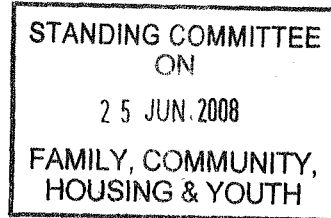


A.O.C. 1/7/08

Submission No. 356
(Inq into better support for carers)



23 June 2008

Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a sole parent and full-time carer for my 14 year old son Samuel who has Batten Disease.

Batten Disease is an extremely rare, rapidly debilitating and regressive neurodegenerative fatal illness which affects approximately 30 children in Australia. This illness rids the child of their physical, intellectual, neurological, emotional, cognitive ability and personality leaving them in a vegetablized state in their late teens to early twenties.

To date my son has the following symptoms:

- **Blindness**
- **Epilepsy**
- **Constant falling due to muscle wastage in legs and lesser extent in arms**
- **Bipolar**
- **Schizophrenia**
- **Early dementia - rapid incoherent and repetitive rapid speech**
- **ADHD**
- **Autism**
- **Night terrors**
- **Insomnia**
- **Excessive obsessive compulsive disorder/fixations**

- **Mood swings – excessive**
- **paranoia, anxiety, frustration, aggression, depression, clingyness and extremely demanding**
- **No concept of anything and unable to be reasoned with**
- **Partly incontinent**

Eventually we will have to endure the following as well:

- **Wheel-chair bound**
- **Fully incontinent**
- **Inability to communicate**
- **Inability to swallow**
- **Violent uncontrollable convulsions**
- **Need for peg feeding**
- **Need for oxygen**
- **Need for throat suctioning**
- **Permanently bed ridden – vegetablized state**

Expected Life Expectancy:

- **Late teens to early twenties**

Since Sam's initial diagnosis in 1998 at the age of five, I have been refused various services telling me my son does not qualify and I have been disgusted with 'professional' staff's attitude towards a disabled person, namely my son, suffering from a mental illness. These encounters are listed below:

- **Disgusting bed side manner by various doctors and specialists when Sam's illness was diagnosed**
- **No Paediatric Neurologist in Toowoomba – means frequent trips to Brisbane which isn't always that easy**
- **Queensland Transport – refused disabled parking permit (3 occasions) – finally had to take my request to a local member to obtain permit on my behalf**
- **Admission to Toowoomba Base Hospital – (one week) September 2004 – ignorant staff who didn't want to listen to me about my son's illness**
- **Admission to Royal Brisbane Hospital - Child and Family Therapy Unit (CAFTU) - September 2005 (three weeks). Again ignorant, uncaring staff. This place is run like a prison and should be shut down. I wrote a lengthy report to the Hospital Board of complaints on my return home to Toowoomba but wouldn't be surprised if anything has changed**
- **Disability Services Queensland – September 2004 – denied Family Support Package**

- **Home and Community Care (HACC) – received minimal assistance for home modifications – up to \$4, 800 towards a disabled ensuite. I had to fight to get this assistance**
- **Centrelink – 2007 – denied Carer’s Payment – was told the doctor hadn’t ticked enough boxes on form even though he had ticked the box stating my child had a terminal illness. Still wasn’t good enough. Had meeting with local member to discuss the form and it’s need for a major change as it didn’t allow for any flexibility. For example, as I couldn’t tick a box to say my son was going to pass on in the next 12 months I was denied the carer’s payment. Finally received payment after 2nd attempt**
- **Medical Aids Supplies and Services – (MASS) - as I already have received one mobility aid through MASS, I have been informed my son is not eligible for any other mobility aids. Not sure what I will do when my son grows out of his current wheelchair.**
- **MASS – don’t qualify for incontinence aids as Sam is not incontinent enough, however fortunately we do qualify for Continence Aids Assistance Scheme – (CAAS)**
- **Commonwealth Carers – 2007 funding – not eligible for funding for intellectually based disorder as my son’s illness is neurologically based even though he is affected intellectually as well**
- **Private physiotherapist – charging \$55.00 for ½ hr visit either to home or school. I’ve since dismissed her as she very rarely kept her appointments which is defeating the whole purpose of Sam receiving regular therapy**
- **Blue Care – physiotherapy and hydrotherapy - made it extremely difficult for us. They didn’t believe that Sam should receive therapy because he was a child and should receive it through the school. Also they didn’t believe that he could be HACC eligible and also have a Family Support Package at the same time so were not very supportive of our needs**
- **Education Queensland - lack of therapy support services ie physiotherapy, hydrotherapy, occupational therapy, speech therapy etc.**
- **I have taken it upon myself to organise therapy for my son to keep him out of a wheelchair for as long as possible. I take him myself swimming twice a week and he does one session through school but this means extra running around for me when I am already sleep deprived and thoroughly exhausted**
- **There are no therapy services provided through the Toowoomba Base Hospital where either Sam can attend daily for therapy or have various therapists come into my home ie physiotherapy.**
- **Respite services – local providers. I have had to cancel some respite workers due to various reasons – stalking/hassling me and not taking Sam’s needs into consideration, a worker taking illegal drugs while clients are in his care. My son was one of these clients. The service provider is aware of his habit but still he is employed**
- **Personal Care – HHelp – Sam was receiving 1 hour so I could do other things in the house, ie prepare dinner, put a load of washing on, have some mother-daughter time, etc, etc. Have since cancelled due to unprofessional staff who did not clean my son properly. This service cost \$ 2 300 for 4 months. I have**

since purchased a bidet for \$ 1 290 however it still does not solve the problem of me having one hour's break to do other necessary things. Also does not give my body the much needed break physically and mentally it desperately needs

- **There is little flexibility when it comes to funding from service providers. We are entitled to 4 weeks per year for my son to sleep overnight in a guest house through one of the service providers. However, since my son needs 24/7 care and these services do not offer this, our entitlement to this funding can not be used for a carer to come and sleep overnight in my home.**
- **As many disability aids and equipment are extremely expensive, there is a desperate need for a second hand outlet for mobility aids and equipment where families can either hire or purchase them**
- **Disability Services Queensland - frequent knock backs for either reimbursement or assistance with expenses for either myself or children. The Family Support Package we receive is worth \$22 000 (the highest amount possible for my son). This amount only covers the bare basics for respite and vacation care let alone anything more, therefore the name is very misleading as there is very little left for myself or daughter**
- **RSL – EACH (extended aged care in the home) package – covering dementia – denied**

I also have a 17 year old daughter Adriarna who is in her final year at school and who also needs her mother's attention and guidance. Adriarna helps me where she can in the home and with Samuel however I want her to spend her time concentrating on her studies. At times my home seems very stressed and topsy-turvy given Samuel's constant ongoing demands and my lack of sleep and ongoing exhaustion.

As my son is only 14, he is not eligible for a disability pension until 16. When he is eligible to leave school we will apply for post school funding package and life style package through Disability Services Queensland however, there is no guarantee he will receive any of this funding. Being a sole parent, unable to go to work due to Samuel's ongoing 24/7 needs makes it extremely difficult to survive financially. I am saving the government a huge amount of money by being prepared to look after Samuel at home but trying to get assistance leave me clinging to hope.

As you can see in the nine years since my son was diagnosed I have not stopped fighting the system and fighting for his rights as a disabled person. My role as carer is continually pushed to the limits. My day consists of organizing and checking on respite, personal carers, organizing home/car modifications, organizing mobility aids/equipment, organizing incontinence needs, organizing hydro and physio for my son, writing letters to voice my concerns and the list goes on and on and on. I never get to the end of my list as something else is always required.

Unlike more common illness such as Leukaemia where 'Shave For a Cure' happens automatically every year or 'Red Nose Day' or 'Daffodil Day' etc. etc., thousands of dollars are raised and these affected children benefit. Fund raising for Batters Disease however is a rarity as it is left to the families of the sufferers and their close friends to promote awareness and hold fundraisers. Personally I am too exhausted, sleep deprived and emotionally unstable to do this anymore. I have fund raised in the past and on all occasions except one I actually lost money as not enough people attended the events I had helped organized and the overheads and running costs still had to be paid for.

I walked the streets in my local city one year for 4 weeks solid to raise money for my own son's needs. I needed funding to aid in the purchase of mobility aids, equipment and home modifications. Although I raised \$4 000.00, it was extremely emotionally and physically draining as nobody had heard of the illness and therefore I needed to explain it to every door I knocked on. At the end of the day \$4 000.00 doesn't pay for much when it comes to the disability aids and equipment needed on a daily ongoing basis.

For three years I wrote letters to businesses, individuals, charity organizations and practically begged for financial assistance to modify my home to accommodate a disabled person. Finally local businesses and individuals came to my aid and it took twelve months to modify my double garage to a disabled ensuite with a sleeping area for Sam and myself. It was all done in these peoples' spare time so it was quite drawn out.

I have contacted several media outlets on several occasions ie Current Affairs, Today Tonight, Extra, Sunrise, Four Corners, Courier Mail, Woman's Day, Women's Weekly etc. etc., to promote awareness of this dreadful illness but nobody is interested in real life issues.

Too many times I am told that my son does not qualify for funding. He is either too young, too old, too short, too thin, too fat, too tall and the ridiculous excuses continues. We missed out on funding available through Commonwealth Carers last year as the illness had to be intellectually based not neurologically based. Even though he is still affected intellectually we were once again not eligible and continue to fall through the cracks. It is almost as if he is penalized for being in this age bracket. I wonder if it will be more excuses for not being eligible when he is adult aged.

As I am trying to keep my son's legs mobile for as long as possible I am frequently looking at physiotherapy and hydrotherapy options. As he is school aged he is not entitled to receive physiotherapy sessions through the public hospital system in the home or at school as the education system is supposed to look after him at school. However the physiotherapist employed by the education department is so busy doing the rounds of many schools she is unable to actually do the physiotherapy herself. Therefore she does an assessment, writes a program and when there is sufficient time the teacher with the help of a teach-aide if one available does some physiotherapy on Samuel. I take him swimming myself twice a week and he goes once with school. This means extra running around for me on top of my already pushed to the limit days. I have and continue to organize other support networks to help look after my son's needs but surely to god there

must be some other systems which can be put in place especially in a special needs school where these children need on-going intensive interactive therapy sessions on a daily basis.

I requested a second white cane be left at the school if in the event of my son's current white cane being broken which has happened in the past. As my son has obsessive compulsive disorder if I can't produce the wanted article immediately I have a manic outburst on my hands. I was told this wasn't possible as the education department couldn't justify another cane being ordered and left at the school if not in use. It cost a measly \$37.00. What 's more important here, the child's safety, my sanity or a measly \$37.00?

I have tried going back to part time work on a few occasions but need to be in a very flexible place of work where I can drop everything and run if I need to collect Sam from his special school for one reason or another. I have even tried working at Sam's special school but this leaves me further physically and mentally drained due to the handling of disabled children all day after already doing a day's work the night before looking after Sam and getting him around. Sam endures many seizures and due to his complete blindness and losing his ability to walk experiences various accidents. I am trying to keep him mobile for as long as possible as it will become more difficult once he is wheelchair bound. He is already 85 kilograms and relies on me totally to help him get around his home and environment.

My body is in constant pain. I attend the chiropractor or physiotherapist when I can afford it to realign my neck, jaw, back, shoulders, arms, hips, knees, etc, etc. This is ongoing and the problems will never go away as I am unable to rest the areas of concern. I can't afford private health so have to wait to find some spare cash. On top of all the other everyday normal expenses that most families struggle with, having the disabled expenses on top really makes it virtually impossible to afford to live.

I wrote letters for three years before finally I received some local assistance from trades people, businesses and individuals who helped convert my double garage into a habitable sleeping area with disabled ensuite for my son and myself.

Unfortunately government departments parted with very little of their money for this modification to be successful.

Also I have an unwell, elderly mother who relies on me occasionally to do things, *although my sister is her main carer. She is working full time and sometimes finds it* difficult to meet all my mother's needs. Finding the time to do her chores as well as care for Samuel and Adriarna leaves me with very, very little time for myself to relax and de-stress.

Carers simply cannot afford to get sick which is extremely alarming and it is my constant worry what will happen to Samuel if I were to pass first. There is no place for these young people to be cared for and I have expressed that I don't want him placed in a

nursing home or mental institution. I often see articles about looking after the aging carers however the younger carers need looking after too. We have a breaking point and I have come very close to mine on many occasions but I will not abandon my disabled son.

I was totally disgusted after I met with Sam's case manager at Disability Services Queensland last week. I mentioned to her that I was ceasing personal care for Sam through HHelp as they were not washing him properly. Her remarks stunned me when she mentioned, oh good we have saved some money and won't need to apply for any discretionary funding. It seems this is all they are concerned about and not the welfare of their clients. It seems I am doing the role of Sam's case manager continually as I do all the follow-ups and find out what services are available. She simply notes this and in a patronizing way tells me what a great job I am doing.

I requested reimbursement for a camera which I installed in the home to view Sam in his room. This way I can see and hear him and continue preparing dinner, washing etc. etc. In the event of him having a seizure or needing my help I can assist him whereas in the past it meant I had to continually look through a window into his room to see if he was ok and have caught him having a seizure. Disability Services Queensland would not reimburse me as they said the following: 'Constant monitoring of individuals is seen as restrictive practice and is not supported'.

I class it as work place health and safety and possibly saving my son from having a fatal attack from a seizure. My god what other excuses are they going to use in order to avoid parting with some government funds.

They also refused to reimburse me the cost of the bidet stating there must be another way. If I can not get personal carers to do the job properly it falls back on me so I'm not sure what other ways there are. Again it is work place health and safety and saves him from getting infections due to poor personal hygiene.

I'd like to know when Samuel's package will be increased. We simply can not survive on \$22 000 per annum with the cost of living and Sam's needs increasing dramatically and the carer's payment staying still and barely making a difference to survive.

I wish somebody would soon give me a break and help me instead of putting up all this red tape and bureaucratic excuses. Unfortunately the people making these decisions which affects the rest of our lives have never looked after a disabled person and often never leave their ivory tower and mix among the real people of this world. I have invited many to come and walk in my shoes for a week but to date nobody has ever taken me up on this. Shame, Shame, Shame.

Yours sincerely

Camille

c.c. The Hon Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services

The Hon Jenny Macklin MP, Minister for Families, Housing, Community Services and Indigenous Affairs

The Hon Lindy Nelson-Carr MP, Minister for Communities, Minister for Disability Services, Minister for Aboriginal and Torres Strait Islander Partnerships, Minister for Multicultural Affairs, Seniors and Youth

The Hon Mr Stephen Robertson MP, Minister for Health