

Submission No. 745
(Inq into better support for carers)

To: The Secretary
Better Support for Carers Inquiry
Standing Committee on: Family, Community, Housing and Youth
P.O. Box 6021,
Parliament House,
Canberra ACT 2600

From: Elizabeth

27/6/2008

To whom it may concern

Thank you for the opportunity to make a submission to this very timely and appropriate inquiry. This submission will firstly give a brief outline of my own personal experience as a carer, followed by details of a research thesis which I completed in 2007 addressing the issues facing the carers of elderly persons in NSW who have acquired a traumatic brain injury. My personal experience of caring for a family member resulted in my return to the nursing profession after a 25 year absence, which has since led to me to a dual career as a renal nurse and researcher in the area of chronic disease prevention.

In addition to this emailed submission, I will also post a hard copy of my thesis for your reference. This research was presented in November 2007 at the national ERA (Emerging Researchers in Ageing) conference in Adelaide and I hope to have a journal article published this year in an appropriate peer reviewed publication. Having been both a carer, nurse and a researcher into the lived experience of a special group of carers in our community, I have a keen interest in being a part of improving the quality of life for all carers and those that they care for.

Yours faithfully

Liz

Submission to: Better Support for Carers Inquiry

By Liz

A Brief Summary

This submission outlines my own personal experience in the role as a carer to an elderly family member and summarises my qualitative honours research project on carers. The project set out to explore and describe the lived experience of the carer of the over 65 community dwelling adult in NSW who has an acquired traumatic brain injury. The data collected included: interviews with six participant carers, specific suggestions from each participant aimed at improving outcomes and a service provider's insights regarding this phenomenon.

From the data, individual stories from each carer were presented. Seven themes were identified. Suggestions and ideas from each carer regarding how to enhance their lives as carers, as well as the lives of the people they care for were presented, with some comprehensive insights gained from the interview with the service provider. The recommendations touched on a range of strategies aimed at improving future support and services for this population. A recommendation was also made regarding nurse education to enhance awareness of the issues facing the elderly person with an acquired traumatic brain injury and their carers.

Introduction (my story)

The events of 1999 resulted in a radical life change for my partner Brad and I. Brad's father Nigel was hospitalised with an acquired traumatic brain injury (ATBI) as the result of a fall at home. We had been living a relatively uncomplicated lifestyle on the far north coast of NSW, a childless couple in our early forties with full time jobs, few commitments and time for each other and our individual interests. We travelled to Sydney to discover that Brad's father had been profoundly changed by the brain damage he had sustained as a result of his fall.

The ensuing weeks saw us making the major decision to leave our jobs, move to Sydney and live in Brad's family home with his mother to enable her to bring Nigel home from hospital, with the three of us forming a team to care for him. At that time we had absolutely no insight into what we were taking on or the challenges we would face. We embarked on a journey as a family that is still ongoing and which has tested us in a way we could never have imagined

prior to Nigel's brain injury. Life for us is not the same since the enormous physical, psychological and personal challenges we have faced.

Life as a new carer to a person with an ATBI was among the most stressful and overwhelming experiences I had encountered. I found myself struggling to walk in the shoes of a carer to a family member with brain damage so severe that making it through each day seemed like a major achievement. All three of us were battling to cope with the issues and challenges we were facing.

We soon discovered that there was very little in the way of services and support for us and that our only alternative was to place our loved one in a dementia home, not an option for us at that time. When we approached the Brain Injury Association we were told that they did not service people over the age of 65, referring us to the Aged Care Assessment Team (ACAT). When we approached ACAT, we were told that because of the ATBI we should get help from the Brain Injury Assoc. That was it! We simply 'slipped through the cracks', with nil services available, except for residential respite care.

So, to cut a seven year story very short, I took the '*if you can't beat them join them*' approach, making the decision to return to nursing after a 25 year absence. Commencing the Bachelor of Nursing, I graduated in 2004, going on to work as a registered nurse in the contemporary hospital system. With the maturity that being in my late forties brought, I had now found my true calling and I was blessed with a passion for my new career I could never have imagined prior to my role as a carer.

Studying at university opened my mind and eyes to a new world view and my previously negative approach to many aspects of my life was turned around. Towards the end of my degree the seeds of a research project were sewn. One day my final year clinical lecturer stated his passion for aged care and research during a lecture, motivating me to approach him with the embryo of an idea to develop a research project about the phenomenon I had been living for the past five years. His enthusiastic response to my vague proposal gave me the impetus to embark on this project, which I completed over a 2 year period during my post graduate hospital training. I was of course delighted to be awarded First Class Honours for this research and am now taking the first steps towards a PhD research project.

The Research Project

Title

The lived experience of caring for a person in NSW who is community dwelling, over 65 years of age and has an acquired traumatic brain injury.

Aim of Research

The aim of the research was to explore the lived experience of the carer of the person with an ATBI who is over the age of 65 and dwelling in the community in NSW. How they accessed services and support and what they perceived could be done to improve these was also investigated. Insight and understanding was gained from the lived experience of 6 participant carers, including the telling of my own story as a participant/researcher. The phenomenon was also explored from the perspective of a service provider.

Methods

From its original concept, this research was motivated by the profound impact of my personal experiences whilst caring for a family member following an ATBI. These experiences necessitated an approach that allowed me to include my own perception of the study topic, whilst still maintaining objectivity throughout each stage and process of the project. The methodology needed was one that enabled the experience of others to be explored, with the researcher reporting her own personal experience using a process that had a data analysis method aimed at maintaining a high level of rigour throughout. Phenomenological hermeneutics was the methodology which addressed all the above issues.

By accessing five carers via a NSW carer's newsletter, a form of volunteer sampling occurred. A service provider also responded, offering her insights into the phenomenon. Interviews of one hour (approximately) in length were conducted, using a semi-structured technique with open ended questions. A series of descriptive and probing questions were devised to elicit participants stories, aimed at gaining maximum insight into the actual 'lived experience'.

Semi-formal interviews with six carer participants were transcribed for analysis and thematic identification. Each carer's story was told in the first person, including the researcher's narrative of her own lived experience of the phenomenon. A service provider was also interviewed, giving insights into the issues facing these carers.

I found it extraordinarily challenging as a beginning researcher at honours level, to address this phenomenon in sufficient detail to produce a comprehensive study of the lived experience of the carer of the over 65 year old community dwelling adult in NSW with an ATBI. The restraints of time and word limits for this thesis, imposed by the criteria for an honours research project have resulted in the outcome being a concise 'snapshot' of the lived experience of these carers, leaving ample scope for further research into this phenomenon. Whilst the following results are gained from looking at a special group, I would suggest that most of the issues raised can be applied to many other carers of the disabled, frail and aged in our community.

Results

The findings were categorised into:

- 1. Seven themes common to all participants**
- 2. Suggestions from each carer on how their role could be enhanced**
- 3. Insights from the perspective of a service provider**

The Essential Themes

Through the insights gained from their lived experiences and those of my own, seven themes have emerged. With each theme, I have included quotes from the carer/participants illustrating how these themes were formulated.

Experiencing frustration

Without exception, each participant expressed their frustration with many aspects of their lived experience. There was frustration at other people (including health professionals) having no insight into the challenges and issues facing the person with a brain injury and their carers. Other sources of frustration include: that people with an ATBI usually lack any form of motivation, not knowing where to ask for assistance, all available services not being appropriate for those with an ATBI, able bodied persons using/holding up disabled toilets and parking spots and lack of empathy from health professionals and service providers. The following quotes best typify this theme:

The biggest frustration was not being able to get the help that we needed. I'd just get told there is no funding available for anything.....That none of the services are appropriate for someone with a brain injury. We were never offered or told where to get a seat for the toilet or a wheelchair. There was no way to find out what and how to access anything. **Hannah**

I feel frustrated at the way people can't understand Terry's state. He looks alright, can sound OK and people have no insight into what we go through. No one seems to understand the issues of brain injuries....I was frustrated at hospital staff's inability to cope with him when he is an inpatient, calling me to complain about him, asking me to care for him. **Dee Dee**

Every night I go to bed a frustrated ball of urrrhhh! for want of a better word to express myself.... Before I had some in home help I would have to go through two to three hours of frustration to get him to do anything physical and then do the day to day stuff feeling like that. **Sarah**

I get very frustrated from the lack of motivation point of view and I don't know how to handle that one....Frustrated at the negative expectations of the medical staff.....with the lack of empathy from health professionals.....with the fact that John will take instructions and education etc. from anyone but me..... with all available programs not being appropriate. **Diana**

Experiencing anger

Anger was another theme common to all participants. Sources of anger included the lack of accessible and appropriate services, lack of information, anger at the person they are caring for and a feeling that some carers had, that they had to resort to angry outbursts to be 'heard'.

Following are examples of how this was expressed:

I'm angry that I was never told initially that Dad's brain damage was permanent. From Jan 05 until June 06 I had to close my business, make all kinds of long term decisions without really knowing what my future would be and whether or not Dad would get better and I would get my life back. **Sarah**

I feel very very upset and cranky with the service providers for their absence of any support or help. **Dee Dee**

I'm angry that I can't access anything without screaming and making a nuisance of myself....that all services seem to have long waiting lists.....that although I found an appropriate group for Ron, I was unable to use it due to being out of our service area. **Diana**

I was so angry all the time in those first few months of caring for Nigel that I began to feel quite unbalanced. Sleep deprivation and the constant 24 hour grind of caring added to my inability to control my angry outbursts. **Liz**

Grieving for life as it used to be

We all have regrets in our lives, however when caring for someone with an ATBI life is never as it was prior to taking on that role. For the spouses there is the loss of the previous relationship. For others it is the loss of lifestyle and perhaps lost friendships from lack of time for friends and family. These quotes demonstrate individual expressions of this form of grieving:

I still grieve for the life that we had before Tom's accident. Although I know it can never happen, I still grieve for those things. It gets easier with time....it's hard to remember my feelings when Tom first had his accident, just devastation and this is the end of my life.... I 'm sad about all the things we'd planned to do that will never happen now. **Hannah**

I feel sad about the change in our social lives with our friends. They all go out to dinner or whatever and we're not included nearly as much as we used to be because Ron cannot add to a conversation, he just sits there.... I grieve for the person who used to be. We always had such a good repartee and could talk about anything and everything. That's all gone now. **Diana**

I grieved for the life that Brad and I had prior to taking on caring for his Dad. I missed the intimacy and freedom we had as a childless couple. Although we chose to do this, I grieved for our pre-caring lifestyle. **Liz**

Experiencing fear

Fear of the future, fear of using respite, fear of the person's condition worsening, fear of having to have the person placed in a nursing home and even fear of the person they are caring for. Each person expressed their individual fears in the following quotes:

I haven't tried to access respite care, mainly because of the dreadful experiences when he is hospitalized. I'm afraid of all the hard work being undone by the stress of going into respite. **Dee Dee**

I'm afraid of putting Dad into residential respite. I feel that it will traumatize and disorient him so much and I'm afraid of what Dad will be like when he returns. **Sarah**

Although I knew I couldn't cope with the increased work of caring for Tom as he deteriorated, I was so afraid of putting him into permanent care. I was afraid of being without him and of what it would do to him. Afraid that he would feel I had abandoned him. **Hannah**

In the beginning I found that I could actually be afraid of Nigel. His personality had changed and I never knew what was coming next or who

he would be each time he woke up. There were some violent outbursts and I feared for our physical safety several times. **Liz**

Feeling misunderstood

Another common theme is feeling that other people just don't understand what carers of the elderly brain injured are living. There is a sense that the world is judging them and/or the people they care for, based on misunderstandings and that others can't comprehend what carers do and why they do it. The following quotes demonstrate the formulation of this theme:

People cannot understand Terry's state. He looks alright, can sound OK but people have no insight into what we go through. No one seems to understand the issues of brain injuries. **Dee Dee**

People don't understand why I talk and act for Ron. They say why can't he speak for himself?.....Not even the doctors and nurses understood what was happening to us. **Diana**

No one really understands what I do as a carer, I'm always so busy. You do what you have to do and I don't think people have any idea what that is. **Rebecca**

Not one service that we found was aimed at someone with a brain injury, not one thing.....even doctors and nurses did not understand the difference between a brain injury and dementia. **Hannah**

I've been surprised at how the medical fraternity and other health professionals just don't get it when it comes down to the day to day care and what that involves. **Cleo**

People have no idea about Dad's condition and how it affects us all. **Sarah**

Some of our friends could not understand why we had given up our free and easy lifestyle to care for Brad's dad. I felt they judged us as strange or weak or something like that because they saw no value in what we were doing. **Liz**

Experiencing isolation

Social and physical isolation are common for these carers. The sense that you are experiencing something that no-one else in your world can understand adds to this feeling of isolation. The carer of the person with an ATBI is also isolated from the life they led prior to taking on that role. This theme is captured in the following quotes.

I feel very isolated, sometimes I feel like a caged Tiger – Like let me out of here. When John was really sick, people were wonderful and rallied round, but now they see John improving and the support has fallen away. They see him as almost better and I guess I don't let on how bad it can be for us day to day.....I think that being able to talk to someone else who has been where I am would be really helpful, because you feel lost yourself and you don't know what to do and at least you would be talking to someone who knows how you feel. **Diana**

I am now according to my doctor socially isolated. I don't want to go anywhere now and don't feel I want to make new friends. My old friends were really good initially but then that support fell away as time went on. They just don't contact me as much as they used to. **Hannah**

The only family are our two kids, one in London and a son in Queensland. There was much rallying initially, but you know everyone had to go back to their own lives and now I just do it alone. **Cleo**

Some days I can cope as carer and other days I find it very, very difficult. **Rebecca**

Experiencing guilt

Guilt is another recurring theme identified from the dialogues. It has been documented that guilt is very common among carers and is a destructive emotion (Payne, 2005, p.41) Most participants felt guilt at the thought of putting their charges into respite care or having to resort to permanent nursing home care. There is a feeling of letting the person down or abandoning them. Another common source of guilt is from the anger and frustration that can be expressed verbally in unguarded moments. This theme is demonstrated in the quotes below:

I have guilt feelings about how I say things, for example, Dad will say 'stop treating me like a child' and I'll say 'well stop acting like a frigging child', but then I have to just walk away feeling dreadful about they way I dealt with him, because he really can't help it" **Sarah**

I feel guilty about losing it with him when his challenging behaviour arisesguilty at the thought of using respite or accessing a nursing home in the future. **Diana**

Although I was overcome with guilt about having to put Tom in a nursing home, the hard work was just too hard. When his bowels became incontinent, all the physical work of cleaning him and the mess up all the time, the bending, the changing his clothes, the lifting, it all became just too much for me. **Hannah**

I used to feel so guilty about losing my temper with Nigel when his brain injury would make life so difficult. I would scream at him and then hate myself..... I still feel guilty that I had to be the one to push for nursing home placement, as I realized that the day to day care was getting beyond us due to Nigel's deteriorating mobility, continence and communication skills. **Liz**

Suggestions from the carers on how their role could be enhanced

Carers Network

Participants have suggested that a process to enable carers to network with one another for support and counselling from others who have 'walked in these shoes' would be of enormous value in reducing the care-giver's burden and empowering them to continue their role long term. With state and federal governments relying increasingly upon families and others to provide care in the community, there needs to be increasing support provided to enable this trend to continue.

The actual strategies required to implement this network need to be further explored, however, most participants in this study have expressed interest in becoming the core of such a support mechanism. It may be as simple as placing advertisements in appropriate media/newsletters to gauge interest in the formation of a network of carers to the elderly person with an ATBI. Formation of a discussion group utilising courageous carers who would offer advice and support to others new to the role may be one strategy of worth. People new to the caring role could be given the telephone contact of a member of the support group with valuable experience to enable access to support when challenges arise or the new carer feels overwhelmed by the burden of care.

Putting Carers in the Decision Making Process

Another area identified as requiring further attention is the need to have carers included by health care professionals in the decision making process. As the service provider and participants themselves have identified, the carer is often either overlooked or totally excluded from this process. A person with an ATBI often has limited cognitive ability to process information imparted to them and lack insight into their own condition, therefore not including family members and carers can lead to dire consequences and less than optimum outcomes.

Short Term Care Delivered by the Experienced

Participants expressed their reluctance to access any form of short term care in their home in emergency situations or to enable them to attend appointments, often to the detriment of their own

health and well being. Participants held grave concerns about leaving the inexperienced to care for a brain injured person in their absence. There was a suggestion that there needs to be a pool of people developed with the experience and skills required to provide appropriate and safe short term care.

Whilst this strategy may sound difficult to implement, utilising people such as myself or others who have lived the phenomenon could be of great benefit to we 'ex-carers', by way of accessing and utilising our expertise, thus giving a feeling of being needed after having 'lost' the carer's role/identity. A recent study in England has demonstrated that the unique role of the carer can and should be utilised as an ongoing knowledge source for care planning and treatment decisions (Galvin, Todres, Richardson, 2005, p. 3). Even short breaks for these carers can enable them to continue in the caring role for longer, with less reliance on expensive and often disruptive residential respite in a nursing home.

More Recognition of Carers and What They Do

Participants and the service provider included in this study identified a lack of recognition in our country of the role of carers in general. They are the 'unsung money savers' of our society, enabling our elderly and disabled to remain in the community. Government funding is required to improve services and support to our carers and educate the public about the vital role these individuals play in providing a selfless, twenty-four/seven service to those for whom they care.

Central Access Phone Line

Accessing services and supports was a major cause of frustration and distress to all the participants. A central line for access to services specific to those with an ATBI was suggested by several participants. Whilst the service provider interviewed for this study stated that such a phone line would be virtually impossible to create due to the complex and convoluted process for funding and accessing services, perhaps this strategy could be partially addressed by the formation of a carers support network. By utilizing their experience in this area, a simple 'word of mouth' form of referral by carers to carers may evolve. Approaching the existing Commonwealth Carelink Service provided to all carers could be a good starting point in improving access to detailed information for this group. Raising such government organisations awareness of the special needs of these carers and their charges may enhance future ease of access to the appropriate service providers.

Implications for Nursing Education

Participants voiced their concern that many health care professionals, including nurses displayed little insight into the issues facing the person with an ATBI and their carers. Participants have all experienced problems when the person they care for is hospitalised or assessed by health care professionals. With the enormous amount of information to be delivered to the contemporary undergraduate nurse, a process for raising student nurses' awareness of the issues specific to the person with an ATBI is currently lacking. This knowledge could be delivered as part of a broader education module aimed at issues for the aged person, including: dementia specific education, information about aged related decline in physical and cognitive function and other issues facing nursing staff in their caring role for the older person. This module could perhaps be delivered either as part of the undergraduate curriculum, or included in a post-graduate nurse programme.

Insights from the perspective of a service provider

Susan responded to an advertisement in the carers Newsletter for participants in this project, offering to give a service provider's perspective on the phenomenon being studied. She is a senior manager in an organisation with links to this area of study and was initially keen to give insights into her experiences when attempting to access support for those with an ATBI and their carers. The interview didn't take place for some months after Susan made contact and in the interim her aunt's elderly husband had a fall resulting in an ATBI. Thus, Susan found herself supporting her aunt in the caring role and experiencing this phenomenon which she had been aware of for many years.

In Susan's words – Her perception of the issues for this group

"I find myself daily looking for services that simply do not exist. We have around 3000 phone contacts per year with 50% of those calls requiring information about services. Finding services is such a confusing, convoluted and complex process that it is difficult to find out what is available out there and who is eligible. It's very difficult to know what info. to give someone. You actually have to spend the time to sit people down and find out what they are actually looking for. We have this system where we just throw information at people, but that overwhelms them. Really what we need to be doing is to sit people down and 'worry' (for want of a better word) through what they are actually looking for. At the end of the day, the reality is that when you hang up the phone that person is still there with this problem that will not go away, they live it 24 hours a day.

The really big issue facing them is that often the organisations that make the decisions for, or who are treating these people will talk to the person with the brain injury but they won't always talk to the carer. Carers will often get ignored by doctors and other health professionals. So the one who *needs* to be vitally involved in the decision making process

is often excluded, particularly if it's a daughter or someone who is one step removed from the person with an ATBI. Issues such as depression and domestic violence (which result from brain injury) are overlooked. The person with the ATBI is consulted regardless of their lack of insight while the carer's concerns are simply not being sought or heard. I think this is the reason that people with an ATBI are often lost in the system because what they are being told is just too overwhelming or there are cognitive issues preventing them from taking the information in. This is a real danger for carers. Simple health issues can become a far bigger problem because of this process, as treatment is just not being given by the Health Professional as they have not heard all the facts and are therefore not fully informed.

I see that the health and welfare system is relying more and more heavily on carers taking responsibility and is giving less and less support to enable them to do that. The medical model tends to quickly dismiss the carers opinion and once again their input is ignored. The medical profession usually put themselves at the centre of these situations and control the information flow. I believe the more appropriate model for this is that the person and their family/carers are at the centre of the process with the doctors, other health professionals and service providers roaming around the periphery and sometimes being included, when they are required or needed. So, every now and then the person's family will go outside the circle and try to get help and then they will regroup and go back to their circle to hang onto each other for support. That circle is their central core of support and their safety net. It's not the doctor or the nurse, it really comes back to that central core and if the person with an ATBI doesn't have that they can become very lost and isolated very quickly.

These carer's lives are so profoundly affected by their caring role and they really need a form of support that enables them to keep up the input required. Carer's support can often be as simple as having a glass of wine and a cigarette or being able to ring up another carer at night who understands what a nightmare of a day they have had. What comes in here is the ability to laugh about what they are going through, because if they can't get it out and laugh about it they are in deep trouble. They need to channel their anger and frustration somewhere or they are not going to survive. They usually access someone who is a close family member or a friend who is living what they are going through and can really understand. It is rarely a health professional who can help with this.

Those people who do survive as carers are able to step back and say 'this is entirely on me and I will do this my way'. You have to be bloody minded, you have to be prepared to stand up for yourself when someone dismisses you and say 'I don't care if people don't like me, I am advocating for the person I care for'. Unfortunately many carers of the older generation are often 'nice ladies' (gentle women from an era where women were not assertive), who are often overwhelmed with their situation and see the direction and advice given by the authoritative figure as per the medical model as absolute. They often have no idea of any other alternative choices or strategies because they simply are not given them. "He will be too much for you to cope with at home, we need to put him in a nursing home"..... They need to see that it isn't about being "nice", it is about being fully informed of choices and accessing what is needed to help this person. They need to be able to assert themselves when required, however, I realise that this is easier said than done.

It's not about screaming like a banshee to get help, because if they do that, they will get dismissed, it's about asking the question and framing it in a way that makes the professional stop and think about what they are doing and whether it is appropriate for the

person they are treating. This is very difficult and to be able to stand up and ask those questions takes a healthy ego and independence. The aim is to get the best possible outcomes for the person they are caring for and themselves. They need to be empowered by knowledge, strategies and support and I am keen to assist carers with gaining these attributes

References

Galvin, K., Todres, L., & Richardson, M. (2005). The Intimate Mediator: a carer's experience of Alzheimer's. *Scandinavian Journal of Caring Sciences*, 19(1), 2-11.

Payne, T., Wilson, C. (2005). *Making the Most of Caring: A booklet for carers of people with a brain injury*. Sydney: No Time to Lose Pty.Ltd.