

A.O.C. 7/7/08

Sent: Thursday, 26 June 2008
To: Committee, FCHY (REPS)
Cc: Advocacy
Subject: Inquiry into better support for carers - submission

To Whom It May Concern,

At the age of 16 I was thrust into the role of young carer when my 37 year old Mother had an horrific car accident. The accident resulted in a severe head injury, 6 months in hospital and rehabilitation and then the ongoing process of her being cared for at home. I shared the role of carer with my then 13 year old brother, my uncle and my elderly grandparents, we very quickly became a family of carers. I cannot begin to estimate the amount of hours our family contributed to the care of my Mother, it was a contribution not only to her survival but to the community. Equally I cannot begin to express the profound impact that this had on our family. Words could never adequately communicate the fear, anxiety, deep sadness and trauma that we all experienced daily for so many years.

My brother and I spent a lot of our school time in hospitals as our Mother battled with severe epilepsy and ongoing acquired brain injury related health issues. As young carers we were offered limited support during the years that we struggled through school trying to get a basic education whilst caring for our seriously ill Mother.

Five years after the car accident our Mother was then diagnosed with metastatic breast cancer, still living with the brain injury we now had a whole new set of duties as carers including managing treatment appointments, buying and dosing medication, frequent hospital stays and so much more. She lived for another six years in the advanced stages of her cancer, it was in her bones and other organs and it was during this time that I became a full time carer. I resigned from my career in marketing and through speaking to my Mother's GP learned about the carer pension. I lived for almost four years as her carer on the Central Coast, away from my friends with my career at a standstill. As my friends developed their skills, saved their money and lived life as typical mid 20 year olds I lived another life altogether. I was not able to take on any employment at all during my time as a full time carer and the process of returning to work after having spent so long on a pension was not easy, I was not given any support to help me to do this.

As a result of my time as a carer I have become a different person to the one that existed before the day of my Mother's accident, in many ways a better person. On the other hand I have become a person who still lives with ongoing post traumatic stress, depression, anxiety and a lack of financial stability. My brother also experiences very similar psychological health issues.

In total I was a carer for more than 11 years from the age of 16 to 28, a carer with no support from the many health professionals that I met and interacted with during that time. My brother and I took care of each other, my grandparents were too old to take on much of the caring, my uncle was a huge support. The resources available to us were non-existent as far as we were aware, not many people asked how we were or took the time to investigate support options for us as adolescents and young adults.

I believe that carers are not recognised or supported in ways that allow them to care for themselves adequately, access opportunities afforded non-carers or identified within the system as being in need of support. Health professionals need to be better educated in ways to identify the needs of carers and where to refer them onto for the support that they so desperately need.

I believe that carers deserve a fairer level of financial support, as a young adult my finances suffered dramatically whilst I lived on a carer pension. I was not able to save for the future and when my Mum died and I returned to the workforce in my late 20s I had to start over financially and this still has an impact on me now in my early 30s.

Carers need to be empowered and supported through their experience of caring, I have gone onto a career in cancer care, the very area that I once feared so much because I am passionate about changing things for the better for others. My brother and I were lucky that we had the strength between us to support each other and accept our role as carer because of the love we had for our Mother. There are many others who are not so lucky. For whatever reason they may not have the support of other family members and so many times I see other carers suffering even more than we did. This frightens and angers me at the same time.

In closing I would like to say that although I feel strongly about the lack of support for carers, I also witness support for

carers slowly emerging and becoming more accessible. I volunteer with an organisation called Home Hospice that provides support for carers through carefully selected and trained mentors, I am a mentor myself and relish the opportunity to be able to share my experience in a positive way by supporting others. I strongly believe that organisations such as Home Hospice need to be well supported so that carers everywhere know that they exist. It is a constant effort for Home Hospice to raise the funds to operate let alone raise awareness amongst the key health professionals that can easily refer carers in need.

*Kindest,
Lisa*