

Submission
No 2

**INQUIRY INTO THE EXERCISE OF THE FUNCTIONS OF
THE LIFETIME CARE AND SUPPORT AUTHORITY AND
THE LIFETIME CARE AND SUPPORT ADVISORY
COUNCIL - FOURTH REVIEW**

Name: Mrs Donna Axiak

Date received: 9/08/2011



Wednesday, 10 August 2011 Tuesday, 9 August 2011

Hon David Clarke MLC, Committee Chair,
Legislative Council,
Standing Committee on Law and Justice.
4th review of the Lifetime Care and Support Authority.

Dear Sir,

My name is Donna Axiak.

I would like you to please consider this submission into the 4th review of the Lifetime Care and Support Authority.

I would like to give some background on why my submission is relevant to your review.

On the 26th day of June 2008, at approximately 4pm my relationship with the Lifetime Care and Support Scheme began, without me even being aware.

It was the last day of term two. My two youngest daughters alighted from the school bus, Alana 14 years old at the time was slightly ahead of Mikaela, 13 years at the time. Alana had just crossed the centre of the rural road that runs in front of our home in Ebenezer, north western Sydney when she was struck by a car.

The why's, wherefores' and culpabilities are not pertinent to this submission.

At the time of first examination by the Doctor travelling on the Care Flight Helicopter Alana was rated a 4/15 on the Glasgow Coma Scale. She was sedated, intubated and flown directly to The Children's Hospital at Westmead. Alana had suffered a very severe traumatic brain injury and from this point on she/we would learn to live with an Acquired Brain Injury.

Alana remained in a coma for six weeks. The first 2 weeks she was in intensive care as she was unable to breath unassisted.

The intubation was removed after two attempts, on day 14. Alana was still non-responsive.

It was on this day that I was visited by a LTCS representative although I didn't actually meet her. She left me a packet of paperwork in a clear plastic sleeve with a note telling me it was our responsibility to fill it in. Considering what was happening, I glanced at it and put it aside.

To set the scene for you;

I met the helicopter at the hospital as I was at work when Alana was hit. My 52 year husband Michael, was at home waiting for our girls to get off the bus. He heard the bang when the car hit Alana. He heard Mikaela's screams as he ran to the road.

He was in shock, he has never recovered. A neighbour drove him the hour to the hospital and he had a minor heart attack in the emergency room. My youngest daughter Mikaela was inconsolable at home surrounded by her grandparents, family and friends while being interviewed by police. My two oldest daughters, Calina 17yrs at the time and Toni 16yrs at the time were doing their best to cope with their grief, hold themselves together, field phone calls.

That first night we had to give permission for Alana to have surgery to relieve swelling around her brain. We were told about permanent brain injury, told that if she survived this was a possibility.

She did survive, but during those first two weeks everything else didn't.

Michael fell apart so badly that he just has never been able to repair. I had to call his Uncle to come from Queensland to be with him. Mikaela, who needed her Mum, couldn't have me because I was unable to leave Alana's bedside. Friends and family held us together. They encouraged Calina and Toni to keep studying as one was in Year 12 & one in Year 11. They brought food and meals to the house and to me at the hospital.

Michael was told by the Cardiologist he needed to have another stent inserted in to a coronary artery. So this was organised from Alana's bedside.

I was asked by the Clinical Nurse if I had filled in the paperwork from LTCS- I almost laughed at her. For the last two weeks I had almost lost one daughter, my family was a mess, my husband needed medical attention for his heart, my small business, our only source of income, was in the hands of my businesses partner, I had no sleep, very little food, I had not seen the sun or breathed fresh air. I had learnt what every machine in Alana's room did, why it did it, what the good beeps were, what the bad ones meant and when to panic and when to pray the hardest. So no, I hadn't filled in the paperwork. Would you?

I started to get messages left on my mobile phone from LTSC so when Michael came in to the hospital with his Uncle who had flown down from Queensland to support him, I handed the package to them and asked them to have our solicitor fill them out- they looked legal, there were questions about the accident, we had not been contacted by the police or spoken to the police so I had no idea "who the driver of the vehicle was". Michael took them to our small town lawyer who had previously handled a paddock fencing dispute for us. This turned out to be a big mistake! None the less they were completed and he sent them in.

Over the following 4 weeks Alana managed to work her way through the Ranchos Coma Scale to Level III.

She was still non-verbal, I was tube feeding her every three hours, changing her nappy, moving her arms and legs, playing her favourite music, talking to her, reading her the messages and cards from her school friends, wiping her face and willing her to open her eyes. I wanted her to see me, smile at me and talk to me, to tell me she was hungry. I remember looking at her feet and legs that had not been damaged in the accident but had now started to drop and turn from the muscles not being used- "just move Alana, just a little bit" I would say over and over.

Alana did eventually do all of those things.

It took three agonising months, Alana's inner strength and determination, the grace of God, a family of steel, friends who gave support and the expertise and wisdom of the Children's Hospital at Westmead Rehab Unit

We reached a point where Alana was required to do a day visit to home in preparation for returning to home full time.

This is when the enormity of the role LTCS was going to play in our lives began to dawn on me. We needed many things "approved" before anything was possible.

Wheel chair, shower chair, railings, our home had to be checked for safety, it went on and on and so did the paperwork. Thank goodness for Alana's Rehab Team who organised everything, liaised with LTCS and kept the stress at bay. Alana's Rehab Team Case Manager, who up until this point had been in the back ground, now became the most important person in our lives. She slowly introduced us to our new lives, our life with LTCS.

On September 22nd Alana left CHW in a wheel chair, with an Acquired Brain Injury. We (our family) all thought that once we got in our front door and sat at the table for dinner that night we could pick up where we left 3 months earlier. How naïve!

Our lives would never ever again be spontaneous or unplanned.

Alana's life would never again be hers. It was from now bound by the discretion and comprehension of an LTCS employee, a co-ordinator, about her rehabilitation needs. It is this aspect of the care that I wish to make comment about.

Alana has had a magnificent team guiding her and helping her move forward with positivity and meaning.

Alana is unaware of the battles that rage in an effort to keep her life as "normal" as possible.

In Alana's Team currently are; her family, Case Manager, Clinical Psychologist, OT, Physiotherapist, Psychiatrist, Neurologist, Carer provider co-ordinator, Support worker, School Special Needs Co-ordinator, School Assistant.

All of these professionals input to the LTCS co-ordinator, they complete CLP, CANS, and PACA's - reams of paperwork and hours of calculations to pursue the LTCS goal of setting goals for Alana.

They use their intimate knowledge of Alana to assess, question and ultimately organise a schedule to promote Alana's growth and ability to lead a meaningful and worthwhile life. On a daily basis I communicate with any or all of these people, they meet with Alana, they understand our family, our circumstances, and they have visited our home and Alana's school on many occasions. No one is omitted from the emails and timetables constructed to build and maintain a meaningful existence for Alana. They deal and help me deal with her setbacks and disappointments and join in the celebrations of achievements. How amazing is this when you consider that Alana is only one child of 20-100 that each of these professional people manage.

These plans are submitted on average every 3 months – always within the allotted time frame and adhering to the strict LTCS guidelines. We then sit in anticipation of the LTSC decision, of judgement.

Alana's life, our life is not only controlled by Alana's brain injury and its subsequent effects but by Life Time Care and the multiple assessments they require her to endure. We just seem to settle into a pattern, a routine that Alana is comfortable with and it's time for a new Care Plan, therefore, bang! More assessments. Each time Alana participates in an assessment of some sort it reinforces her disabilities to her. Assessments are proof to Alana what she is incapable of. I realise the best decisions for Alana can only be made by having the correct reading of her needs and ability however there has to be a more efficient and less intrusive way to achieve this outcome. An option that does not leave Alana exhausted, depressed and in need of further intervention.

Each time Alana experiences these emotions it is shared by a whole family; it impacts on all our lives, our wellbeing not only as individuals trying to lead a productive life but as a family unit that has endured great tragedy, lives with timetables, plans, backup plans and disappointment.

So we make ourselves and Alana available for each of the assessments, meetings and appointments. We arrive on time, we are prepared. We are always open to suggestions and ready to comply to any requests. We then deal with the aftermath of Alana's questions and upsets for days sometimes weeks afterward.

We do this so that the CLP's can be approved and we can settle as quickly as possible into yet another routine. Unfortunately the nothing with LTCS is that simplistic.

On one occasion in September last year, one current plan had concluded, the next plan although submitted had not yet been approved. I was terrified Alana would have no care, could not go to school or therapies because we had not received approval for the next plan period. The deadline arrived – I arranged for time away from work, for grandparents to come and help out because if care wasn't approved we would have to be there for Alana. Her not being able to go to school was the worst part, although she had a care assistant by her side and it was a couple of hours it was her only link to her old life. Alana's case manager kept in touch trying to calm us. It became intolerable so I contacted Alana's LTCS coordinator by email (as I wasn't able to get through via phone). She told me not to be concerned. Easy as that. Ridiculous. Our now normally stormy life had been under unbearable stress waiting for approval and I am told "don't be concerned".

Do LTCS fully understand their impact on, not only Alana but our entire family, our lively hood and most importantly of all our wellbeing?

To have worked hard and made sacrifices to ensure your children have the best possible chances in life, better than those you had, to nurture aspirations and promote their dreams and ambitions, love them more than anything in the world and have that destroyed by a split second; a pool accident, fire, or, in our case a motor vehicle – to watch on helplessly as strangers turn into miracle workers and take total control of your child's very life is unbearable but then moving forward, surviving, we now wait apprehensively for tick of approval from LTCS before any family decisions are made, because since 28th June 2008 that's what our life has become.

LTCS uses a unit of measure called; "*reasonable and necessary*".

I am not understanding of how this measurement is applied or exactly what it consists of.

I know what a metre is as I can see it, I know what a Kilogram is because I can feel the weight but I am not able to tell what *a reasonable and necessary* is.

It is my concern that it is an abstract term that will have a different bearing depending who is using it. A metre is always 100 centimetres- there is no question or contradiction but *a reasonable and necessary*? Is this open to interpretation? I haven't been able to find it listed in as a standard unit of measurement – anywhere.

When presented by pages of information and explanations by professionals who have an in depth and personal knowledge of the participants abilities, goals (the magic word), family and lifestyle why then does a LTCS coordinator, who has no first hand connection with the participant have the power to make life choices on their behalf?

Is “deemed reasonable and necessary” applied differently in keeping with each participant’s needs?

It seems that “deemed reasonable and necessary” is a judgement call, an onerous decision open to one LTCS coordinator’s individual interpretation and experiences, being applied to another person, often a child’s life which then in turn effects the wellbeing, physical, emotional and mental, of a whole family unit.

No-one from LTCS has ever meet Alana. Not even her coordinator. Even though it states in LTCS, Doc no: IF04/07 Parent Information form;

“The Authority appoints a LTCS coordinator who will visit you and your child to find out more information about the accident.”

The same document also states;

Who decides what services my child will receive?

The LTCS coordinator will arrange for an assessor to provide expert advice about your child’s rehabilitation and care needs. Your child will be assessed as their needs change. The assessor will usually be a member of your child’s rehabilitation team.

LTCS coordinator does not arrange for “expert advice” this is done by the hospital, the case manager. The expert advice is handed over and then judged- “deemed reasonable and necessary” It is a misleading statement.

I am not ungrateful for the services we are afforded by LTCS. The system itself is a magnificent step forward, its conception in 2006 opened doors for young people with acquired catastrophic injuries. As the registered owner of four family vehicles and another four work vehicles I have never balked at the addition to the CTP Green slips that fund the system. Now as the mother of a Life Time Care Participant, I applaud the change; Lump Sum payments to claimants for non-economic loss and future economic loss still payable but care, treatment and rehab being funded for life. This ensures the claimant should never want for health care resulting from the injury, no person can take advantage of the “payout” or their funds dwindle while their needs may increase. I don’t feel, especially now living this, that anyone would dispute the benefits under the Act.

With its birth in October 2006 applying to children under 16 and its inclusion of adults in 2007 the scheme should be still considered in its infancy. It is my hope that as guardians, the Motor Accident Authority and the Standing Committee are open to consider the thoughts and experiences of those of us who through necessity and despair offer our children and their future into the hands of LTSC and your parenting skills.

A scheme such as this with all it has to offer needs to evolve and grow. As with the very children it was designed to protect, it can only do this by accepting to, at least consider, the guidance and experience from those who shall walk in its shadow for a lifetime, in our case, my daughter's lifetime.

Thank you for taking the time to read my submission.

Yours Sincerely, Alana's Mum.

Donna Axiak