

Watch this space

2020 Workshops

Understanding Epilepsy & Midazolam Administration

Brisbane

Thursday sessions
(9.30am - 1.00pm)

- 16 January
- 06 February
- 12 March
- 09 April
- 14 May
- 11 June
- 16 July
- 13 August
- 10 September
- 15 October
- 19 November

Gold Coast

Wednesday sessions
(10.00am - 12.00pm)

- 11 March
- 13 May
- 24 June
- 12 August
- 11 November

Cost:

\$60 for both sessions
\$40 for 'Understanding Epilepsy' only

* Free for Epilepsy Queensland 'Financial Members' who have epilepsy and their immediate family.

Epilepsy Training by Video Conference

Save time and money

Speak to us about the convenient option of using a video conference for your next Understanding Epilepsy & Administration of Midazolam training.

Contact us on: 07 3435 5000 or

training@epilepsyqueensland.com.au



Purple Day Celebrations 2020

'Go Purple for Epilepsy'

and help us make a difference to people whose lives are impacted by epilepsy.



Toby Turtle

Purple Day for epilepsy QLD

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LIVEwires

Newsletter of the Family Support Program



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10th Annual Queensland Epilepsy Symposium

On 31 October, Epilepsy Queensland hosted the Tenth Annual Queensland Epilepsy Symposium, *Thinking outside the box!*

Once again we were honoured to have a high calibre of speakers delivering talks on a wide range of epilepsy topics including genetics, early intervention, future medical bionics, sleep, fitness to drive, anxiety & depression, social cognition research, valproate & pregnancy, midazolam, functional neurological disorders, epilepsy diets & executive functioning skills.

Laureate Professor Ingrid Scheffer started the day discussing 'How genetics is transforming Epilepsy Care'. With the discovery of epilepsy genes, more & more patients are being sent for genetic testing. Professor Scheffer outlined the importance of this testing, particularly for people living with developmental & Epileptic Encephalopathies.

At the most basic level, genetic testing aims to uncover variants to the normal. Neurologists must then collaborate with geneticists to determine whether those variants are related to the person's epilepsy.

As this is an emerging field of epilepsy, not all identified genetic variants can be interpreted & therefore some results may not be immediately beneficial but rather await further research to be fully understood. However, for others

identifying an underlying genetic cause for their epilepsy can help:

- Determine prognosis
- Guide management
- Avoid unnecessary investigations
- Determine reoccurrence risk within a family
- Allow for patient connection with international communities living with the same genetic epilepsy
- Provide hope for a future cure.

It is hoped that improved genetic understanding will lead to the development of precision medicine in the future & therefore improved patient outcomes.

Overall, the Symposium was a great opportunity to gather the epilepsy community; neurologists & other health professionals, people living with epilepsy, families & carers; to provide education, support & hope for the future.



Services Team

In September 2019 we held the e-Connect program for teens and young adults living with epilepsy. The purpose of this group is to provide opportunities to meet other people, share experiences in a safe and supportive environment, develop various communication and lifeskills and ultimately have fun along the way.

This session focused on self-worth and self-identity, using a range of activities to address the topic. One of the most enjoyed activity was a game show activity – which also brought out individuals' competitive spirits – it was a lot of fun.

The group made and shared lunch together. Burgers and chocolate cake was a huge success (even for a few parents who had some left overs)– but fried rice and apricot balls – not so much, which was probably expected!

The afternoon is a flexible time, where participants engage in activities of interest, or try something new – such as craft or arts; ball games; board games; music and dance etc.

Mum of Kirsty shares “Today my daughter attended a workshop for teens with epilepsy run by Epilepsy Queensland. She had an absolute ball and hasn't stopped raving about her awesome day! And most of all she says everyone was the same as her. Best mental health therapy ever! She can't wait for the next one. She met new friends, cooked, played games, did some team building and self-esteem activities. This has been an extremely powerful activity, Thank you!”

For more information on the next session, or to chat to a Services team member about activities for younger people, please contact us on Ph. 07 3435 - 5000.



NDIS Update - Minister's Five Year Plan

The Minister for the National Disability Insurance Scheme (NDIS), Stuart Robert, on 14 November announced his plan to improve the NDIS for the benefit of all Australians.

The objective of the plan is to deliver a world leading NDIS that improves outcomes for all Australians with disability, their families and carers – including an estimated 500,000 participants over the next five years.

The Government's NDIS plan has six core focus areas:

1. Quicker access and quality decision making
2. Increased engagement and collaboration
3. Market innovation and improved technology
4. A financially sustainable scheme
5. Equitable and consistent decisions; and
6. Improve long term outcomes.

Whilst there are a lot of initiatives that fall under these areas, some important information to come from the speech relates to assistive technology and approvals.

Improvements implemented earlier this year, and appear to be having a positive impact on people, include:

- the inclusion of low-cost, low-risk items under \$1,500 in a participant's plan without further assessment, quote or approval;
- reducing the number of quotes required to no more than two for items above \$1,500;
- only requiring one quote for the replacement of an item valued between \$1,500 and \$15,000; and
- the inclusion of appropriate repairs and maintenance funding in all plans.



In the Pipeline...

Joint Plan and Draft Plan Summaries

In order to reduce requests for plan reviews the NDIA will also commence the national rollout of joint planning meetings and the provision of draft plan summaries from April 2020.

Providing a draft plan summary – so often asked for by participants – will enable them to review and amend their personal details, goals, living arrangements, informal community supports and other community supports, and social and economic participation prior to a plan being developed.

Similarly, joint planning will allow a participant, Local Area Coordinator and NDIA Planner to collectively discuss a working version of the plan and included support funding before it is approved.

Joint planning will lead to a greater understanding for participants about their plan, how it was developed and how to use it. To read the full speech and hear more about the initiatives underway and planned, refer to: <https://ministers.dss.gov.au/speeches/5266>

As always, we would love to hear your experiences with the NDIS. Being informed helps us improve the experience for yourself and others.