

NSW Carer of the Year 2012: Maria Heaton...



Maria Heaton's life revolves around caring for others. Her youngest child Tiarna was just three years old when she died, nine years ago. Tiarna and her brother Tristan who is now 16 were both born with lissencephaly, a rare brain disorder. While caring for Tristan, and raising her eldest child Danika, Maria has also worked as a nurse at the Sydney Children's Hospital and as a volunteer and advocate for various charitable organisations. Through her current work as a paediatric palliative care clinical nurse consultant, Maria supports terminally ill children and their families. Late last year, Maria was named the 2012 NSW Carer of the Year.

You can hear an online interview with Maria with the ABC on the following Link. http://blogs.abc.net.au/canberra/2012/10/nsw-carer-of-the-year.html?site=canberra&program=canberra_drive

Maria was kind enough to give us her acceptance speech to include in our newsletter. It gives us a great insight into the hard work and perseverance that she has achieved. Congratulations Maria.

Across NSW alone there are over 800,000 carers who do exactly what I do on a daily basis. I am in no way unique or special. My life changed with the birth of my son Tristan and daughter Tiarna. Until they came into my life I lived with blinkers on, my focus was very limited, I just thought about my husband Fabian, my daughter Danica, my career, paying off the mortgage and building a future for us. My children's special needs made me

broaden my focus; I began to look at life differently. I started to think more about others; appreciate what I had myself and think about how I could use my experiences, knowledge and skills to help other families who were going through the same thing.

We receive support in the way of in home respite; this enables me to pay it back through some voluntary service and also by speaking about my family. I am passionate about people with intellectual disabilities and the inequalities that they face in life. Being from a health background I try to advocate specifically for people with intellectual disability to have better health outcomes.

“Being a carer is like a roller coaster ride; it is full of ups and downs”

For me, being a carer is like a roller coaster ride; it is full of ups and downs. Once you are buckled up there is no getting off. You are in for the long haul. The only thing that will end your role as a carer is the loss of your loved one and that prospect is too painful to contemplate. Caring for a child with a disability is not the same as caring for a child without a disability. When you have a child with a disability you are time poor, financially stressed and are physical-

ly exhausted. It is impossible for a family to cope on their own.

In order to care for Tristan in the best way possible we have needed support to meet Tristan's needs which are 24/7. The saying, you need a village to raise a child is especially true when it comes to a person with a disability. Families cannot do it alone; they need support in order to care for their loved one in the best way possible. All families are not the same and every family's needs are different therefore they need a choice of supports.

Briefly with regards to support for people with disability, the way to ensure optimum support is to acquire your disability with an accident in which there is insurance cover. Being born with a disability like Tristan, acquiring a disability due to health reasons or through an accident with no insurance unfortunately does not guarantee you the supports that you need. My hope is that the NDIS will level the playing field so that every person with a disability receives all the support that they need.

I would like to say that since having Tristan and Tiarna our lives have not been all smooth sailing. However, our family has gained so much from these two beautiful children.

1. Tristan has taught me **patience**; he has the most relaxed personality. He just waits for us to meet his needs, he never demands our attention.
2. He has taught me **trust**; he has so much confidence in us meeting his needs. He trusts that we will have his best interests at heart.
3. He has taught me **love**. He has made me understand how to love someone so much that their needs become more important to you than your own.
4. He has taught me to **smile** through pain and suffering.
5. He has the most infectious, happy smile that in his presence I **laugh** more than I do away from him.
6. He has taught me about **spirituality**. Tristan's reason for being is purely spiritual. He makes me want to be a better person. He has made me feel for people with disabilities so much that I want to do everything I can to make it easier for them and for families like mine.
7. Every minute of every day, Tristan makes me feel **blessed** to be his mother. He is a very charming boy and anyone who meets him and spends time with him and tries to get to know him will benefit from the experience. The

biggest difficulty is that Tristan is unable to communicate in a traditional way and therefore getting to know Tristan takes time.

Being a carer is a very fulfilling role, I was very career orientated before Tristan and Tiarna, now I just strive to be a good mother and a good person. Life is less about me and more about others. Along this journey I have met many wonderful people that I would have never have otherwise crossed paths with and for this I am grateful. The success of my day is now measured by a smile from Tristan, the opportunity to assist a family like mine, a day of good health and the opportunity for quality family time.

I believe that everyone in life has a choice; our family chose to be happy, to focus on providing Tristan and Tiarna the best quality of life possible and to work on relationships. My achievements would not be possible without the loving support of my husband Fabian and daughter Danica.

And most importantly the only reason that I am here today is because of a couple of very kind and generous hearted people Janice Oliver, Jim Simpson and Prof Les White who have taken time out from their own busy life to nominate me and support me. Thank you from the bottom of my heart. ●



Emotion-Based Social Skills Training for Children with Autism Improves Children's Emotion Skills, Social Skills and Behaviour...

Emotion-based Social Skills Training for Children with Autism Improves Children's Emotion Skills, Social Skills and Behaviour

Preliminary results from the largest intervention study in the field of Autism in NSW are now available. This study examined Emotion-based Social Skills Training (EBSST) which aims to promote the well-being of children with Autism and prevent the onset of mental health concerns. EBSST was developed in the Department of Psychological Medicine at the Children's Hospital at Westmead and aims to develop children's skills in understanding their own and other's emotions, problem solving, and emotion regulation. There are two versions of the program: 1) EBSST for High Functioning Autism and Asperger's Syndrome and 2) EBSST for Autism and Mild Intellectual Disability. EBSST is conducted with children aged 8 to 12 years old, their parents and teachers.

In 2010 CHW collaborated with Department of Education and Communities to provide facilitator training to 64 School Counsellors to deliver EBSST to 271 children, their parents and teachers around NSW. The study involved evaluating differences between a treatment group and delayed treatment group. Changes in children's emotion skills, social skills, and behaviour were examined after treatment and at 6-month follow-up.

Results indicate that in children with Autism and Mild Intellectual Disability, par-



ents and teachers reported significant improvements in children's emotion skills comparing the treatment group to the delayed treatment group. Parents also reported significant improvements in behaviour. The treatment group maintained gains in emotion skills at 6 month follow-up as reported by parents. In children with High Functioning Autism and Asperger's Syndrome, parents and teachers reported significant improvements in emotion skills and social skills in the treatment group but not in the delayed treatment group. Teachers also reported improved social communication skills and parents reported improvements in emotions and behaviour in children in the treatment group, compared to those waiting to receive EBSST. The effect size of the intervention is large, providing statistical evidence to validate the positive feedback provided by those involved in implementation in the schools. The findings also provide evidence of the importance of a model of emotional development in Autistic Spectrum Disorder.

This study supports the effectiveness of EBSST in teaching children with Autism to understand their own and other's feelings and emotion regulation. This study is a great testimony to the strength of the partnership between NSW Department of Education and Communities and the EBSST team at the Children's Hospital at Westmead. Results from the study will be presented at the 2013 Asia Pacific Autism Conference and the International Association for the Scientific Study of Intellectual Disability: Asia-Pacific 3rd Regional Conference.

If you would like more information about EBSST, including how to become a certified in delivering EBSST in 2013 or how a child you know can be involved in EBSST, please email ebsst@chw.edu.au

