

27/6/08

Glynis

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

As a former Carer for my husband who passed away as a result of Multiple Sclerosis in 2004, I am passionate about making life better for current Carers in Australia.

I volunteer as a peer support worker and Carer advisor for the MS Society Vic/NSW, I facilitate a Carer Support Group and work full time in Local Government in Resident Support as a Team Leader.

I was a finalist in the 2007 Inaugural National Disability Awards personal achievement section. I feel a section should be added to the Awards to incorporate acknowledgement of Carers.

Carer education should be promoted. Education for new Carers, service providers, health professionals, Public Sector staff, the broader public and any interested parties.

I feel that my role was often not recognized, appreciated or acknowledged. Health professionals, in particular, did not always listen to my opinions or respect "the way I did things" I was often told that the way I managed my husband's care was not the "correct way", they often did not respect "what worked for us". The problems I faced included financial, emotional and physical.

My husband had MS (predominately a young persons disease) we had a young family of six children. I had to work to make payments on our mortgage, manage the added cost of medication, aids/equipment and education etc. which then compromised my husband's and children's care. It was a constant juggling act. My social life was non-existent.

Emotionally, there was very little assistance for my entire family over the 25 years I cared for my husband. As MS is a progressively debilitating disease there were constant periods of adjustments (both emotionally and physically), this put vast amounts of pressure on myself and children. Many times my marriage was in danger of collapse as a result of not coping emotionally. If my marriage had broken down this would have put a far greater burden on Government resources than providing support such as counseling and respite. Emotionally, my husband's illness had, and continues to have, a big impact on my

children. There is very little support for children of people with long term illness/disability.

Physically, there was very little help at the beginning of my role as a carer. This did improve when my husband obtained a funding package although this took 5 years of applying and was not without it's own problems. Waiting lists and red tape were a constant battle to deal with. I soon learnt "the squeaky wheel gets the oil" theory.

The most help I needed with was respite, particularly for a younger adult disabled person. I realize there is a shortage of respite services for all people in need but this demographic is often neglected. To place a person in their 20's, 30's 40's or 50's in an Aged Care Facility for respite is incredibly difficult for their Carer. The person in need often fights/opposes the idea of going in to respite, especially in to a place that is not suitable to their needs. This puts added emotional pressure on the Carer.

I think the Government can better help Carers by providing more age appropriate respite and permanent placements for people in need. I kept my husband at home against years of medical advice purely because there were no age appropriate places for him to go to.

I suggest a respite scheme set up similar to the CAAS scheme. A person will be assessed as needing respite they then could be allocated a nominal amount each year to be used to access in-home or facility based respite and the cost would come off the total allocated. The person would lose any unspent funds at the end of the financial year. This would take the financial burden of respite away from the person/ funding package. This could then be used to access private service providers/local Government services/ facilities of choice.

The role of Carer Case Mangers should be developed or incorporate this role in to existing Case Manager Role. Most Case Managers in my experience only consider the client (person with the disability) without considering the opinions/impact on the Carer. This role would also help the Carer to obtain/retain employment.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

Glynis

It was the early 80's. I was in my late 20's and I had been through a bad marriage, a divorce and had 3 small children under 5. Then I met Shane, the man of my dreams; he had a very similar story with three small children of his own. He had been living with an undiagnosed medical problem for 7 years since he was 21, but had no obvious symptoms except for a bit of a strange walk. He referred to his condition as **"IT"**

We married in 1985 and combined our 2 families, this gave us six children under six, as there are four years and five months between all six of them.

Shane had an attack of **"IT"** on our honeymoon. We had been for a long walk down many, many steps in the Blue Mountains, we turned around to walk back and he couldn't move his legs. It took us hours stopping every few steps to get back up to the top. I wanted to go for help but he was determined to make it back up on his own (a sign of things to come). He deteriorated slowly from there. There was talk of **"IT"** being Multiple Sclerosis (MS) but all the doctors and specialists we saw disagreed with each other, some said MS, some said MS and another unknown neurological condition and others said **"IT"** was something else altogether but they didn't know what. Shane had to give up work, he had been a butcher at a meat works. He could no longer do this, as it was very physical.

I began to work two part-time jobs one starting at 5.00am so I could be home in time to get the kids to school the other in the evenings after they were home.

Over the next 4 years Shane's health slowly deteriorated, his limbs progressively became weaker and his balance was affected. In 1987 he had to stop driving and hand in his license. Our lives consisted of doctors, hospital appointments and stays, tests, procedures and both alternative and conventional treatments. We tried everything and traveled everywhere including interstate in an attempt to get some help and answers. Nothing helped and we did not receive any answers.

In 1989 after waiting seven months for an appointment Shane was one of the first people to be tested by the only MRI machine in Victoria. The results came in and we were told, twelve years after his first symptoms, **"IT"** was definitely MS. The Doctor said that it was such an unusual case of MS that they would like to write him up in the Australian Medical Journal. We were shattered by the news but also relieved that we finally had an answer, something we could put a name to. A week later the Doctor called to say that we should forget that diagnosis because the machine was faulty and showing up the same thing in everyone that had been tested by it. Back to square one!

Emotionally there was a huge strain on the children and our marriage. As Shane cognitively deteriorated his memory became worse. We argued constantly about things that I had told him that he could not remember.

He would be moody, depressed and frustrated, all of which I could not help him with. As he physically deteriorated he would get angry with everybody, for example; if the children didn't clean their rooms he would believe it was because he couldn't check up on them. We tried psychiatrists but all they wanted to do was medicate him, there were side effects with this type of medication and he eventually refused this.

When you are carrying out personal care for your spouse the lines blur between husband/wife and nurse.

I was married, but for many years I didn't have a partner I could share things with, such as a joke or some family gossip. I didn't get a cuddle when things were getting too much to handle, I didn't have anyone to tell me that I looked nice now and then, there was no partner to make love to.

Shane's medical needs were met but his and our family's emotional needs were never addressed.

All the time **“IT”** had a huge impact on our family financially. I continued to work 2 part time jobs as it was too difficult to survive just on the pension and it had become clear Shane would never return to his line of work. The children couldn't have those special treats that most take for granted. We always had to choose outings that didn't cost much money. Christmas, Birthdays and Easter were always a struggle. As they got older the most fashionable and “label” clothes that their friends had were financially out of our reach. They often had to decline invitations from their friends, as we simply could not afford it. The children, for many years had to do chores around the house that most of their peers didn't have to do.

I had many family, friends and health professionals such as social workers and hospital allied health workers that tried to talk me into getting some assistance, such as home care or personal care for Shane. I was reluctant to accept help because he didn't want strangers helping him and I felt it was my role as wife and mother to take care of my family, I felt it would have been a sign of failure if I asked for help. I did however after a lot of pressure submit applications for funding.

Shane had been attending a day program for a few years twice a week at the Multiple Sclerosis Society. They would provide a taxi to pick him up from our home and return at the end of the day. The Manager and Social Worker decided that Shane would be “better off” doing something else. After many discussions and meetings with key stakeholders such as Physiotherapists, Occupational Therapists and Social Workers, Shane enrolled at RMIT to complete his VCE. This was a huge step as he had left school as a fourteen year old at the end of first term year eight as his grandmother was raising him alone and was financially unable to keep him at school. He used a computer for the first time in his life.

Shane found it very difficult to accept the decline in his health. He would refuse to use aids and equipment that would have made his life easier. He felt it was giving in. The biggest hurdle was accepting a wheelchair fulltime, instead using crutches and furniture walking.

Shane was walking with crutches and furniture walking, he had a bad fall, I took him to the doctors the next day saying his shoulder was "a bit sore" The doctor suggested that he take some Panadeine and come back in a few days. He went back and said it felt a little better. A month later Shane said to me that his shoulder was still sore, I rang the doctor who ordered an x-ray. The doctor called and said that Shane had a broken shoulder. He had been using crutches with a broken shoulder for a month. Six weeks later, another fall and a crushed vertebrae, resulting in a hospital admission. Shane was then forced into a wheelchair fulltime. He had completed 2/3rds of his course when this happened and did not complete it.

It was 1991 and Shane had another MRI, we were told he **probably** had slow progressive/attacking MS, so from then on that is what we called "**IT**". Although many doctors were still skeptical.

In 1993 a social worker suggested that Shane register with Commonwealth Rehabilitation Services (CRS) to retrain in the hope of obtaining employment. CRS assessed Shane including asking him his preference of work and his interests and arranged for Shane to do work experience at a pet store, he was meant to be there for six weeks on a minimal wage. They were so impressed with him they kept him on for six months on full wages.

When this ended CRS then set up another six week work experience program at The State Animal Research Farm within the Department of Agriculture, Shane needed a motorized wheelchair to enable him to complete this position so CRS hired one for him. This lasted for a year. They again were impressed with his work ethic and offered Shane permanent part time employment. This meant that Shane had to purchase a motorized wheelchair, he was not eligible for State funding because he was registered with a Commonwealth Department and the Commonwealth Department didn't offer money for aids or equipment. I wrote numerous letters and obtained many supporting letters. I also applied for grants and made close to one hundred and fifty phone calls to raise \$4,500 needed for the wheelchair. After nine months of advocating, campaigning and lobbying, the wheelchair arrived. Shane then had the opportunity to take up part time employment; the Dept of Agriculture retrained Shane and he went on to perform a variety of duties including switchboard, reception, data entry and data analysis.

I had begun my own business to give me the flexibility to help Shane, so our life then meant us getting up at 6.00 am so I could shower and dress Shane and give him time to rest before I drove him to work and arrive at 8.30 am. I would then continue on to my work until lunch time then I would go to pick him up from his work, drop him back home, get him some lunch and make sure he was settled for the afternoon and then go back to work myself. I also had to get the six kids organized for their day with three at high school and three in primary school. I would then return home after work and start the evening routine of meals, showers, homework etc...

By this time I was exhausted, I gave in and made inquiries about a personal carer to come in and shower Shane, but back in those days he could only get a Linkages funding package which was considerably less than now. The service provider Multicare that would eventually expand to become Australian Home Care Services was the only provider at the time that would start that early but they also charged higher rates to start at 6.00 am that his package didn't cover. I did however start receiving home care from the local council.

In 1995, after submitting new applications four times a year over five years for funding, Shane was granted an In Home Accommodation Support (now known as Home First) package. Shane then had to have an assessment done to ascertain his needs and how many hours a week care he would need; this involved an assessment officer coming to our home to ask a series of questions. We were asked how long it took to do each individual task involved in Shane's care.

This was a very involved and comprehensive assessment including showering, dressing, brushing teeth, shaving, toileting, preparing and eating breakfast and cleaning up after each of these tasks. The amount of time to complete each task was then calculated and the amount of 26 and $\frac{3}{4}$ hours a week was approved. We then began receiving services.

In 1996 Shane had a catheter inserted, at first it was an in dwelling catheter then a few months later it was changed to a supra pubic catheter. This gave him so much trouble with infections and bypassing over the years that I ended up changing them myself instead of waiting in a hospital emergency room for hours or waiting for a Royal District Nurse to show up at the house. I did not get the years of training that a nurse does, it was all on the job, learn as you go. Sometimes I got it right a lot of times I got it wrong.

Not long after I also began caring for my mother who had emphysema, lung cancer and was oxygen dependent. I did this for the next 3 years initially going to her home each day and then in my home after she moved in with us.

The help I was getting was much appreciated, the carer came in each day, and showered Shane then showered Mum as she had a small funding package also. It also allowed me to have a few hours a week respite, which was wonderful. I was back to part time work.

In 1998 Shane had to stop work as his disabilities, including his memory loss, and hospital stays increased. His swallowing had deteriorated, he was assessed as needing thickened fluids. He was also advised that he would need a peg feed to stop him aspirating (choking) resulting in repeated pneumonia's. We researched peg feeds, spoke to people involved in them, discussed it at length and made an informed decision **NOT** to have one inserted. We were told that this realistically meant that Shane would live no longer than 2 years.

I applied for an increase in support and after seven months on a waiting list for another assessment, an increase of hours was granted of the maximum of 34 hours a week. At the same time Shane was assessed as needing a hospital bed and air mattress to help alleviate pressure sores.

Shane's needs for aids and equipment were always changing and there were often long waiting lists for assessments, funding and for equipment to arrive.

We have always been a "strait talking" sort of family and as Mum's cancer had worsened we had a lot of "euthanasia" and "quality of life" talks. We spoke about and completed both power of attorney and medical power of attorney documents. Both Shane and Mum had said that they thought that quality of life was the most important thing to them and they didn't want to continue if they were in uncontrollable pain or couldn't continue to participate in life.

Christmas Eve 1999 Mum lost her battle.

Over the next six years Shane had hospital stays for pneumonia or urinary tract infections, often both, every one or two months, each time the medical staff would call me outside the hospital room and ask me if I wanted him to be treated. I was told even if he was treated, he might not respond to the antibiotics. I always felt that despite the fact that I had medical power of attorney and even though he was cognitively getting much worse, he would know when the time was right to stop fighting. I was so grateful for the talks that we had. It was a decision I did not want to make on behalf of someone else even though I knew his wishes.

In March 2004 during another hospital visit, Shane turned to me and said he had, had enough. By this time he had been bed ridden for two years and was paralyzed from the neck down, he had been in constant pain for almost twenty years and had been on morphine for five years. He had no control over his bowels or bladder. The doctors respected his choice, removed the drip and told him he most probably had two weeks to live.

Shane was turning forty nine the next day.

With help from the Palliative Care Team, Shane came home and continued to defy the odds as he had always done, the doctors and nurses would just throw their arms up in the air and say they didn't know why he was still alive. In August he hemorrhaged and was rushed to hospital by ambulance. He was in and out of consciousness for two weeks; we were told that he wasn't going to survive. Shane, in true form, woke up and said "I'm starving, what's to eat?" He rallied again and came home on the 6th September.

On the 4th October 2004 Shane passed away at home, just short of our 20th wedding anniversary.

I requested an autopsy to determine exactly what "IT" was that Shane had for 27 years as there had been so much doubt and conjecture over the years. I felt it was important for the children and grandchildren to know, in particular one daughter, as her mother-in-law also has MS. At the same time I donated Shane's brain to research.

The result came back; Shane had Multiple Sclerosis and nothing else. The faulty MRI was right!

There was always a constant stream of meetings with various individual stakeholders to discuss and plan the most effective way to take care of Shane's needs (and very occasionally my needs also). The Care Manager from AHCS would come to my home for reviews every six months to update Shane's Care Plan and discuss any changes that needed to be implemented as his health deteriorated. Shane's Case Manager would complete a home visit monthly. The Physiotherapists, Occupational Therapists and Speech Therapists were seen on a regular outpatient basis. There would be Case Meetings with all involved parties. Shane was always happy for me to act as his advocate as he trusted me to put his needs, wants and desires first.

I received 34 hours a week of care. This left 134 hrs a week that I had to take care of Shane, maintain a house, maintain a garden, pay bills, do the shopping, spend time with my children and grandchildren, have some sort of social life etc etc.... and, oh yes.... Sleep.

Sleep deprivation is what is used as a form of torture in wartime.

But this 34 hours is what kept our family going and enabled Shane to stay at home. Without that he would have been in full time care many years before. And I deeply appreciate that he didn't have to do that.

This is a list of some of the people/services involved in Shane's care over the years that all had input in his day to day living:

GP, Neurologist, Neurosurgeon, Urologist, Psychologist, Psychiatrist, Vascular Surgeon, Orthopedic Surgeon, Pain Specialists, Pain Clinics and Assessments, Physiotherapists, Occupational Therapist, Speech Therapist, Social Worker, RDNS, Palliative Nurses, Case Managers, Care Managers, Personal Carers, Home Carers, Service Providers, Funding Bodies, Assessment Officers, Ambulance Officers, Hospitals

This is a list of some of the tests and procedures involved in Shane's care:

X rays (too many to count), IV drips (again too many to count)
Blood tests (way too many to count), Mylograms, Lumbar Punctures, MRI's, CT Scans, EEG, ECG, Skin Biopsy, Nerve Biopsy, Muscle Biopsy, Tests for lead and mercury poisoning on Shane's hair, Videofluoroscopies, Urinary flow x-rays, many different eye tests, Surgical Sympathectomy, Non-Surgical Sympathectomy, toe amputations.

Treatments for Pneumonia (too many to count), Cellulitis, Osteomyelitis, Tunnel vision, Double vision, Pressure sores (many), Asperation, Many ambulance trips to hospital.

There were also many, many medications and treatments. Shane had to often take medication to combat the side effects of other medications, at some stages taking up to 32 tablets a day.

There were numerous application forms, assessments, and waiting periods to deal with to obtain funding, equipment and modifications. As Multiple Sclerosis is a degenerative disease Shane's physical needs were ever changing. Equipment would become outdated or unsuitable very quickly.

This is a very brief overview of what someone with a chronic illness may go through. I could talk for hours about the series of problems and obstacles we faced during this time and believe me there were many. Including, access to buildings (even doctor's rooms), discrimination, obtaining appropriate services, funding and equality. It was a constant battle.

This all sounds very depressing and doom & gloom but it was not always the case.

Having a family member with a severe disability gave my children a great insight in to being tolerant, patient and to have empathy for people with a disability or are not mainstream.

We laughed a lot when things went so wrong we would have cried.

Once Shane had accepted that he had cognitive problems including memory difficulties it was a great source of amusement to him and the rest of the family.

Shane perfected the art of convincing people (even Doctor's and Specialists) that he was following everything they had said to him. He would have a full conversation with someone, when they left I would ask him if he knew what the conversation was about and he would say no. I would then have to explain it all again in a way he could understand.

As the kids got older they thought it was a great money saver that they could give him a present, take it back and give it to him again for the next occasion as he would have forgotten about it.

Shane would watch a movie on Foxtel in the morning, ask me if he had seen it when it was repeated in the afternoon, then ask me if he liked it and should he watch it again, which he usually did.

I used prompts like “Oh you remember so and so from so and so” He would always say “no” in front of them, sometimes quite embarrassing!

Then he would rattle off a phone number he had not rung for 10 years.

In the days when Shane was still walking, but with difficulty, and then in a wheelchair, he would often get stuck (always in self opening doors) or have difficulty with access. There was ALWAYS an 80 year old man (usually on a walking stick himself) that would try and help.

There was the time we were at a restaurant, we had finished our meal and Shane reversed his motorized wheelchair out, what he didn't know was that he had caught the leg of the chair behind him and had dragged a grandmother having dinner with her family across the room with me screaming at him to stop. We managed to contain ourselves until we got outside and then split our sides with laughter.

Finally, when I knew Shane was terminal I had to re evaluate my life, I was 47 years old with 6 children and 7 grandchildren. I had not worked full time for 28 years and had not been to school for 31 years. I went back to school and enrolled in Certificate 4 in Disability.

When Shane passed away the company that had provided our carers called me and asked me to come and interview for a position in their office. I was successful and began work as a Coordinator. I then went back to school again and obtained my Advanced Diploma in Disability Work.

I have progressed in my career to become a Team Leader working with children with Intellectual Disabilities and Challenging Behaviors and now working for my Local Council and am now studying for Batchelor Applied Science-Disability.

Throughout the years I had to learn to advocate for Shane, myself and my family. I joined disability groups and mailing lists. I was invited to form a state quality assurance respite committee for the MS Society. I became involved with WRDN (Western Region Disability Network)

For over 10 years I have facilitated a carers support group for partners/parents of people with MS.

I am a current peer support volunteer for carers of people with MS.

Shane's disability has given me a chance at a career that I probably would not have contemplated. I have met some miraculous people, both with a disability and without and have learnt a lot about the human spirit.

I know I only made it through by having such an amazing group of family and friends that always supported me emotionally. Practically, there was not a lot anybody could do.

I am now 51 and engaged to a remarkable supportive man who is a past primary carer. He spoils me rotten and understands what I have been through because he has been there to a degree himself. It is still difficult to accept being looked after instead of the other way around but I am slowly getting there.

I would like to stress to you the importance of the carers we had in our lives. Carers become part of your family and your life.

You have to be comfortable with that person.

Most of our carers were good, a few were excellent, and a few were absolute shockers.

A co worker commented the other day "Imagine having to get up every day at the same time because that is when your carer arrives". Well, that was my life for many years.

It **IS** an intrusion having people in your home.

You have **NO** privacy.

You **CANNOT** be flexible according to your desires of that particular day.

You **HAVE TO** rise, eat, work, entertain, shop, do household chores and sleep to a schedule.

Your freedom of movement is taken away from you.

I have heard said that "Oh it's only a short shift, it's not a priority!" or "Don't worry, the family member can do it if we have no one to fill the shift" but believe me **EVERY** shift is important and good quality care is also important.

People that are dealing with a disability either themselves or a family member do **NOT** need the added burden of a program that does not run smoothly. They have enough to deal with.

A person with a disability and their families do not **WANT** carers in their lives they **NEED** them.

An illness or disability affects the whole family **NOT** just the person. It is very difficult for family members to leave their ill, loved one in the care of a stranger.