

5th August, 2012

To the Parliamentary Inquiry Committee,

As a family we have experienced first-hand Palliative care services.

My child, [REDACTED] had an undiagnosed Neurological Progressive condition. Amy was born on the 20th February, 1996 and passed away four years ago on the 17th June, 2008, she would have been 16yrs old now.

Our experiences caring for our child [REDACTED] have prompted us to provide you with our story and our comments regarding paediatric palliative care in Queensland.

We acknowledge the difference that exists between disability and palliative care but we also recognise the cross over that is intrinsically linked for many children with complex medical conditions.

It is our hope that by sharing our personal experiences and recommendations we can contribute towards highlighting the need for continued change within the paediatric palliative care and disability landscapes.

Please find attached a more detailed account of my child's story that supports my comments.

Yours sincerely

Regina Miller

AMY'S STORY

Amy was born on the 20th February, 1996, she was always a healthy and smart, fun loving and happy child. When she was almost 9yrs old and finishing grade 4, Amy started to have seizures, clusters of them. The first time she ended up having 9 seizures and after a few days in hospital, the Doctor said that if she had more seizures that it was epilepsy. A week later we were back in hospital with more seizures and that was the start of our journey. There were many hospital visits after that and they list of medication that was trialled grew bigger and bigger. Every day Amy would seem to lose some of her abilities, first it was thought that the different medication was contradicting each other and making her symptoms worse but after a few months and more medication trials the doctors called us in to tell us in a very scary meeting that what the actual problem was a lot worse than first thought. They started off by saying that the seizures where merely a symptom of what seemed to be some sort of progressive neurological disorder. They went on to do many tests both here and overseas and came up with no answer every time. What was certain was that we were losing a bit of Amy every day.

Amy was sick for a total of three and a half years, in that time she lost a little bit every day, within the first year she had completely stopped walking and not long after that she lost the ability to swallow her food and had to be tube fed straight to her stomach. She eventually lost her speech and then her neck control, towards the end she also lost her ability to use her hands and open her eyes properly. The one thing that she never lost was her sense of humour and her ability to understand what was going on. For the most part of Amy's illness and even though we had an excellent team of doctors that were looking after Amy and monitoring her regression, we were very secluded and alone. Whilst there are some great services for children who have well known conditions, there were no services for children with rare or undiagnosed conditions. It was a time where we needed the support and we were very alone. I felt that there was nowhere to go get answers or just to talk about what was happening let alone the fact that we really needed help to look after Amy. Amy would wake up approximately every 20 minutes through the night to be turned because she was sore and uncomfortable, and regularly through the day, she would need to be taken to the toilet regularly throughout the day because that was the other one thing that she was very conscious of and would ask to go.

Six months before Amy's passing we found the only Children's Hospice in Queensland at the time. Zoe's Place was an amazing place. I was very hesitant to send Amy anywhere as the prospect that someone else would be looking after her really scared me. Every time Amy spent in hospital I had stayed with her every second of the stay. I really needed help and respite from the full time 24hr care that Amy needed. The staff at Zoe's Place were fantastic, Amy started off going there every Tuesday night and I would pick her up on Wednesday. It was great being able to sleep through the night even if it was only once a week and being able to reconnect with the rest of the family, my other children and partner who I didn't have time for due to Amy's care needs. As well as the care they provided they were able to listen to me and talk to me about what was happening, we were watching Amy slip away daily and they sat me down to explain what was happening to her and what we would be expecting to see as time got closer to Amy's death. Without Zoe's Place this last part of our journey wouldn't have happened as smoothly and as well as it did. It's a terrible thing to lose your child, but it doesn't have to be horrible. They were able to help us through it in a relaxed and caring manner. Towards the end Amy stayed there twice a week to give us time together and her the medical attention that she needed and when the Doctor told us that Amy needed palliative care, Amy spent the last two and half weeks at Zoe's Place. What that meant for us was that Amy didn't have to go to hospital to die, she felt that hospital was for people who were sick and we didn't want her thinking that she was sick for her last few days. As our family consists of two sets of parents, having everyone at our home was really not something we wanted to do either and Zoe's Place was able to provide a neutral place where everyone was welcomed to come and spend time with Amy. We were able to sleep there and had as many people as we wanted to come spend time with our beautiful girl before she passed away. No one else would have been able to provide this for us. They helped us organise everything for her funeral and gave us counselling afterwards also.

Because of the services that this Children's Hospice provided, we were able to trust someone else with our child's care, somewhere other than hospital, where Amy felt that she needed to be sick to go. They were able to help us not only with respite but counselling and moral support. The hardest thing a parent has to do is to tell their child that they are going to go to heaven and that you are really going to miss them but they will always be in your heart, I was really lucky to have had the help and support that Zoe's Place provided me with. Exactly a year after Amy passed away at Zoe's Place, it closed down. I'm not sure what happened but what I do know is that there were hundreds of families in their books and many more would be in great need of a similar service like what Zoe's Place provided and there is nothing in place for all those families. As I said I was really lucky to have found and used their services but what about all those other families that don't even have the choice of either using them if they chose to or not. It's not everyone's cup of tea but at least it was there, now there is

nothing in place. We desperately need something that families can access here in Queensland, as the closest thing we have is Bear's Cottage and that is in Sydney, who wants to go all the way to Sydney for a children's hospice when we need the most support and need to have our families and support systems close by. My daughter was unable to fly on a plane, and there would be many children and their families unable to make the trip also, so what happens to them. They need to choice of whether they want to use the service or not. I thank God everyday that I had the opportunity to have had the help of Zoe's Place because without them out experience of the death of my beautiful daughter would have been completely different and not something I can honestly say went smoothly and not a horrible memory at all. It is my hope that more funding is given to the establishment of another Children's Hospice and hopefully Hummingbird House is able to provide the services to the many families that need the support. I will endeavour to help in whatever I can do to set up this wonderful cause and hopefully it will be sooner than later that Queensland families can access this service as I did when I needed the help the most and I had someone to turn to.

Regina Miller

