overpayment. I wasn't able to; I was still devoting every penny to paying this lady's accommodation bill.

I actually felt too exhausted to appeal, but it also felt like a deep injustice that there was no give-and-take from Centrelink towards me after all I had given over many years, and in the light of the huge costs I currently had to pay for this lady.

The principle seemed important to defend, and anyway, I couldn't pay the bill, so that tipped the balance in favour of appealing against it. Despite the limitations of my low morale and overwork, I was still able to feel faintly curious as to whether any compassion or consideration could arise out of their appeal process.

My memory of the process is a little vague now, but I had to fill in a form where I explained everything and asked if I could be exempted from having to repay this fortnight's overpayment. A customer service officer rang and told me that my request had been declined. He told me I could appeal, and asked me if I wanted to. I said yes, and he recorded it on my file as their decision not having been accepted by me, and a review requested.

After a few phone calls from different officers (where I again pleaded my case each time), I finally received a letter and a six-page 'Decision Statement'. This explained all the details of the investigation and what legislation they had relied upon to determine that they could allow me to be let off for \$194.10 of the bill, but the remaining \$465.86 was my debt and I had to pay it.

I have now been working and receiving an income for eleven months, and in that time I have been steadily trying to recover my financial position. I still haven't quite been in a position to pay this bill yet, and I am waiting to be contacted and notified that it is well overdue and that I have now incurred overdue interest charges and fines and things.

## **The second hostel**

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Now in her second hostel, the lady I care for began the long and difficult task of fitting in and getting to know people. As with the first hostel, most of the residents had dementia and that was hard for her. Their constant repetition of questions, and their confused and often bizarre conversation triggered quite intense agitation in her. This was exactly the kind of thing that our experience had taught us she could not tolerate.

Our first impressions were very positive – the place seemed clean and orderly, and it boasted a very appealing décor, however when it came to management of her there were constant problems from the beginning. Care was provided by a rotating roster of about 15 different people. Some were reasonably caring and sensitive – many were not.

The hostel would frequently run out of her tablets, and she would have to suffer headaches or nausea, or other symptoms, without the support of her prescribed medication.

The failure to supply her routine medications became so serious at one point that I had to put my concerns in writing to the manager (see Attachment A). Despite my efforts to be respectful and diplomatic in what I wrote, my representations were not really appreciated.

I received a written reply from the manager explaining that it was partly the fault of the chemist that there were so many errors in the Webster packs (errors in the Webster packs were common, but an equally

common problem was the hostel allowing her medications to run out and not bothering to ensure a new supply was obtained). The manager told me that because of these errors they were going to change to another chemist.

This, however, never happened, and the medication errors just continue.

As a result of asking hostel staff to ensure that her prescribed medication was made available to maintain her mental and physical health, I became 'persona non grata'. It seemed that the more I tried to ask for some basic standards of care over time, the more unpopular I became. This introduced a new layer of stress both for me and for her.

A shortage of nursing staff meant she was co-opted into helping other residents with tasks like filling out their menu requests each week. Under our previous arrangements, it wouldn't have been recommended that she even filled out her own.

She felt out of place from being too young. Most of the others were in their late 80's and 90's, and their children who came to visit were older than her, being in their 60's and 70's!

It was nothing like an ideal environment for her, for many reasons, and I spent a lot of time and energy helping her to deal with the many challenges that confronted her.

After a few months a friend wryly commented to me, 'no-one told you when you started your new full time job that you'd still have to do your old full time job'.

Because of having so many people around her, each day by lunchtime the lady I care for had what she described as 'mental exhaustion' – her head would be completely overloaded, it would spin and hurt and she would feel like it was going to explode. She would feel quite beyond her ability to cope and couldn't do anything other than sleep all afternoon, and hope no-one would come and wake her or talk to her.

She would have managed better if she had been able to spend each weekend at home with me. The peace and quiet at home, and the lack of any conflicts around medications, strengthened her to cope better with the weekday situation. However, the aged care guidelines only allow residents to be absent from the hostel 53 nights a year – or one night a week, if you didn't have any other absences in the year.

Staying home each weekend would require twice that many nights away, unless I made a special trip down on Saturday morning, and returned her Sunday evening. This creates a whole lot of extra driving for me, compared to picking her up on my way home from work on a Friday, and eats into my weekend quite significantly. She also gets less benefit with only one night away, compared to two.

### **Her health status deteriorates**

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She persevered from November 2007 until May 2008, when she had a disturbing episode. I had been feeling that the daily denial of what she really required would gradually build towards something serious. I knew from years of caring for her that you can't break those rules and get away with it.

In April her headaches were getting worse, and she had a few strange neurological signs, so I got a referral from her GP for us to see a neurologist. Despite all my attempts to secure an earlier appointment, the first one we could get was in October – a 6 month wait.

In mid May she developed a migraine headache that was more intense than her usual headaches, and was accompanied by a feeling of pressure in her head.

Her head got worse and worse, until after another week or so she was lying holding it in the middle of the night each night, and crying with the pain. Her conversation became slightly confused, and she collapsed in the Bank one afternoon. After two weeks of this, (and me taking her twice to her GP, who said just keep taking the headache tablets), she had a major amnesic episode. The hostel rang me at work to say there must be something wrong because she didn't know who any of them were.

I came immediately and found that she didn't know who I was either; she couldn't even tell if she had known me for a long time or if she had just met me. She didn't know who was in her family, or where she lived. She knew nothing.

I got the doctor's agreement to arrange for her to go to hospital, as he had advised the hostel just to monitor her overnight. She was then admitted to the neurology ward where she remained for almost two weeks. She



began to regain her recognition of people on about the fifth day and fortunately she regained all her memory gradually over the next three weeks.

In this episode she also lost her ability to co-ordinate her feet and legs and needed physiotherapy to be able to walk again.

Strangely enough it wasn't a stroke, and no brain event could be discovered on scans other than damage to the twelfth cranial nerve, which only explained a few of her symptoms, and not the memory loss or the loss of co-ordination. Her neurologist later said he could only put it down to being some kind of migrainous event.

Her headaches continue to be a problem, and as time passes she is gathering more and more neurological symptoms. She is now restricted to lying in a dark room most of the time to prevent a worsening of her migraines. She is unable to watch television for more an hour or two anymore, as it now causes her to feel agitated. This is serious, as TV has been a lifeline in giving her something to fill her day.

Although her memory returned, now, six months later, her comprehension is not what it was before and she gets easily confused even when trying to work out very simple tasks. She has since also had two two-day episodes of delirium or temporary dementia.

I am starting to realise that, since the many scans and tests haven't provided an explanation of why all these symptoms and events are occurring, it may simply be a result of the chronic over-stimulation she experiences when exposed to situations of ordinary everyday life, as she is at the hostel. When I think about it, experience has taught us that it is the kind of thing that will happen when she is not protected from all the little demands of daily life.

### **The care option breaks down**

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In September 2008, she started saying to me that she doesn't feel she can cope with the stress of never knowing whether her medications will be available, and the other general stresses of the hostel environment from both residents and staff. The strain of being there is starting to make her depressed, she said.

Now in October – almost a year since she went to the second hostel – she has said to me that she doesn't want to stay there anymore – she needs to return home where she is not over-exposed to interactions with others, where her ability to sleep and rest isn't prevented by a rigid daily routine, or the disapproval of staff, and where there is consistent sensitivity to her special needs. She is home this weekend, and she is saying she doesn't want to go back to the hostel.

This places me in a difficult position. I believe that she probably does need to come back home – I am starting to think that her serious neurological symptoms may not resolve until she returns to the quiet, peaceful environment of home, since none of her symptoms have responded to the numerous medications the neurologist has so patiently tried.

She has genuinely put in a huge effort to try to make the hostel work, and it hasn't – partly because of her special needs and circumstances, and partly due to the standard of care being provided at the hostel.

However, the situation that made us seek care for her in the first place hasn't changed: I cannot be at home (I cannot afford to leave my job), and she cannot be at home alone.

As I began to realise that she probably does need to return home, I first felt a little panicky. Then I reassured myself that I had heard lots in the media lately about how important carers are, and how much the government and the community values them, and that there are lots of resources available now to support them.

I met someone whose husband is in a wheelchair, and even though they both work full time, they get 15 hours a week of in-home support. A person comes each morning and helps him to get dressed and whatever else, and they also help with housework etc. Even though this family lives in South Australia, I brightened when I heard their story, thinking that perhaps there really is help out there now.

### **Looking for supports**

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I started to think that if I could get someone to sit with the lady I care for, or even just do housework around her so she is not alone, it may be manageable for me to have her back and keep working.

I began investigating what kind of care package may be available to us that would allow me to remain at work, with her having someone at home with her. I estimated that we would need a minimum 15 hours per week. We could probably manage on this basis. It does put a lot of strain back on me, but this probably cannot be helped. There is a lot of strain on me anyway, even while she is at the hostel, because of the significant care issues there.

I had applied back in January 2008 to my employer, a State government department, to work a four-day week (10 hrs a day) instead of my present five-day (8 hrs a day) week. This was partly so that I could have a day off in the week, working four days, having her for two days, with one day to myself. In August I still hadn't received a reply, despite numerous gentle reminders from me. I then wrote a letter to my manager formally requesting that a decision be made, and explaining that my request is partly due to my responsibilities as a carer. It is now October and I still have heard nothing.

At this point, with the lady I care for probably having to return home, the four-day week has become essential for me. I knew better than to think that we would get enough hours of support for her to have company over five days – four would be the most we could cover, and I felt instinctively that this would be a stretch. My four-day week would mean I wouldn't get home till late in the evening, though, and she would definitely need someone with her.

I googled 'respite for carers', and rang an agency whose details came up. They told me they only provide a service for people with physical disabilities. I then found one that catered for people with mental illness, and spoke to the woman who told me if I was lucky I may get 2 hours support a week.

I then decided to go direct to government and contacted the Commonwealth Department of Health and Ageing's 'Carers Helpline' – incredibly you only get an answer machine when you ring that. One time previously it took a fortnight for someone to ring me back.

The Department's website says that 'Commonwealth Respite Centres are located around Australia to help people find care and support to continue living independently in their own homes' – this sounded promising. When they rang they told me that they fund Commonwealth Respite Centres to provide respite services, and for me to contact them.

I rang the Respite Centre and was told that I could apply for some support but they only provide support in the short term, they couldn't guarantee what would happen in the long term. Furthermore, it would usually only be a couple of hours a week at most. They asked how many hours I would need, and I said a minimum of 15 hours. They said perhaps I could get 5 hours at a pinch, they couldn't be sure. They offered to mail me their information.

The more agencies I spoke to, the more I found that there was going to be little support available for us. I would lament this fact when talking to them, saying I thought with all the positive publicity and promises about carers that there would be resources, and virtually every agency agreed, saying 'yes, it all sounds good doesn't it, but in reality there are almost no services available'.

Each of them said probably two hours, and some said maybe up to five a week if we were lucky.

I am becoming anxious, and thinking, 'what if I am not granted the four-day week?'. I still don't know whether I will be. My manager has told me it is unlikely. With me at work five days it just wouldn't work – that is too many days alone in a week. A month down the track she would be depressed, lonely, isolated, at risk of self-harm and then hospitalised – and we would have relinquished any place in the aged care system, with little hope of being offered another as a result.

I am starting to feel a sense of constant strain as a result of the scary prospect of having no good options, and the burden of fearing what may befall her.

It is possible that while ever she is at the hostel her neurological condition may remain untreatable, and she may gradually become a high-needs resident with a tragic and preventable level of suffering in line with her current symptoms.

There is also the irony that it would be cheaper for government to provide me with 15 hours care a week than to pay for her to be at a hostel AND she is taking up an aged care bed, which are in terribly short supply.

All these problems could be solved by a simple allocation of 15 hrs of support a week, but from what every care provider has told me so far, this seems quite unachievable.

While getting increasingly depressed and frustrated by the lack of resources, I would read documents like the State government's Policy Directive (Document Number PD2007\_018) 'Carers Action Plan 2007-2012', which says 'Our plan includes significant new support for those living with mental illness and physical disabilities, as well as expanding measures to support carers'.

They claim to have a 'clear and consistent philosophy', that 'carers must not be taken for granted. And the best way to acknowledge and honour our carers is to offer them more support and better support'.

They acknowledge that 'Carers are more likely to be unemployed or not participating in the workforce than non-carers'. I was a case in point, able only to perform part-time work for the first eight years, then out of the workforce altogether for the last three years of caring for her.

They specifically state that carers will be 'supported to achieve physical and emotional well-being and to participate in work and community life'.

The policy declares that: 'Carers are supported to combine caring and work', with 'strategies that support carers to combine caring and work including mechanisms that promote family friendly practices in the workplace and the provision of flexible services to support working carers.'

From my point of view, and no doubt from that of many others, it's just not happening - it seems like a whole lot of rhetoric.

The same policy document says that they have allocated \$556,000 recurrently to develop the capacity of NGOs in NSW to respond to carers; that Local Area Health Service initiatives to identify carers and raise carer awareness through Carer Support Services has been funded \$2.4m per annum; that there are a range of respite services funded through HACC and CSTDA (over \$150m recurrent); that increased support services to family and carers through NGOs is receiving \$3m recurrently; and that Direct support to carers through NGOs funded under local carer grants totals \$3.7m one off, in total.

This is a lot of money. How is it that with all this, they cannot provide 15 hours of support a week for me to remain at work, and this lady to have an environment that meets her needs and relieves what is currently a significant burden on the health system? One wonders how all this money is being spent if there are so few actual services on the ground.

I began to realise there wasn't, in fact, going to be much support available and I had better think laterally to try to find a solution. Where could she go out to, to have company and some interest in her week that wouldn't place demands on her that would overwhelm her? She would probably be able to cope with one day a week at a senior citizens centre if it was fairly quiet and orderly, and she only had to do what she felt she could.

I went to such a centre and found it alive and buzzing with retirees. It was loud and busy and I was told 'no dementia, must be able to walk around and care for herself'. At first I figured she may cope with going there for a few hours a week, once she felt familiar with the people and the place. Later when I thought about it, though, I realised it was probably *too* 'alive' for her – these retirees would definitely want to chat in an animated way and she wouldn't cope. I relegated it to the category of 'only to revisit if we can find nothing else'.

I did ask while I was there if they provided any transport, and they said, 'no – she would have to get herself there'. This would rule her out, so I enquired if there may be anyone coming from our area, and the volunteer told me there wasn't. It didn't seem like the kind of arrangement they encourage.

I asked this volunteer what else there was and he referred me to the local 'District Activity Centre', and gave me a brochure. I felt hope again as I read their brochure. It sounded ideal. They provided day activities, and outings, and meals AND transport, and their brochure says 'The District Activity Centre is a Home and Community Care Program (HACC) jointly funded by the State and Federal governments . . . HACC provides a range of services to people who are frail aged, people with disabilities and their carers'.

Frail aged was more the right kind of group, because they wouldn't be so chatty – she needs quiet, friendly company – and if they were participating in outings, they may not have dementia. I rang them immediately, thinking they would probably become an important part of our answer. The woman who answered told me that they only provide a service to frail aged, and unless this lady was over 65 she wouldn't qualify.

In vain I quoted their brochure back to her, saying "it says 'people with disabilities and their carers' – this lady is on a disability pension, and I am her carer" – she corrected, "that's frail aged *with* disabilities". "Then, the brochure should say 'frail aged AND with disabilities'", I protested, "because it reads like they are two

separate categories". She insisted that their funding is specific in saying that they can only cater for frail aged – over 65. If they took anyone under that age they would lose their funding.

She added (salt to the wound) that they do have some younger ones but they have been coming for a long, long time – no new younger ones, it is specifically ruled out in their funding guidelines.

I had to go to the doctor and while there I scrutinised their noticeboard for resources for carers. There were lots of them. Most of them I had already canvassed and we missed out for one reason or another. But there was a community transport option there I hadn't rung yet.

When I got home I rang them, thinking that if I could get transport, perhaps I could arrange for her to be transported to the senior citizens programme that doesn't do transport. The transport people told me we may or may not qualify, they weren't sure, but I could apply to be assessed. I put my name on the assessment list. I will be assessed over the phone in two or three weeks, and we will be notified of whether we qualify for a service a week or two after that.

As one-by-one we became ineligible for all these options, I then started to wonder about whether I could just pay someone to come and be with her, and help with the washing, cleaning and housework. I made an enquiry of one service I heard advertised on radio - 'Just Better Care'. Their rate is \$37.00 an hour. Unaffordable.

On the question of me paying someone to 'mind' her, though, I have to say that I have given a lot to this lady over the last 12 years – sacrificed a lot of opportunities to participate in society, spend time with friends and family, earn an income and to do what I want with my own life. I really don't see that I should have to now pay someone to mind her so I can go to work, even if it was affordable. It seems only right that I should receive some support from the community to look after her.

And that is where we are up to. I have rung many, many agencies only to be told that she is either out of area, or would have to be frail aged, or over 65 years, or that the service is only for people with dementia, or that for some other reason we are not eligible. The lady from the HACC information line said, "it is hard when they need a service and there is just nothing out there for them".

I can hardly believe the myriad reasons for being disqualified for a service; the almost complete lack of support available to allow me to remain in the workforce and be a carer; the inappropriateness of the lose-lose situation for her, for the community and for government that my lady's circumstances comprise; and the falsehood of the impression given in the media about carer resources.

Standing back and looking at the whole experience since I have had to return to work, I can only say that encounters with the so-called support agencies – Centrelink, Aged Care Department, aged care Hostel, Department of Health, even some of the NGO's responsible for service provision – leaves you feeling like a soldier bloodied from battle.

It all causes me to wonder about government, and about the notion of community, and about the values we say we hold as a society.

## **What to do?**

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Now I don't know what to do. I am torn. I don't find it easy being a carer. There are many sacrifices you must make on a daily basis. I would rather live alone and only have to think for myself. I would like to be free to just go out when I want to, and be available to dedicate myself to the projects I am, or would like to be, involved in.

However, this lady is really seriously debilitated from being in care in an institutional setting. She has aged ten years in the last year. She cannot get her basic needs met at the hostel. She doesn't want to be there and realistically she is not coping there anymore.

I have the dilemma of knowing that if she came back home, her neurological symptoms may well resolve over time. That makes it hard to leave her there.

But I know from past experience that I cannot live on the pension, and so I don't have a choice about leaving work. I cannot relinquish my job.

If I was able to receive 15 hours support a week, I believe we could manage without me ending up compromising my health.

It appears that the most support I can count on is 2 hours a week. I can't see her coping with being alone so much, and I cannot manage to look after all her personal care and work full time with that level of support.

At the time of writing I can hardly imagine how we are going to resolve this terrible dilemma. The most likely thing is that she will leave the aged care hostel, that I will lobby and lobby until I get 5 hours of help a week and then we limp along with that half-baked arrangement, but I think it is really unacceptable that it should be this way.

Not having adequate supports sets her up to fail, and it makes it likely that she will end up having regular hospitalisations – a distressing experience for her and I, and an expensive outcome for the community.

It makes all the representations we see in the media about the importance of carers, the commitment to resource them, and the actual claims that support is available, appear untrue.

## **Conclusion**

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I have gone into this amount of detail because I feel that without it, it is very hard for a non-carer to ever stand in the shoes of a full-time carer. It is the kind of role where you actually cannot imagine the difficulty involved without actually being in that position.

This Enquiry is an important opportunity to develop some real understanding of the enormous pressures and pains of being a carer, so I offer this story in the hope that it adds to the development of this understanding.

## **PART TWO**

### **Further observations about the reality of being a carer**

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There are lots of difficulties and deprivations that come with being a carer if you do not have some secondary form of income support apart from the pension. Apart from the loss of freedoms, the other sufferings result mostly from poverty.

I came to realise that whether the pension was adequate or not depended a lot on whether you fully own your own home. If I did not have mortgage or rent payments to make, I could have lived alright on the pension. You still wouldn't be able to afford to participate much in society, but you could manage your basic bills if you were very careful, and you could get by without accumulating debt.

Many examples of these 'difficulties and deprivations' you encounter in everyday life couldn't have been included in the story above without it becoming too long. However, they shouldn't be overlooked, because they inflict additional suffering daily on the carer that adds a bitter edge to the other sacrifices made.

For this reason I will briefly list some of the other demoralising events and realities that came with being a carer, for me. These are just a few, the ones that easily come to mind, as there is a never-ending stream of them – in fact, daily life is made up of mostly of hardships for carers who have only the pension, and who have either a rent or mortgage to cover.

At home, the guttering on the house is so rusted that there is a risk of flooding of the residence whenever it rains heavily. On two occasions it has actually flooded, resulting in some of my furniture and belongings, and the carpet, being ruined. I have dug trenches and installed rainwater pipes to try to improve the drainage, as this was within my means to do. It was hard physical labour, and it was weeks of work, and it is not a complete solution, but I had to do what I could to mitigate the problem. It won't be properly resolved, and the risk of flood removed, until such time as I can afford to get the guttering replaced. Until then, I am always anxious when it rains.

The pipes are rusty and produce rusty water and we live with that. I did an online search and found that consuming rust isn't harmful, so we run the tap if we've been away for the day and clear the worst of it, and overlook the rest.

As a carer you live in fear of something going wrong which would require a tradesman. We had a serious problem with our septic tank when the absorption pit failed. It started with a soggy patch in the back yard and ended up a week later with black maggots crawling up out of the toilet bowl. I had never seen anything like it! You can't convey the sense of panic and powerlessness that rises up when you are confronted with a major

health threat like this, with the knowledge that you have no capacity to do anything about it. I decided just to get a plumber in to tell us what was wrong, knowing we couldn't actually get it fixed, but I felt we at least needed it diagnosed. I explained on the phone that we were only seeking to have the problem identified, and that we wouldn't be able to get him to fix it, so that he wasn't coming out on false pretences. He came out and told us what it was, and thank heavens, was also able to tell us that there was a welfare fund within the water board to help people who had a serious problem and couldn't afford to get it fixed. I had never heard of this. The water board resolved the whole problem by putting us on to the sewer without charge. It doesn't bear thinking about what would have happened if this fund didn't exist.

We lived without a fridge for about two months when it broke down, and was going to cost more to fix than it was worth. Finally a relative gave us one they no longer needed. Living without a fridge is not easy. There is a terrible sense of doom when something essential and expensive like a fridge breaks down, and you have no idea when you may be able to replace it or get it fixed.

I had dental problems that remained for 18 months till my mother paid to have them fixed. My mother has helped at some crucial moments; I don't know where I would be without her.

It is depressing to hear the Harvey Norman and Bing Lee ads on radio or television, as they itemise interesting-sounding consumer goods that you know you cannot have any of. Watching Getaway on TV can also get you down, as you are reminded that other people have holidays. (As for many carers, I haven't had a holiday in the 12 years I have been a carer). For me, watching shows like Getaway wasn't all that depressing because it was so far out of my reach I could just enjoy seeing the places, knowing I needn't even contemplate the possibility of ever going there myself. However, there is a tangible sense of being excluded from life and from society, that is inherent in watching these great things on TV.

It is the same with plays and movies that are advertised, and interesting-sounding places like the zoo. Hearing about them just makes you feel alienated, and sad that you are unable to participate. There is a sense of anger too, at the imbalance and injustice of society, when you hear of politicians spending money wastefully, or on unnecessary things, or highly paid bureaucrats gaining a pay rise, or someone being paid millions of dollars for playing cricket or winning a game of tennis. There is a quiet sense of rage and despair, to think of that money joining all the other money in their accounts, where it won't even be noticed, yet what a difference a tiny fraction of it could make to your life. It always used to make me worry for all the carers sitting in their lounge-rooms listening to these things. I would worry about them having to endure the terrible injustice of it, and I would worry about how demoralised they must feel at being unrecognised and unsupported by the wider society.

Living with broken appliances and a falling-apart house that you cannot do anything about is just depressing. The sense of an endless future caring for your person, and your life being confined and defined within that role, while being bound unavoidably to poverty, is depressing.

The inability so often for others to understand the needs of the person you care for, or the constraints it puts on what you can participate in with them, is depressing. You see your other relationships suffering and declining and there often isn't much you can do about it.

I missed out on participating in countless interests and events because I couldn't go out anywhere unless I could find someone to mind this lady for me. That isn't easy to do. Sometimes in the evenings I could take her to her brothers to stay so I could go to a meeting of some kind, but he lived a long way from where we did, and to go out I would need to take her to his place beforehand and then go back there to collect her after. Having every outing preceded and followed up by going via his place kind of undermined the sense of freedom I could have gained from going out, and meant going out was often more effort than it was worth.

I did at one stage place an ad locally to find someone to come to our place to be with her, so I could go out. This started out alright, but broke down when the young woman stole some of our belongings, with the assistance of the lady I care for, who helped her carry them to the car when asked to!

Apart from all the things you cannot have or do as a full-time, pensioner carer, there are also the trials you face when interacting with services and institutions, such as the following.

One day I had to take the lady I care for to a physiotherapy appointment at a major public hospital. The car park was too far for her to walk from, so we stopped in the 'ten minute parking' out the front and I took her down to the physiotherapy section. She wouldn't have been able to find it on her own, or cope with talking to the staff on her own. Once there we were taken straight in, and so I had no opportunity to return to move the car. I got a \$79.00 fine. I appealed against the fine, explaining the circumstances, and my appeal was refused. I even pointed out the irony that it had been incurred during Carer's Week. I do believe that special

leniency should be extended to carers in such circumstances. You are often dealing with problems that prevent you from complying, and incurring fines on top of everything else is very demoralising.

It can be a real problem getting hospitals to talk to you when you aren't a relative. In my case, though, my lady was so clearly reliant upon me, and she was unable to give them accurate information about her own health, that generally medical wards did share information with me. Even though she came from a big family, no other family members assisted with her care. They struggled to understand or accept mental illness, and found it easier to criticise our handling of the situation than to get involved and help, despite requests from us.

Adult mental health wards have been, in our experience (and the experience of many others, see the 'Not for Service' Report), unhelpful environments, and they actively exclude carers. The new Mental Health Act promised to improve this situation, however, unfortunately the Act only states that carers must be consulted if a patient is scheduled (held as an involuntary patient). Once the schedule expires, or if the person was not scheduled in the first place, there is generally no collaboration about treatment, discharge or post-discharge support.

Even though I am working full time, I still have a lot of responsibilities for the lady I care for. I have her home each weekend and provide the transport for her to get there and back, I organise and take her to all her medical appointments, and go in with her because she wouldn't be able to understand what the doctor is saying, or know what to ask, or remember what she needs to do. Despite all this, and the fact that I have previously been on the Carers Pension for three years, I don't qualify for carers leave at work. Under the provisions of the NSW Industrial Relations Act 1996, carers are defined as being one of the following:

- spouse, de facto spouse or same sex partner
- child, including adopted, foster, ex-nuptial or step child
- parent, including foster parent or legal guardian
- grandparent
- grandchild
- sibling

I am not any of those. As a result, I have to take this lady to her medical and specialist appointments in my own time. There are a lot of these appointments, even more so as her health has steadily declined, but there always were a lot. The hostel would only put her in a taxi or an ambulance – they are not staffed to attend appointments with a resident. This would never suffice for the lady I care for, so it leaves me with no choice but to take her.

One thing I often reflect on with awe is that my situation is easier than that of so many carers. The person I care for is likeable, yet the caring role has still been enormously difficult and demanding. I cannot imagine what it must be like to care for someone who is not very likeable, or who has intolerable behaviours that continually push you beyond your limits, as many carers do. It must be soul-destroying. I have a great respect for the carers who do this, and I feel pity for their plight. It isn't enough to sympathise, though, we need to see change that relieves them of having to be in a situation that is too much for them.

## **General Observations**

As a carer, you end up feeling like you are in a straight-jacket. Even putting aside for a moment all the practical demands of being a full time carer, you are surrounded by a million things that don't work, which also have a domino effect of making other things not work, and there's nothing you can do to remedy any of it. This is quite torturous when you like things to work well. It is oppressive, and the carer becomes debilitated by it.

Carers often feel alienated from society. It feels like anything and everything that everyone else does or has is denied you, and you do begin to feel like a social outcast, excluded from the community through a combination of poverty, and the limitations of not being able to do anything you couldn't take the person you care for to - with nothing you can do to change the situation.

Even if you have a good earning capacity, as I do, being skilled in a number of things, the role of being a carer saps your energy. The relentless 24 x 7 nature of the carer role is oppressive. It eventually renders you unable to do the things you would have had the energy to do years before, at the start of your role, to relieve some of the hardships that come with being a carer. There is the limitation, too, that you can't earn more than \$68.00 a week without losing some of your pension, and that undermines any motivation you may have been able to muster to try to improve your lot.

That sense of depression that comes from being 'sentenced' to being a carer forever with all the privations that go with it, is significantly ameliorated if you are able to participate in the workforce. Not only do you get some income, but you have a life. You are out in circulation, your skills are being used and developed, and you don't have to feel that life is passing you by.

The lady I care for would not be aware of the extent of my sacrifice for her, or of how challenging I find the caring role to be. Friends and family can be preoccupied by what they miss out on by virtue of your caring role, and so they, too, can be limited in giving appreciation for what you do. It can be a lonely path. As a society, we need to be mindful of the suffering, and the threats to mental health, of those who care.

Those who care need to have someone who cares for them, and in many instances, this has been missing. It is no wonder that in the national happiness study, carers were found to be the least happy and fulfilled people in society, with a low morale score significantly lower even than the unemployed. You are fully employed, over-employed in fact, unpaid, and struggling in a whole range of ways. The two words that best characterise the plight of many carers are poverty and powerlessness.

After all this gloom, though, it must be recognised that there is a positive side. It is rewarding to experience the love and security felt by the person you care for, towards you. It remains one of the greatest things you can do on earth to care about others and to improve their lives in real ways, and there is great opportunity for personal growth in being a carer.

All that has been said so far could apply to any carer who is on the pension, has no secondary income, and is paying rent or a mortgage. That is, whether they are caring for a person with a physical or intellectual disability, or a mental health issue, the experience is probably similar.

Each of these caring situations also has its own unique challenges, though. For someone who is caring for someone with mental health issues, there is often an additional load of worry to cope with.

Clinical depression is a dark and dangerous thing. The journey through the seriously down periods is a long and challenging one for both the sufferer and the carer, as you work together to try to bring your loved one safe out the other side of each episode.

Obviously spending huge amounts of time and energy with someone in this state does affect your own emotional state. This submission has not really even touched on that whole side of the struggle – the emotional strain of living within the aura of the illness, and worrying about the sufferer in the midst of their illness – focussing instead on the practical difficulties of being a carer.

It must be remembered, though, that when there is a mental illness, whether it is depression or schizophrenia or whatever it may be, all the daily practical struggles referred to above, occur against a backdrop of the emotional demands placed on the carer.

Often, the carer must call on everything within themselves to remain tuned in to the needs of the person they care for. They must also put in a super-human effort to detect whether the person they care for is a risk to themselves, and to try to figure out what extra supports they need to cope, including whether they need to be hospitalised, and if so, to pursue that challenging prospect.

Hospitalisation is a challenging prospect both because the unwell person often doesn't want to go to hospital even if they need to, and the adult mental health wards are so unpleasant that you have conflicts about sending them there. Then when you do finally get there, after a gruelling 12 hours or more waiting in casualty, the staff and the systems at the wards impose challenges of their own by their often inflexible and unhelpful attitudes and practices.

As I have tried to convey, the challenges for carers are many, and the pressures placed on carers can be enormous. Probably many carers in one sense give up any hope of actually having a life of their own compared to others. I hope this Enquiry is able to make some real changes that can ease the burden for this special group of human beings, the carers.



## PART THREE

### Some recommendations for change

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In this section I identify some general principles that I have drawn from my experience or from my observation of other people's experience, followed by some recommendations, which I have categorised in line with the terms of reference.

#### Principles

The recommendations that I make below are based on the following general principles.

Participation in the workforce should be a basic human right for carers, as it allows them to get beyond the four walls of their residence and have a life. For participation in the workforce to be possible, carers have to be allowed to earn more without losing so much of their income (particularly for those who can only work part-time), and they need the availability of in-home support, or out-of-home respite, for the person they care for.

We need to learn to value the disabled, the mentally ill and the elderly in a way that leads to us being respectful towards them. This combination of humanity and professionalism needs to be taught to all aged care staff, and indeed to human services staff in all settings – aged care, general medical, and psychiatric. We need a major culture shift that effectively empowers consumers, and allows them to have a voice when their care is less than good. We need a major culture shift that raises the bar in terms of what kinds of practices and responses constitute an acceptable level of care, both physically and emotionally. Apart from the intrinsic importance for the consumer, this issue affects carers because their ability to have relief or respite is affected by the quality of care available to the people they care for.

There needs to be much more generous provision for carers – provision that would enable them to participate in society. It is enough that they bear the burden and the limitations of having to be responsible for someone else, without them having to endure the intense poverty and social exclusion as well.

There needs to be a new commitment to quality-of-life for carers. We need an innovative model that is capable of assessing each individual family's access to income-creating opportunities, costs associated with providing care, and their current assets, and then creatively levelling the playing field so that carers or carer families are not caught in the poverty and powerlessness trap.

Quality of life implies, among other things, the availability of respite. Carers who are coping with, say, a noisy, violent 'adult child' of theirs who demands their attention 24x7, as some do, should be eligible for much more respite (or indeed, a permanent care option) than someone whose carer responsibilities are less onerous. (Often, the opposite is the case, as respite care agencies offer less respite to people who demand more resources to care for, due to budgetary considerations. I have seen where the very worst of cases are not eligible to receive respite at all, because the noise and violence cannot be accommodated in a group residential setting.)

Families who are caring for people whom they find too difficult to care for should always be offered the opportunity of full time care for their loved one.

Every care situation is unique. When the issues that lead to needing a carer are mental health related, there is a huge degree of sensitivity and delicate judgement required for an 'outsider' to be able to form a fair and accurate assessment. It is necessary to believe the account of the family/carer since symptoms or behaviours may not present consistently, or may not be acted out in the presence of a stranger.

The provision of a more compassionate and tailored set of services for carers, seems to me to carry with it a need for improved strategies for identifying unjustified claims for carer status. The system could become too expensive to operate if carers were generously supported, and there were not adequate mechanisms to prevent people from gaining carer status without being in a genuine carer situation.

Finally, I have a suggestion in relation to respite, that anyone who qualifies for the carers pension should not only be offered regular respite, but for that respite to actually be mandatory. To not take it up would require applying not to take it up, and the decision as to whether to grant the exemption to be assessed by an understanding committee comprised at least half of carers or ex-carers, in addition to government representatives etc.

Reasons for mandatory respite are that:

- Sometimes the carer would like a break, but they couldn't face sending the message to the person they care for that they want a break from them
- Sometimes the carer might like a break, but they would bring future retribution upon themselves by saying so
- Sometimes the carer might like a break, but the person they care for completely refuses to go
- Sometimes the carer may need a break and be completely unaware that they do – a common experience once burnout has set in
- Sometimes the person being cared for may like a break, or may benefit from a change of scenery or carer, and the inertia of a long-term care arrangement may prevent this unless it was mandated
- Mandatory respite would allow the opportunity for an objective assessment and review of the care needs of each person, allowing the care burden of the carer to be assessed and their level of support customised to their particular care, and life, needs.

Respite is currently under-supplied, both in terms of the amount of respite available, as well as the flexibility and type of respite available. Some respite options will not work at all for some consumers, and there is a strong need for resources to be made available that can allow respite to be customised to the individual needs of each person or family.

There must be sensitivity towards the mix of consumers in a residential respite setting. For example, my lady would be frightened by being with people with bizarre behaviours, and she would be demoralised to be housed with a house full of people with physical disabilities. Ideally, people who have carers because of problems like depression or acute anxiety or phobias, could be accommodated together without feeling like they were being identified with people they have nothing in common with, thereby avoiding a crisis of self esteem or identity that may result from this.

## Recommendations

In accordance with the four categories identified in the Terms of Reference:

### ***The role and contribution of carers in society and how this should be recognised***

The role and contribution of carers should be recognised in as many ways as possible, such as:

- Perhaps an annual Carers Award in the same way as we have Australian of the Year, to raise the profile of carers in the mind of the public
- Free admission to places like zoos, the theatre, the movies etc for all carers and the people they care for, all year round. This may allow them to feel included in society, and give them an opportunity to get outside their four walls, and thus be strengthened to carry out their carer role. This would cause them to be healthier emotionally and would lead to better care

### ***The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment***

One major barrier to participation in social or workforce activities is the inability to leave the person you care for. To address this we need a range of flexible respite options, where respite can occur: in-home by a 'minder' visiting (either day or evening, so carers can go out socially, too); or out-of-home by the person being cared for being taken on an outing, or attending an (appealing) respite centre for either day or overnight care. If carers are to be freed up to participate in employment, respite needs to be readily available on an ongoing, long-term basis.

The second major barrier to participation in society comes from having no money. As hard as it may be to determine fairly, and to administer, I would recommend that the principle be 'to each according to his needs'. In other words, support is given according to the needs of the situation and the access to income each family has. In some carer families, there is access to income by one means or another, while for other carer families or individual carers there is not, and they are condemned to sub-standard living unless generous support can be provided by government. This would require a system of discretionary giving by government, which I recognise is notoriously difficult to operate honestly and fairly. Decisions would need to be determined probably on a local basis with assessment being conducted by an understanding committee comprised at least half of carers or ex-carers, in addition to government representatives etc.

In the employment sphere, State government (and other employers) need to broaden their definition of who is a carer to include someone who has been on a carers pension due to carer responsibilities, or who can

prove a need to provide care to a person with special needs, so that they can qualify for such things as carers leave.

### ***The practical measures required to better support carers, including key priorities for action***

Carers need to be given a special status in relation to general and psychiatric hospital wards so they are included in care decisions and care planning for the person they care for. Their expertise in relation to the patient needs to be respected and used to contribute to quality of care.

In relation to admission to a mental health facility, there is an urgent need to amend the Mental Health Act to say that clinicians (including psychiatrists) in psychiatric facilities must liaise and consult with carers whether the patient is scheduled or not.

Carers, if they are suffering unavoidable financial hardship, should be provided for generously in various ways. Their pension should include a contribution on a sliding scale dependent upon their means, towards the cost of rent or mortgage, so that all carers are guaranteed a minimum standard of living. That is, income support that is capable of balancing their income with their unique costs. Ideally, support to a family where there is a significant care arrangement taking place should be customised to their needs and resources, rather than one-size-fits-all. It would be a huge help if the cost of their accommodation could actually be covered somehow, if they do not own their own home, as the pension is only enough to live on without the cost of rent or mortgage.

Carers should be provided with the opportunity for an annual holiday if they are unable to secure one for themselves. This should be with or without the person they care for.

Increase the amount a carer is allowed to earn before the pension is reduced, and increase the value of the pension itself. Using myself as an example, where I restricted myself to very basic living costs, and had a mortgage expense the size of an average rental, my outgoings exceeded my income by \$20,000 over three years. As a rough rule of thumb, this may imply that the pension is around \$7,000 a year (or \$134.00 per week) less than a realistic income.

### ***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.***

At the risk of sounding repetitive, accessing the same opportunities and choices as the wider community, and being able to make choices within your caring role, is all about the availability of respite, and having money to do things.

Transition out of caring is made possible by long-term care environments where the person you care for can receive quality care, including:

- A pleasant environment in terms of clean, modern buildings and attractive décor
- Consistent supply of prescribed medications
- Access to a competent medical practitioner in care (current rules require the doctor to visit the hostel, and many doctors are not prepared to do so)
- Staff with adequate professional training so that they know to be kind and concerned when a resident is distressed and they are willing to learn how to be sensitive to the special needs of residents
- Hostel environments specifically for younger people
- In aged care hostels, there should be a ruling that as far as possible, residents who do not have dementia are grouped together, either in terms of having a separate wing, or adjacent rooms, or at the very least, being grouped together for mealtimes, so normal conversation can be enjoyed
- Greater flexibility in relation to being absent from a hostel. Currently in an aged care hostel, social leave is only permitted for 53 nights a year – after that there is a charge of \$70 per day for any further absences. There needs to be the possibility of approval for extra nights away, especially for people who are too young to be in an aged environment, or those with mental health issues who may need more contact with their previous carer, or more time at their previous home than one night a week allows.
- When a person moves into a care facility, and out of the home of the carer, the significance of that care relationship needs to be acknowledged by the facility. In our experience, the hostel told me 'we are the carers now' (although I still came in handy for unpleasant jobs like sitting up in casualty all night when the person I care for needed admission to hospital, or when she needed taking to medical appointments). They also told the lady I care for that she would need to 'cut the apron strings'. I knew this would threaten the success of the placement, and suggested instead that it

would be better as a 'shared care' arrangement, which some of the staff accepted, while others did not. The previous carer often remains enormously significant to the person going into care, and this should be recognised in practice, with the previous carer being perceived as being included in the care team, where appropriate.

In relation to having a future, carers need to be provided with a superannuation scheme. The government needs to place a regular contribution into a super account for each carer so that at the end of a lifetime of caring, they can experience some of the same kind of security those in the paid workforce enjoy.

Some of these suggestions may sound like a 'blue sky' wish list, but they are what I as a carer see as being a basic requirement in order to create fairness for carers, to protect the mental health and general well-being of carers, and to show ourselves to be a compassionate and civilised society in supporting people who carry an onerous burden.

MM  
October 2008

I would like to thank the Committee for how flexible they have been in extending the deadline so that carers get a chance to make the contribution they would like to, to this Enquiry.

**See below for Attachment A**

**'Attachment A'**

(Manager)  
Thursday, May 08, 2008  
(the Hostel)

Dear (Manager),

I am writing to you because of two concerns, one in relation to Susan's medication, and the other about Susan's scabies treatment.

I don't know if you are aware how often Susan's medications are unavailable to her, but it has been a consistent problem that her medications run out, or there are errors in her Webster pack.

As you know, going back a while, on a couple of occasions I had to approach staff because the medication errors were serious enough that they threatened Susan's ability to cope.

In the last couple of months things have seemed quite improved, however recently there have been numerous errors some of which I feel I must bring to your attention.

Last Tuesday 29<sup>th</sup> April, (the Hostel) ran out of Valium in the morning, and Susan had none from then till Thursday evening. In that time she experienced anxiety, restlessness, incoordination and dizziness probably as a result of going straight from two or three a day to none. She told staff, but no action was taken to remedy the situation.

In the same week, from Thursday 1<sup>st</sup> May, Susan's Voltaren was missing from her Webster pack in the evenings and it was absent for a few days before being fixed, even though Susan told staff it was missing.

On Saturday morning, 4<sup>th</sup> May, Susan was told that her Panadeine Forte had run out and there wouldn't be any for the weekend. She had no pain relief for her frozen shoulder at the same time as not having her regular dose of anti-inflammatory (Voltaren).

Susan went all day Saturday without pain relief, then on Sunday morning the carer told her at breakfast she would give her an ordinary Panadeine, since there was no Forte. Susan says that she gets no benefit from ordinary Panadeine, but she took it anyway. However, this carer had a belief that Susan can't be given Valium and Panadeine at the same time and so she was denied her Valium. Some carers seem to have their own understanding of what goes with what, such that Susan is occasionally denied what she should be able to have, as in this situation. When Susan tries to explain that it is ok to have them together they do not believe her.

Around mid-day on Sunday the carer told Susan that she had found the Panadeine Forte, however she said she wasn't able to have one till mid-afternoon, as the carer hadn't given her the ordinary Panadeine until around 10.00am. She was not offered a Forte during the afternoon and by 4.00pm Susan rang me as she was beginning to feel very anxious and distressed. In fact she also had aggressive impulses for only the second time ever in the time that I have known her (the previous occasion being when her medication was incorrect while she was in (mental health ward)). She even stated to me that she didn't know if she could go to tea because she wasn't sure she wouldn't hit someone. As you know, a desire to be aggressive is completely out of character for Susan.

I think the effect of being under-medicated, and erratically medicated in various ways, for the previous week, along with the frustration of her medication either not being there, or being there but the carers being unable to find it, combined to create a level of physical and emotional distress that became unmanageable for her.

I didn't want Susan to miss tea, and I was concerned by her level of distress, so I told her that she must go and see the carer and tell her that she isn't really coping and she needs her medication. She agreed to do this and call me back. She rang back a few minutes later and said she had gone and seen the carer, who was in the office doing paperwork. Susan had explained to her that she was feeling bad and needed her medication, and the carer said she was busy and she would give it to her at tea time.

Susan wasn't able to have her Panadeine Forte at tea time because it would then only be three hours till the bed time medication was given and she would have had to forego the bed time one, which she must have. This is partly why I specially asked her to go and see the staff member straight away at 4.00pm, as she could still have had both her lunchtime Panadeine Forte and then her Forte at 8.00pm when they do the rounds.

Susan had her Valium at tea time and this thankfully settled her enough for her to be able to manage for the evening. It was only by me talking her through, and together us coming up with strategies to manage her feelings, and the sensations in her head, throughout the afternoon and evening that she got by, though.

The carer then forgot Susan on the evening rounds, and Susan finally got her first Panadeine Forte for the day at 8.45pm after she buzzed for the nurse. The carers have been increasingly forgetting Susan on the evening rounds, probably because her medications are described as being PRN, even though Susan really has them routinely at present.

Yesterday Susan was told again that they had run out of Valium. She went to the carer in the morning and said to her that she would need one for the evening. When she didn't hear any more by the afternoon she said to another carer that she really needed her valium for the evening and she asked if it would be in, to which the carer replied there was 'no chance' that there would be any Valium there by the evening. Susan went without her Valium last night as there wasn't any, according to what she was told. She had problems sleeping through the night.

Susan said that (*the RN – nurse*) had said this morning that she thought she knew where there was a Valium tablet, and she went off to find it, but Susan never heard any more from (*the RN – nurse*) or anyone else, and she went without all day. (*Name of a nurse assistant*) was on tonight and thankfully she was able to find some. Susan described her head as being 'crazy' this afternoon, and almost impossible to cope with, due to not having had her Valium to settle her when she needed it. Again, Susan had had none since yesterday morning.

I have not told Susan that I am writing to you, as it would worry her. Nor do I want to create tensions between myself and (*the Hostel*), however, I find it hard to accept that (*the Hostel*) can't ensure a consistent supply of prescribed medications, and I know that Susan suffers significantly as a result of missing her medications, and this does not seem fair.

Furthermore, it takes a lot of time and effort on my part to try to calm Susan when she is either feeling the effects of having missed essential medications, or she is just disturbed by the unpredictability, and lack of routine, and the frustrations associated with getting her tablets.

With regard to the first scabies treatment, I was concerned that Susan was left to apply the cream herself when she has little real use of her left arm, and so there were areas she certainly couldn't have reached, and in fact she hurt her left arm trying to reach them.

Susan would also have a limited ability to recognise which areas of skin had been covered, and really the whole process should have been supervised, ideally with the nurse doing much of it.

The instructions on the tube indicate that a whole tube should be used on a person, and possibly more than one tube if the person is above-average size. I was alarmed to hear that only half a tube was used, as the chances of eradicating the scabies mite are reduced unless the treatment is fully applied.

(*The Manager*) I realise that you try to provide a high level of service at (*the Hostel*), and Susan benefits from many positive aspects of being there, not least of all the very caring atmosphere that you create. Despite that, I still need to be able to communicate the problems that continue to arise in relation to medication as it undermines her quality of life and her ability to cope with daily events, and I hope you will accept these comments in the spirit in which they are made.