

**Submission – Better support for carers**

**Submission No. 1034**

(Inq into better support for carers)

*Recd 28/1/08*

**1. The role and contribution of carers in society and how this should be recognised;**

1a. Role and contribution of carers in society - I can speak about my own role and contribution as a carer of a family member with a mental illness, and also a little about my family's although of course I cannot express theirs as they themselves would. There are 2 phases to my role and contribution as carer. The first phase occurred from the time when my sister was first voluntarily admitted to hospital in October 2004 until her relapse and return to hospital in September 2007 and I will call this phase 'before relapse'. The second phase is all the time since her relapse and subsequent diagnosis of schizophrenia and I will call this phase 'after relapse'. Throughout I will talk about these two times separately as while the concerns for health and wellbeing of all are similar, the expression of the roles as carer are distinct. These phases could equally be related to as before and after diagnosis as a diagnosis was made whilst my sister was in hospital after her relapse.

Before relapse:

Life throws us all many challenges and looking back on the first few weeks after I found out my younger sister was very unwell, was in hospital and had had a psychotic episode, I really can't imagine continuing life in such a fearful way as I did then.

It was so unexpected and I was so unprepared. Returning from overseas where I had been travelling and working for a little over two years, I felt there were things I should be doing to help but didn't know what they were. I also felt there were things the 'system' should be doing to help me and my family and didn't know what those things were. A frustrating time spent struggling with denial, guilt, resentment and apathy and as a result often feeling powerless, uninformed and disconnected.

Throughout this time, my sister got on with her life - moved interstate, resumed studies, maintained different jobs sometimes commuting up to 2 hours each way and kept in touch with family - all the while taking care of her appointments and medications and often in great distress. A turning point perhaps was when my sister decided to stop taking her medication and begin a less stressful lifestyle,

however her time soon filled with multiple jobs requiring her to walk long distances.

After relapse:

A new challenge for us all to face was when in September last year my sister became very unwell again, a chance for us to look at what we had missed in supporting her which seems was so many things.

I began to visit regularly, making interstate weekend trips twice a month, and to collect pamphlets, brochures and anything else I could find from hospitals, health centres and the internet. I began to realize how much I could make a difference both in my own family and in the community and to become aware of how much I wanted assistance and training to further support my sister in her recovery and for these reasons I first contacted GROW.

As part of the Grow-Better Together Focus Group, I felt ownership of my newly chosen role as carer and have since become a regular participant. Through the program I am developing my ability to communicate with my sister in friendship and also my ability to distinguish when to act and when to let time pass. I also get to contribute to other members in the group and together we de-centralize our struggles and move forward with the next challenge. These days when visiting my sister our goal is to explore and enjoy life. For me, the practical application of cognitive behavioural therapy and the social aspect of meeting others in similar circumstances through the "Grow - Better Together" carer support group has made a profound and valuable difference to my role and my contribution both to my own health and wellbeing, that of my sister and family and that of the greater community.

1b. My contribution before relapse was, in my own words, inevitable. I was scared, uninformed, struggling financially. We all did our best. I arranged a last minute trip to Sydney to visit my sister over a weekend after she said she had been having suicidal thoughts. I arranged for a family catch up prior to my sisters trip overseas, paying for her flight from Sydney to Melbourne and using my frequent flyer points accumulated from my overseas trip to bring my step-father, her father, up to Melbourne from

Tasmania. My sister visited us in Melbourne for her 25th birthday and we had a lovely evening, the happiest we had been together in a long time. Between these 3 visits were many weeks and months sometimes with very little phone or text or email contact in spite of these being relatively affordable options. At this time I was escaping into the Melbourne night life, drinking regularly, not getting enough sleep and working short-term contracts whilst collecting more and more debt.

1c. How this should be recognised - I can speak about how I think recognition of the role of carer would make a difference to the quality of life of the cared for, the care giver and the environment and society in which they participate. Recognition of carers through government policy to facilitate early, transparent, respectful, open and inclusive dialogue between the consumer, the carer and the helping professionals (doctors, nurses, social workers, case workers, police, teachers, emergency workers) where the consumer and carer are willing.

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

2a. Barriers to social participation for myself are that I am here on a Friday evening after work hours writing this submission rather than on the telephone to my sister, or catching up with friends or work colleagues or family friends. A barrier for me has been worry and lack of sleep, often social time with friends and family was impacted either by my determination to voice my concerns or by my withdrawing from social interaction. Another barrier is a sense of repressed impatient urgency particularly with work colleagues naturally only partially informed of the complex details of the circumstances and my schedule as carer and I have not participated fully at social times unless one on one relating to dealing with my immediate concerns which include money, diet, sleep, being in touch with family and friends, interstate travel, study, work and, more recently, exercise. Participation in group events has at times seemed onerous and I have less sense of myself as the person who could participate in any social gathering at whim, and as someone who laughed easily at the ridiculous. These days I seem to relax only when conditions are 'right', usually with family or close friends, and

this has an impact on regularly feeling disconnected with other lesser known people around me like work colleagues and class mates. Taking care of getting sufficient rest, taking control of my budget and planning my eating and exercising has been accomplished over time and been supported by communication with friends and family and my support group which has allowed greater freedom to enjoy social interactions in the everyday life. A barrier at the moment appears to be my use of time, I spend much of my time both in and out of work hours getting informed through searching the internet and this also impacts on social participation at work.

2b. Barriers to economic participation for myself are that since my sister's relapse in September 2007 I have chosen to visit my sister regularly in Tasmania whilst maintaining my existing life in Melbourne which has a financial impact. Every 2nd weekend I got a flight to Tasmania and between about September 2007 and January 2008 I had spent approximately \$3000 on flights. Similarly from January 2008 until now. To accomplish this I arranged a personal loan consolidating my existing debts and continued to use a credit card along with my reasonable income to purchase the flights. I am fortunate to have paid overtime in my position, and used this to offset my flight costs by depositing about \$1000 on my credit card at the end of January. At the same time I received a gift of \$2000 which brought my credit card debt to \$0 for the first time since about October 2002, about 6 years - I still had my personal loan to manage, at that time just under \$10,000. Since then my credit card debt has again escalated to nearly its maximum of \$5900 in about 4-5 months and I now have to seriously reconsider my plan. This has involved extensive restructuring and I have a plan that could reduce my debt by about \$2000 whilst maintaining visits once a month instead of every fortnight. To do this I have reduced my optional additional payments on my loan in order to better service the higher interest rate debt on my credit card, I have committed my savings plan of \$50 a fortnight towards my credit card debt, and I have restricted my spontaneous daily spending as much as I think I could stay sane on. At the moment it appears to be quite expensive to keep myself sane but I am confident that over time I can enjoy life and support my sister with more effective use of my money. Changing habits of a lifetime takes effort and discipline and forgiveness when it doesn't all work according to the plan and support from others.

At the moment I am not fully participating in a 'saving some money towards my commitments' context, and I am not fully participating in a 'pay off my loan quick' context as these regular payments are servicing my credit card debt. If I don't take control of my spending and reduce my outs to less than my incoming, I will live with interest payments on credit card debt for the rest of my life and never accumulate savings and never pay off loans quickly. The no doc and low doc loans housing loans available mean I could potentially buy a house whilst being gainfully employed but at the moment I would need to buy some distance from my workplace and my ability to visit and support my sister would be drastically reduced. I am happy renting at the moment, and recently moved into a one bedroom flat about half an hour from my work. This was a good choice for improving my control over my environment as previously although my up front and ongoing costs were lower whilst in share accommodation with one other, at that time I was not taking care of my immediate health needs such as going to sleep on time or eating breakfast on time and often felt angry and disconnected because of this from the person I was sharing with who naturally was not closely aligned with my own commitments or schedule. Since I have moved, we maintain a good friendship and I have maintained better health. How do we participate economically. What happens to my income, chances for promotion, chances for training, budgeting, chances to build savings and reduce debt (probably the other way around), chance for investment, travel interstate and travel overseas, full participation in hobbies and exercise, health supplements and alternative health, doctor visits, operations, appropriate footwear for work and exercise and social activities, skin treatment and personal care are all areas I could find explicit examples of barriers to economic participation though I have really run out of time here.

2c. Particular focus on helping carers to find and/or retain employment - To find employment requires not giving into discouragement for long periods of time. Gaining my current position seemed to take a combination of timing and readiness and as it is a stable position I am currently less prepared to take risks for greater fulfillment or flexibility or money which is a compromise I have chosen and a compromise I am fortunate to be able to choose.

**3. The practical measures required to better support carers, including key priorities for action;**

3a. Practical measures - financial, recognition, policy, health system support, community support, education, empowerment.

3b. Better support - What is already being done in the way of support? I don't actually know. I personally have received no direct support from the government in my role as a carer since 2004 and little support from the health services. The most useful support has come indirectly through the government funded carer support group of which I was a member of the focus group to set up and which has been running since February 14th when it was launched in Hawthorn this year.

3c. Key priorities for action - Proactive collection and collation of case histories in every state, every district, every council area, society is currently blind to the impact that maintaining carers and consumers as dependants in a disempowering system is having on so many aspects of health and wellbeing.

**4. 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.**

4a. Strategies to assist carers to access the same range of opportunities as the wider community - I see a great opportunity to implement policy to support unpaid carers which I see would breathe life into the health and wellbeing of the entire nation. I suggest the unpaid carer demographic is complex and pervasive to our society, with similar concerns, risks and positive potential to paid carers. Unpaid carers might not be living full time with the person they are caring for, they might be in a different state as I am, and thus require knowledge of services in multiple regions both to support themselves and the person they are caring for. Unpaid carers are probably time-poor and money-poor. They are just as

likely to have more than one person requiring care in their immediate circle of family and friends. If they are working this impact their work. If they are studying this impact their study. If they want to take control of their future they have 2 futures or more to consider, their own and that of the person they are caring for.

4b. Strategies to assist carers to access the same range of choices as the wider community - Not everybody who recognises opportunity will take it up, and this is true of the wider community as well as carers. The role of the government as I see it is to make opportunities known and available to carers and to society in general through education and by facilitating dialogue between stakeholders. This relates not just to the health sector. If others can be aware of the commitments of consumers and carers than the negative impacts can be reduced and the positive impacts shared.

4c. Strategies to increase the capacity for carers to make choices within their caring roles - It took my sister's relapse, my commitment to be part of her recovery, my participation in a leadership course, my acknowledgement to myself that I could contribute something to others, my founding participation in a support group targeting my exact and particular circumstances (caring for someone with a mental illness) and my speaking publicly about all of the above to consolidate for myself my role as a carer. Not everyone in more challenging circumstances than my own or that of my sister's has had such a structure to increase their capacity to make choices within their caring role. Many parts of the day or week I wish life was other than it is, and then I am brought back to reality by trusting that by working together we can achieve whatever we set our minds and hearts to.

4d. Transition into and out of caring - for myself the requirement for me to be a carer preceded my willingness to take an active role as a carer by many years. As a child and teen and adult I did not demonstrate acts of caring easily nor express to others their value to me. Now my goal for myself and others is that to care is an ordinary and normal way of life and that the person being cared for deserves to also join in society in this way and to care for others and fulfill their own unique individual potential as they see fit. My current concern is that, as did my own journey to self awareness

take its own path and its own time, so to will the journey of the person I and others care for and what will happen if I am gone before the journey is full circle. This is a concern for many carers, what will happen after they die? I think support for carers and those unwell would be good to include an awareness of holistic and recovery based approaches to life.

4e. Effectively plan for the future - I can imagine there are many people in our society who are impacted by similar concerns without a context of recovery is possible and without a voice and without support. I believe caring for our health and wellbeing can become normalised such that we have strong, connected, communicative communities responsive to the wellbeing of the whole and I believe this can start with our community health services and our support groups and our education system and our government policies to proactively locate and support those in need. While there are people in need, we all suffer the effect. While we have a plan for cohesion and are responsible for learning from our mistakes along the way there will be better support for all of the members of our society.

End of submission



### **Background information to submission**

Demographically, I am a white, educated, single female aged 35 with a permanent job working full-time in the IT department of an inner Melbourne company with high superannuation contributions and agreed rate increases. After being in this position for more than 12 months I now earn about 59K per annum (gross). Australian born, I was delivered in inner Sydney, visited grandparents on the Sunshine Coast in Queensland, was raised in country and small town Tasmania and have some evidence of Irish and French heritage. I have a Bachelors degree in Science from the University of Tasmania majoring in applied mathematics (Hobart, 1992-1998), an Advanced Certificate in T.E.S.O.L from the Canadian Institute of English (Toronto, 2003) and am currently studying a Masters degree in Applied Linguistics part-time with the University of Melbourne in computer assisted language learning (Melbourne, 2007-2010). I have traveled, worked and studied overseas for extended periods (total 2 years 2 months 1 weekend), both in countries and regions where English is not the official language (Russia, Mongolia, People's Republic of China, Tibet, Nepal) and western countries (Canada, New Zealand).

Although this might look promising for the future, it is only part of the picture.

Education - In my immediate family, I am the first to complete university education. Without Austudy and other government benefits this might not have been achieved when it was (1992-1998), on two occasions I did not complete coursework as provided resulting in a withdraw and failed multiple subjects, sometimes more than once. Tertiary courses including TAFE and trade apprenticeship have been completed by members of my immediate family and university courses have been started and deferred. All members of my immediate family have worked full-time at some time, received

government benefits at some time and worked part-time or casually at some time. My step-father is now and often has been self-employed.

Finances - I have multiple debts and live beyond my means. Despite being educated and intelligent, I am being a complete moron about money. Before traveling (October 2002) I arranged a \$3000 overdraft, not unusual. In January 2006 after returning from traveling December 2004 I had not paid this off and applied for a credit card which I got to the value of \$5900, also perhaps not unusual. The overdraft was increased by \$500 to attend a funeral (August 2006). After August 2006, responsible only to myself, I had a total of \$9400 in bank debts (plus HECS/FSS exceeding \$14000 as yet unpaid and also multiple loans from family and friends possibly exceeding \$3000). The interest on the bank debts would have exceeded \$1000 each year.

Assets - I do not own my own home or car and have basic household furnishings in my one bedroom rental flat. I owned a car in the past and sold this before traveling overseas. I now have my motorbike learners permit with plans to save for a helmet, protective gear and motorbike in order to travel efficiently between home (Balaclava), work (South Melbourne), study (Parkville), support group (Hawthorn) and training and development (South Melbourne) agreements with less waiting time for public transport particularly after dark.

Relationships - I have not had a relationship for over 5 years with none on the horizon and have no children from previous relationships. I never met my biological father and after the accidental death of my mother (September 1980) I became the eldest female in our household of 4, at the age of 7 assuming many responsibilities for my younger half-brother and half-sister aged about 2 years and 2 months respectively at that time. In addition I supported my step-father with household duties which increased with my abilities, naturally as I became more capable I was able to assist more.

Health - My lifestyle is beyond my physical means so to speak and as such I am being a partial moron

regarding my health and wellbeing. In the past I have regularly kept late hours whilst drinking excessive amounts of alcohol in smoky environments and sometimes eating too much rich food before undertaking moderate to extreme activity whilst tired, hung over and dehydrated then returning to work or study or both without sufficient rest. I know a number of people who could say the same thing. Since about April 2004 I have struggled with a chronic health concern as yet undiagnosed with some progress made using dietary restrictions on yeast, carbohydrates, sugar and alcohol. In April 2005 I was diagnosed with having had Glandular Fever sometime prior and I am currently unaware of if or how this has affected my current health. In November 2007 I was diagnosed with Coeliac Disease which added avoiding all gluten and gluten-containing products to my existing dietary restrictions.

Interests - In my spare time I like to either spend time being active doing something in the fresh air like camping, bushwalking or going to the beach or something like dancing or socialising over dinner and when indoors I like to expand my reading and knowledge through books, movies, music or internet - indoors or outdoors I love to take photos and share any good ones with my friends and family.

A lot of what is described in the submission is taken from what was shared in public at the Kingston Arts Centre as the "Grow - Better Together" carer recovery story on Saturday, 31st May 2008 and as such may or may not stay directly on the key points. Of course I would like more time to fully describe my circumstances and what I think could make a difference to others, however like many people in similar circumstances with something to say, I have avoided and procrastinated and questioned my own validity until the last day. I assert that many others are out there in our society who have not presented their views on the last day as can be determined by the fact that between May 2008 and today the 4th July 2008 there have been 26 submissions published to the website out of a population that no doubt has evidence of many more carers than that, probably even in just one suburb of Melbourne, and maybe even through just one community health centre.

That is all simply background information to the intention and purpose of this submission which is to capture some of the impact on my own personal life of being a carer and to elicit some of the ways in

which I think carers in a similar situation to my own could be better supported in Australia.