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Natalie's Story

My husband Anthony and I have been blessed with two beautiful daughters, Lisa & Natalie, and we live in Cairns. At about 15 months of age, Natalie started to suffer febrile convulsions. Not that unusual, but as the months passed, the convulsions changed; becoming longer, presenting differently... it became quite apparent that something wasn't right. After a 40 minute full body seizure on our lounge room floor and subsequent admission to hospital at 2 ½ years of age, further testing was undertaken and we were soon swamped with multiple different diagnoses and very limited information.

By this stage, Natalie had been transported to hospital 14 times via ambulance, each and every time admitted overnight, and sometimes 2-3 nights. Anthony has a fly-in-fly-out job, so it is only by the Grace of God that I have girlfriends who answered my calls, usually between midnight and 3am, to come and get my eldest daughter from the hospital to take her to school etc. My closest family are in Brisbane and the rest are in Sydney or Hobart.

The initial diagnosis was Polymicrogyri (PMG). We were told that some of Natalie's brain was either missing, had died off, or was simply just not working. We had never heard of this before and our paediatrician had not faced it either, so of course we turned to Dr Google...possibly not a helpful place to start! Soon after, followed the epilepsy diagnosis with the advice that we would need to travel to Brisbane for further testing. Not knowing if PMG was degenerative and with no one able to advise us, this was a very tense time!

We soon realised that the diagnosis was only the beginning, treating the seizures was a process in itself. We tried the first of what would be many anti-convulsant medications. We gradually increased the dose, all the time watching for any of the multitude of less than pleasant side effects. After about 6 weeks of a very grumpy, tired 3 year old, we were advised to swap drugs. This meant decreasing one drug and starting the next, again watching for the same unpleasant side effects. Natalie coped with the new drug a little better, but we quickly learnt...YOU CAN'T MISS A DOSE! Now, please understand, I didn't forget! I had the drug in the syringe, about to give it to Nat, when her big sister threw up. Of course, I was distracted, sorted out my big girl, and off to work I went. At 11.30, my husband called to say the syringe was on the bench at home, still with the medicine in it. So, only 4 hours late the drugs were given, but, it was still too late! The next day, off we went in an ambulance again, where the paramedic quite kindly pointed out, that the seizure was my fault, as I had delayed in giving Nat her medicine.

Eventually, we had our tests booked in at the Royal Children's Hospital, so off to Brisbane we went. Natalie hated this testing! Every medical person or therapist we met with was quite politely told (by Nat), I don't like you, go away, don't touch me! So as you can imagine, 4 days of this was quite trying. After persevering for over 2 hours to commence one of the tests, it was decided to sedate Nat, so as to fix the 26 probes to her head (should have been over 50, but the nurse took pity, and only used the essential ones). After sleeping off the sedation (20mins), the probes were discovered by Nat, and physically removed (they used human concrete) within 3 minutes. A total waste of a day, with not much achieved...sigh!

This is when we got the next lot of diagnoses – left side Cerebral Palsy (CP) & Pachygyria (another rare brain malformation) & even less known about this one, plus a problem in Nat's vascular system. They used words like odd,

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Natalie's Story

continued...

peculiar, unusual, never seen anything like it, not sure if it is a problem, not sure if it is PMG related or something different... as if we weren't already overwhelmed enough by what we were facing! Our neuro advised us, Natalie is writing her own medical journey, and no one has any idea what she can or can't do, or what limitations this may have on her life.

We later discovered Natalie was also having seizures in her sleep. Whilst the brain sparks were not triggering outwardly obvious seizures, the brain was constantly sparking, and sending odd messages around her body. This type of epilepsy is a little more uncommon, and is similar to something called ESES. Again, there was little information but we were told it was more prevalent in sleep, making Natalie more prone to sleep seizures and therefore more at risk of dying in her sleep. Is it any wonder I hug my little girl so very tight when I say good night? As a Mum, this was and still is incredibly frightening. Mornings where Natalie sleeps in, my mind races...do I go in and wake her, when obviously she is tired, and needs her sleep, or do I leave her? If I leave her, will I go in later and find her dead? What a shocking process to work through – just because your 3 year old is tired, and has slept in!


We have had multiple trips to Brisbane, MANY tests & unpleasant procedures, a cocktail of different drugs in varying combinations and doses, regular doctors and therapy appointments and I find myself constantly watching Nat. I know we all watch our own kids, but this is a whole new level! If she is quiet, I wonder why? What are her eyes doing? I'm asking questions like, "Nat talk to me, are you ok?" There is never a minute in the day when I can relax...is someone else watching her, because I know no one watches her as carefully as I do?

Playgrounds are frightening – we need to go, so her big sister is not left out, but for Natalie they are scary! Will she fall? Will she bump her head? She is already clumsy, so climbing and playing are not easy for her. A bump to the head, can bring on a seizure. A knock to the body, can bring on 'body shock', which can also bring on a seizure. But she is a little girl, I can't wrap her up in cotton wool and not let her develop!

All of this aside, today, whilst we are still having issues, we are doing ok! Natalie takes 4 different anti-convulsant drugs, plus steroid treatment, which we are trying to get off and we are in the process of commencing the Modified Adkins Diet in an effort to gain some control of seizures. Nat is in Prep, at Freshwater Christian College, where she receives aide support, and loves school. She is cheeky, mischievous, stubborn, yet adorable, and all who meet who are drawn in by her charm. She has an unmistakable, very strong personality!

We try to keep things as "normal" as possible for her. She attends swimming lessons once a week and is getting there. We have to watch her closely when in the pool and the CP holds her back, as she sometimes forgets she has two legs. The left leg is often left dangling in the water and not kicking. She absolutely adores her big sister Lisa (8 yo), and is desperately trying to ride a bike (whilst turning me even greyer!). Whilst the future for Natalie is unclear, we remain positive & hopeful, especially for new treatment options in the near future!

Sally



Lucy is excited, tonight is the very first disco at her school!


Everything goes well at the disco until Lucy suddenly has a seizure ...

Lucy's First Disco by Robin Adolphs is a touching story about a young girl's first seizure and how her friends support her when she returns to school.

After a long career as a primary school teacher and living with epilepsy herself, Robin set out to write a children's book that would help those living with epilepsy so their school friends understand what it is all about. Robin has developed teacher resources, free activities, and downloads on her website www.robinadolphs.com to accompany the book and is generously donating a portion of her sales to Epilepsy Queensland.

Available now for purchase at Epilepsy Queensland!

To purchase a copy for your child, and their school or daycare please contact us on 07 3435 5000
(regional Queensland phone 1300 852 853)
or email pr@epilepsyqueensland.com.au.



THE TEA ROOM
A Friendly Space for Young People with Epilepsy

The TEA Room is the first online international forum specifically for teenagers with epilepsy and allows them to share, chat and learn with other teenagers around the world.

Developed by the Scottish Epilepsy Initiative, this new free global social networking site connects 13-19 year olds from around the world who are suffering from or are in the process of being diagnosed with epilepsy. Launched in January this year, the site already had users from around the world.

One of the biggest problems facing people with epilepsy is the social stigma associated with seizures. Teenagers in particular can feel embarrassed and "shut out" because they feel different to their peers; so The TEA Room is a wonderful way for them to engage with other young people who can relate to their situation and problems.

The TEA Room provides instant access to an online community of friends who face similar challenges living with epilepsy, although discussion is not limited to health issues.

In many parts of the world, people with epilepsy and their families suffer from stigma and discrimination.

If you would like further information about the TEA room please go to www.thetea-room.com



Purple Day for epilepsy QLD
26 March

Join us to raise funds and awareness during March

To find out how YOU can get involved call **1300 852 853** or register at www.epilepsyqueensland.com.au

epilepsy queensland inc

Epilepsy and Tuberous Sclerosis Information Day

Tuberous Sclerosis Complex (TSC) is a genetic disorder that causes tumours to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs. It affects individuals in many different ways, with varying rates of progression and degrees of severity. This diversity and variation make it challenging to determine what healthcare is needed to achieve the best quality of life for a person with TSC. For many, tumours in the brain can cause seizures and as a result TSC is one of the leading genetic causes of epilepsy.

On Sunday 21 February, Epilepsy Queensland partnered with the Lady Cilento Children's Hospital and Tuberous Sclerosis Australia to deliver an Epilepsy and Tuberous Sclerosis Information Day. The morning session focussed on Epilepsy, with Dr Kate Riney, Paediatric Neurologist, Lady Cilento Children's Hospital, starting the conversation with 'Understanding Epilepsy'. She comprehensively covered all the basics - What is epilepsy? What are seizures? Seizure types and what do they look like? Diagnosis; Clinical investigations and their relevance; Genetics; Treatment options; as well as some specifics on epilepsy presentation in TSC. As always, this was an interesting and captivating presentation which provided new information even to those well versed in epilepsy!

Alison Alsop, RN and Educator, Epilepsy Queensland, followed with a very relevant discussion on 'Living with Seizures'. She drew on her experience working with clients at Epilepsy Queensland, as well as her experience of being a mum of a child with epilepsy, to accurately and sensitively unpack the "human" experience of living with seizures. Many were able to relate to the varying emotions experienced along the way and the "predictably unpredictable" nature of seizures.

And finally, Dr Honey Heussler, Developmental Paediatrician, Lady Cilento Children's Hospital, rounded off the morning looking at 'Development in Children with Epilepsy'. She prefaced her talk with the obvious . . . "It's complicated" . . . and went on to explain Development in terms of its Domain - Gross, Fine, Speech and Language, Social and Personal Skills and Adaptive Function; Developmental delay vs Atypical development; Genetic, Environmental and Biological modifiers of development and finally Development in Children with Epilepsy and TSC.

The afternoon session focussed specifically on TSC and we were privileged to learn about 'Genetics of Tuberous Sclerosis' from International expert Dr Hope Northrup, Geneticist and TSC Clinic Director, University of Texas. Dr Northrup managed to breakdown a very complicated subject and present it in a way that made it "easy" to understand, covering basic genetics, as well as TSC specific genetics, including heritability and family planning.



Epilepsy Queensland's Alison Alsop

Dr Peter Trnka, Paediatric Nephrologist, Lady Cilento Children's Hospital and Dr Andrew Mallett, Nephrologist, Royal Brisbane and Women's Hospital continued on with 'TSC and the Kidneys'.

Overall, it was a positive collaboration between Tuberous Sclerosis Australia, Lady Cilento Children's Hospital and Epilepsy Queensland, which helped to bring together individuals with TSC and epilepsy, their families, friends, carers, educators, health and disability workers! Epilepsy Queensland would like to thank Clare Stewart, Tuberous Sclerosis Australia, for her dedication to making this day happen!



**Tuberous Sclerosis
Australia**

ABN 20 681 174 734
Incorporation no. Y07116-42
Registered Charity CC25313
CFN 13968

About Tuber Sclerosis Australia

TSA is the only organization dedicated to TSC in Australia. We help in the following ways:

- Provide phone and email support for TSC affected families
- Publish Reach Out, a regular magazine
- Maintain a detailed website of TSC related information and resources
- Connect a network of TSC families across Australia, including an online discussion group
- Hold conferences and seminars for families and health professionals
- Manage the TSC Professionals Network for health professionals experienced in managing TSC
- Advocate to improve access to best practice care
- Fund and stimulate TSC research in Australia.

Find out more at www.tsa.org.au.

Memorial Service

Saturday 16 July 2016
2:00 pm
Mercy Place
371 Simpson Road, Bardon

This is a non-denominational service. All are welcome ... to all those who have lost a family member or a friend to epilepsy related causes ... whether you are an Epilepsy Queensland supporter, friend or your work brings you in contact with people with epilepsy.

Contact Jenny Ritchie at Epilepsy Queensland for more information.

WHAT'S ON IN 2016..



'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

- Are you up to date with current epilepsy terminology and treatments?
- Does your respite organisation manage seizures appropriately?
- Does your school and respite organisations have an up to date management plan for your child?

Epilepsy Queensland is holding monthly workshops in our Woolloongabba office on:

14 April	25 August
19 May	15 September
16 June	20 October
14 July	24 November

We can also tailor training to suit your needs and are happy to travel to you.

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

Epilepsy Queensland holds monthly workshops at Benowa:
25 May • 20 July • 7 September • 30 November

REGIONAL VISITS

Disability support workers, child care workers, teachers, nurses, allied health professionals, volunteers, people with epilepsy and their families are invited to attend 'Understanding Epilepsy' Workshops in the following areas:

21 April • Gladstone
17 May • Mackay
2 June • Mt Isa
4 August • Longreach
18 October • Charleville

SUPPORT GROUPS

Brisbane Adult Support Group

9 July • 5 November

Northside Support Group

4 May • 11 August • 11 November

Parents of Children with Uncontrolled Epilepsy Support Group

7 June • 5 September • 6 December

EVENTS

26 March • Purple Day
16 July • Memorial Service

For further information on any of the above events please contact Epilepsy Queensland on 07 3435 5000 or 1300 852 853 (Regional Queensland) or email epilepsy@epilepsyqueensland.com.au.



Telling your story is a great way to raise awareness about epilepsy. We are keen to raise the profile of epilepsy and increase community understanding and acceptance of epilepsy every single day. You can help so much by volunteering to tell your story in our publications and the media.

Please contact pr@epilepsyqueensland.com.au if you're interested in assisting or just want to have a conversation about what may be involved.

Are you currently providing care for a family member, friend or neighbour who has a disability, mental illness, chronic illness or for someone who is frail aged? Take some time out for you this year.

JOIN A CARER SUPPORT GROUP (CSG)

Come along to meet with other carers, share stories, advice, share a morning tea and hear from guest speakers on carer issues at any of the following Carers Queensland groups:

Capalaba CSG - 1st Tuesday each month

Capalaba Place, Council Library Meeting Room, Noeleen Street, Capalaba

Wynnum CSG - 1st Wednesday each month

Wynnum RSL, 174 Tingal Road, Wynnum

Brismen CSG (Men's Group) - 1st Thursday each month

Venue differs due to activities

Brisbane South CSG - 2nd Thursday each month

The Shed, Carers Queensland, 15 Abbott Street, Camp Hill

Inala CSG - 4th Thursday each month

Inala Respite Centre, 16 Lorieket Street, Inala

Parent CSG (for carers of children U18 years) - 1st Thursday each month

Logan North Library, Cnr Sports Drive and Springwood Road, Underwood

and/or 3rd Thursday each month

Carindale Library, Westfield Carindale, 1151 Creek Road (near Millennium Boulevard), Carindale

Browns Plains CSG - 3rd Wednesday each month

Logan West Library, 69 Grand Plaza Drive (opp Browns Plains Plaza), Browns Plains

Logan CSG - 3rd Thursday each month

Logan Central Community Health Centre, 97-103 Wembley and (cnr) Ewing Roads, Logan Central

All groups meet from 10am - 12pm

For more information and to receive monthly notices confirming activities & venue/s call Brisbane South Office on 3723 5001.



How NDIS ready are you?

Are you caring for someone with a disability?

Want to know more about the NDIS?

Why not come along to a FREE NDIS workshop?

The workshops are interactive and practical. Topics covered include:

The NDIS and you
Your future with the NDIS
Caring beyond the now

Refreshments will be provided. Seats are limited.

REGISTER NOW! Call 1800 242 636 or email ndis@carersqld.asn.au.

Upcoming workshops 10.00am—2.00pm (9.30 am arrival)

Tuesday 19 April - Wynnum Manly Leagues Club

92 Wondall Road, Manly West

Wednesday 27 April - North Leagues Club

1347 Anzac Ave, Kallangur

Wednesday 4 May - Nudgee Golf Club

1207 Nudgee Road, Nudgee

To organise care for your loved one so you can attend a workshop please call Commonwealth Respite and Carelink Centre on 1800 052 222.

Do we need to update our mailing list?

We hope you enjoy reading the Livewires newsletter. However, if you no longer wish to receive Livewires, please let us know by calling 07 3435 5000 or 1300 852 853 (Regional Queensland) or emailing pr@epilepsyqueensland.com.au.

We would also greatly appreciate being advised if you have received multiple copies at the same household, so we can update our records accordingly. Thank You!



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