

Every Child Matters

**National Conference on Children & Young People with Disabilities &
their families**

TRISTAN and TIARNA's Life: A Family's Journey

Introduction

Advances in health care and technology have extended the lives of chronically ill children, many of whom survive to adulthood. In the past 50 years the care of this population has shifted from hospitals and other institutions to homes and communities (Meleski 2002). It is every child's right to be an integral part of a family and to be cared for by that family. However, when a sick child is discharged into their parents care and goes home to be cared for by their family, do we provide them with adequate support to fulfill their caring needs?

Wiley (2005) states that, "Care in the community is good and care at home is even better" for the client but it is not necessarily so for the family. Forde et al 2004 have written that parents who have a child with a disability experience significant and persistent levels of stress. However, Schwartz and Gidron (2005) report that the reward and satisfaction of providing care for a chronically ill child may outweigh the burden.

Reasons for Presenting this Paper

My reason for presenting this paper is to give you service providers insight how difficult our lives are and to support us as much as possible to give our children the quality care that they deserve. Wiseman 1996 states, that it is imperative for service providers to understand the experience of care giving for a child with a disability from the care giver's perspective to benefit not only the parents but most importantly the child. We do not want sympathy what we need are your understanding and to be dealt with fairly when we ask for your support. It is my goal, that on conclusion of this presentation, the audience will have gained some insight into the support network needed for a family to effectively care for their child with a disability at home.

The essence of this paper is about respite care. I would like to present the paper in two sections.

1. Back ground information about our family
2. Respite care

Family Profile

Let me introduce to my family. My family comprises of my husband Fabian, eldest daughter Danica (13 years), son Tristan (11 years), younger daughter Tiarna who passed away in 2003 aged 3 years and 3 months and who would have been 8 this year. My presentation is dedicated to her memory.

Tristan and Tiarna were diagnosed with Lissencephaly. For those of you who are unfamiliar with the condition it is a neuronal migratory disorder. Around the 4th – 5th month of the pregnancy cells migrate from the centre of the brain to the surface. In Lissencephaly this migration does not occur. As a result the entire surface of the brain is either smooth or has abnormal folds. There are a few types of the condition. Both Tristan and Tiarna have Isolated Lissencephaly Sequence and their entire brain is affected i.e. they have the severest form of this illness. Lifespan is much shorter than normal and children who feed orally usually live longer than children who are tube fed. All children with lissencephaly have severe mental delays and poor control of movement similar to children with cerebral palsy. Still, some do make limited developmental progress. Other common problems include poor feeding, frequent seizures and repeated episodes of pneumonia.

For those of you who question the wisdom of having a third child I must say to you that the decision was not made lightly, far from it. Our genetic risk was 5% for a boy and we were told that it was 100% safe to have a girl. Tiarna's diagnosis has made us the only family in the world with a male and female child with Isolated Lissencephaly Sequence.

Time in hospital

Tristan was born on the 20th September 1996 and was diagnosed when he was 12 days old. Tiarna was born on the 24th May 2000 and diagnosed when she was 8 days old.

Most of my presentation will focus on Tristan because he has made a longer journey than Tiarna and also because their lives were so linked that when I talk about one of them it is like I am speaking for both.

The medical team told us that the condition was incurable and that treatment would focus on the management of symptoms. The most urgent being seizure control. The next three months of Tristan's life passed in a blur of frequent presentations to emergency with Tristan having prolonged seizure activity. Tristan responded poorly to most of the anticonvulsants and all of the standard drugs used to stop a prolonged seizure did not work on Tristan. A family meeting was organised for the end of December, at this meeting Fabian and myself were told that nothing more could be done at the hospital to help Tristan. It was the medical team's decision that Tristan be discharged from hospital and transferred to a community-based centre to be cared for. We could then resume our lives as normal i.e. get back to work and all other general activities that we did before Tristan was born. We were also introduced to the local Community based team DADHC so that we could access the service if required. We were told that there was no need for us to present to emergency unless we were not coping.

Fabian and I visited the community-based centre called Allowah Children's Hospital. Our first visit was very confronting, every single child there was severely disabled and some of them had been there for years. We did not want to send Tristan there to live; we wanted to try to care for him at home. On January 7th 1997 Tristan was discharged into our care. The medical team's recommendation was that we take him home and love him because he would most likely die within the month.

Goals for our family's future

Fabian and I discussed the plan for our future, we were determined to have a good time with Tristan and we wanted Danica to remember having fun with her brother. In life you always have a choice with the way you deal with what life brings your way. It was a conscious decision from the word 'go' that we wanted to give our three children the best life possible and to enjoy them as much as we could. We regularly accessed the community and sometimes looking back because of the fear we had of losing Tristan and the pressure we felt to have fun times with him we actually did more fun things with Tristan as a baby than we did with Danica. In research by Gibson (1995) a mother reflected, 'If anything good has come out of this, I smell the roses a lot more. I was a workaholic before and made time for the kids at the end of the day. Now the kids come first. Work is always there. I spend more time with my family- they come first'.

Time at home

When Tristan was sent home his seizures were occurring for hours on a daily basis, he had a whole spectrum of seizures and was requiring suctioning and oxygen. We worried about how we would cope with the level of care that he required. One of the doctors suggested that we put him in a bedroom and only check on him once every four hours when he needed something, such as a nappy change, feed or more medication. It was meant to be a helpful suggestion to encourage us to get back to normal.

Research has shown that the health of a chronically ill child is extricably related to their parent's overall well being. Whitney 2005 states when a child is chronically ill and parents must be on-call every day and night of the week to attend to and care for their sick child the parent's health becomes compromised and their ability to care for their child is lessened. Tristan slept in a bassinet in our bedroom and in four weeks time we had run ourselves ragged. We had to accept that we could not keep this up long term. It made us seriously reconsider the option of using Allowah Children's Hospital as an out of home respite for Danica and us. I have to add that the only reason that we qualified for Allowah Children's Hospital was because we had top-level private health cover. We finally conceded that in order to provide Tristan with the quality care he deserved we would have to use out of home respite care. We set up a routine of taking Tristan to Allowah on Friday evenings and picking him up on Sunday mornings. We desperately needed two nights of uninterrupted sleep to recover.

Respite care

The local community based team was from the Department of Community service, which is now called the Department of Aging Disability and Home Care. A nurse on the early intervention team became our caseworker. A few months after Tristan's discharge from hospital we were allocated three hours of in-home respite care a week and I was given access to a counsellor who would make a monthly home visit. When the hours were allocated to me the case worker told me that I could use the hours on a needs basis, i.e. if I was having a particularly bad day I could get someone to help out. The reality of course is quite different.

I was allowed to access a nurse from an agency. The nurse had to be booked the previous week and I had to use my three hours in one go because no one wanted to travel to my house for less than three hours of work. Adjusting to a stranger in your

home is difficult; trusting your sick baby with her is even harder. Having in-home respite care is not for every family. It is really very hard to have someone in your home; our home at the time was small so the carer could not be confined to one area with the child. She needed to access the kitchen for feeds, the toilet; the medication was kept in our bedroom for safety (so she even came into our bedroom). If you are a private person it is a big hurdle to overcome. It was much harder for Fabian than myself and for many years I had to arrange the respite care so that the person had left before Fabian came home. He was not comfortable leaving the children with a carer while we went out so we never used it for that purpose. The respite care helped me to complete my household chores like cooking, washing and shopping without having to worry about the kids.

The person that I had the most difficulty dealing with was my caseworker. I found her extremely difficult to deal with and I used to make myself sick with anxiety every time she was due to pay us a visit. She was very forceful with her suggestions and made you feel that she knew best. Every visit she would tell me that I was not using the out of home respite enough. She was very judgemental about how well we were coping and frequently told me how lucky I was that Tristan was my second child that it was far worse for another mother whose first child had disabilities, she told me I was so fortunate to have a medical background and to be able to speak English fluently so that I could advocate for my family.

I could never understand her motives for always telling me stories about how other mothers were struggling while I was coping so brilliantly. It was only years later that I discovered that the in-home respite hours were given to us as part of a trial. It was called the 197 Program because there were 197 subjects in the trial. The in-home respite was never meant to be long term. Tristan was a perfect subject for the trial because he was only meant to survive for a short period of time. He however had other plans and it is a miracle that he is still with us today.

A turning point in our lives

When our beautiful girl Tiarna was born we were the experts by then. No one made any dire predictions or gave us any helpful suggestions on managing Tiarna. DADHC however were quick to recognise that we had our hands full and increased our support services. Unfortunately Tiarna only survived for three short years. Until Tiarna's death we used out of home respite service (Allowah Children's Hospital) once a fortnight to be able to rest and to give Danica our undivided attention.

On July 16th 2003 we took Tristan and Tiarna to Allowah Children's Hospital as usual, two hours after dropping them off we received a phone call that Tiarna was struggling with her breathing and was being transferred to hospital. When Fabian and I got to the hospital; Tiarna looked like she was having an asthma attack. However, hours later when the usual asthma treatment did not help the doctors sat us down and told us that Tiarna was not maintaining her airway and that she was not a candidate for ICU or ventilation. Tiarna struggled for two days and then seemed to recover. Fabian and I thought that the doctors had got it wrong because Tiarna looked back to normal. We were told that her life could be measured in days and weeks not months and years. Sadly on the 19th August after her condition deteriorated significantly Tiarna died in our arms surrounded by the people she loved in her home.

At the time of Tiarna's death Tristan was also very ill. He was so ill that the day after her funeral he was admitted to hospital with a respiratory illness. It was a horrible time when we thought that both of our kids would die days apart. Until Tiarna's death we had thought that the only way that we could lose the kids were due to pneumonia or a prolonged seizure. Dying from a floppy airway had never been discussed. What I have since learned is that if you have a floppy airway your air passages are narrower. Any respiratory infection can cause swelling of this already narrow airway and it could be fatal.

Tristan had been attending school since the age of 5 and ½ years. His attendance was poor because he was always catching respiratory infections. Finally in 2005 the school recommended that he be tutored as a distance education student. This was the best thing that had happened to our family. Tristan liked school but he would attend school for a few days catch something and then be home for weeks recovering. It made things much more difficult for him and for us. Out of home respite was another risk to Tristan's health because he would catch infections and what was meant to give us a break for two days actually ended up making us work harder for weeks and our stress levels were constantly up and down. Fabian and I decided then that we would not use out of home respite for Tristan because after Tiarna's death we felt that sending him anywhere where he was at risk of catching a serious respiratory was as good as sentencing him to death. We knew that we could not live with that.

The in-home respite that we receive meets our needs perfectly. We have remained on the same hours since 2003, over this time Tristan's health has significantly deteriorated. He requires more frequent suctioning, is on continuous and not bolus feeds and uses CPAP at night due to obstructed sleep apnoeas. We are happy to care for Tristan over night. And we get help during the day. This helps me to go to work, take Danica to school and to several after school activities that she does. It gives me the opportunity to not have to worry about Tristan every minute of the day because someone is watching him for me. I am able to concentrate on enjoying Tristan, we go on outings, do his school work, read books, go for walks and have fun. In-home support is the best thing for our family; it has meant the difference between coping and not coping. We want Tristan with us at all times. Whenever Tristan and Tiarna were away from us we felt incomplete as a family. Out of home definitely does not mean peace of mind, because you worry and the guilt of leaving them elsewhere made us so miserable that we never really felt that out of home respite worked for us.

In order to continue to receive in-home support I have had to fight tooth and nail to hold on to the service that we receive. Over the twelve years of Tristan's life we have had to deal with many different case workers and managers. Some of them were wonderful caring people and some of them we hope never to cross paths with again. Till today Tristan is on interim funding and not recurrent so every three months we have to stress about whether funding for our in-home respite care will continue or be stopped.

Funding for respite services

Our family has had a relationship with DADHC for close to 12 years. It is one of the relationships that we have because of Tristan's disability. When you have a child with a disability it throws you into a whole new world, a lot of work goes into maintaining,

strengthening and enduring relationships that we would never have had if Tristan did not have a disability.

Over the years the relationship that has been the hardest to maintain and sustain has been our on going relationship with DADHC the funding body for our in-home respite service. This funding has given our family the opportunity to have Tristan as an active member of our family as you can see from our family pictures.

However, every time we have a meeting with DADHC regarding our family it makes me sick with worry and fear. DADHC has so much control over our family because without the support that we receive through DADHC we would not be able to effectively care for Tristan's needs. I would not be able to be a good mother to Danica because I would be too tired after I had done my best to care for Tristan's physical needs, nor will I be able to work. My husband and my relationship would also suffer. Even with all the support that we receive life is not easy, Fabian and I care for Tristan for half a day. We wake up to him several times at night and we always put him to bed ourselves. We want to be involved in his care but we could not possibly carry the whole burden ourselves. Our relationship with DADHC is so difficult because the power is so unequal.

Whenever DADHC decides it is time for our family's funding to be reviewed a review is called. I have learned over the years that there are different kinds of reviews but no one ever took the trouble to explain clearly about what was happening. Another thing that I have learned over the years is that a review is always about reducing funding but it is never openly discussed. The most recent discussion that I had about our family's funding made me feel incredibly vulnerable. The discussion about the number of family's requiring services and the fact that I was receiving a service that was not available to other family's who needed it left me feeling really guilty until anger took over and I said to the DADHC representative that she was making me feel that I should apologise just for the fact that Tristan was alive. I remember one review being called a month after Tiarna had died. I said to the person at the time that Tiarna's death had reduced our funding needs by half and surely a review could be put off to a later date.

I have heard the word equity mentioned numerous times and I question it. How can it be equitable to partly meet the needs of any family? I feel for any family in a situation similar to ours and do not feel that I am taking anything away from another family like ours; we should not be made to feel that we are competing for services. I think that every family who needs help should get help.

How to make reviews tolerable

- Have a set time for reviews to occur, so that families have adequate notice and can prepare.
- Explain the process clearly to the family.
- Make the whole review process open and transparent.
- Try to understand the stress that the family experiences during the review process

CONCLUSION

This has been one of the hardest presentations to make. I am a nurse and most of my presentations have been to medical staff regarding caring for children like mine. I have

tried to make them understand that our kids also need love, stimulation and good health care like any other child. It is usually a very positive, uplifting presentation about the fun we have with our children. Families like mine struggle on a daily basis to stay positive and we need to be able to focus on the positives in our lives. Unfortunately in order to continue to receive funding we have to highlight the difficulties we experience and it can really get us down.

I ask all of you service providers to try to be aware of the difficulties that families like mine experience and to please be compassionate when interacting with us. There is so much more to say but I have tried to tell you all as much as possible in the 20 mins.

My final message to every one here is that I feel very blessed to be the mother of my three children. All my kids give me so much happiness every day and I love them with all my heart.

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