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Little Poss' Birthday Party 2017

On Saturday 10th June 2017, Little Poss club members joined us as we celebrated Little Poss' Birthday. It was a lovely morning spent at Darling Point Special School & a great opportunity for Epilepsy Queensland staff to catch up with some of our families. Many enjoyed having their faces painted & Peebo & Dagwood, twin clowns, kept both the children & adults entertained with their comedy magic show & balloon animal sculpting. The highlight for many though was meeting Little Poss! The kids all got a chance to have a photo with Poss, sing Happy Birthday, help blow out the candle & to eat the scrumptious cupcakes. It was a fun morning had by all. Special thanks to The Good Guys for sponsoring this event & helping to let children & families living with epilepsy know that they are not alone.



The Little Poss Club is run by Epilepsy Queensland especially for children. It's FREE & EASY to join! Simply head to our website www.epilepsyqueensland.com.au & download a membership form or contact us & we will send one out.

What do you get?

- ~ An official membership certificate signed by Little Poss
- ~ A welcome Pack on joining
- ~ A bi-monthly newsletter full of great fun and games (one per household)
- ~ Chances to win fantastic prizes
- ~ The opportunity to meet other Little Poss Club members
- ~ A Birthday Card on your birthday
- ~ A special invitation to Little Poss's Birthday Party
- ~ Get all the latest Little Poss news plus heaps more!

THE PELICAN STUDY

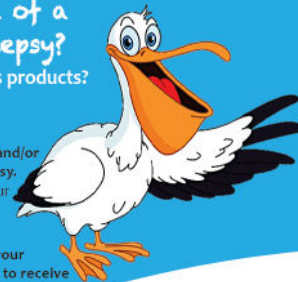
Paediatric Epilepsy (Lambert Initiative) Cannabinoid Analysis

Are you the parent or guardian of a child aged 0-16 years with epilepsy?

Do you currently treat the epilepsy with cannabis products?
Or have you previously tried cannabis products?
Or have you never used cannabis products?

We would like to interview you about your experiences with and/or opinions towards cannabis product use for your child's epilepsy. Interviews are strictly confidential and can be conducted in your own home by one of our trained researchers, or at the Centre for Children's Health Research, Brisbane.

For those currently using cannabis products, we will analyse your product for cannabinoid content and you will have the option to receive individualised feedback. The results will help us understand how these products function to potentially treat childhood epilepsy.



To register your interest, or for more information, please contact:
✉ lambert.pelican@sydney.edu.au
☎ (02) 9351 0746 or 0439 804 551
http://www.sydney.edu.au/science/lambert/get_involved/pelican.shtml





Safety: Around the home

When it comes to children, safety is always a priority, however, when the child also has epilepsy, the considerations are even greater! Parents & carers must consider many things when caring for a child with epilepsy, but safety around the home is a great place to start.

As each child with epilepsy is unique, the cause, type & frequency of seizures will vary & so too will the risks. Similarly, living arrangements are all different - some families may have multiple children, have pets, have a low or high set house – the variations are endless. Although having seizures may increase the risk of injury, it does not need to define the person's lifestyle and what they can do.

Below is a list of considerations to assess and ultimately minimize risk to your family member with epilepsy, yourself and others:

Kitchen

- Consider a temperature controlled hot water service
- Have hot drinks in a mug with a lid
- If using a dishwasher place points and sharp objects down & close door when not in use
- Consider cupboards with recessed handles

Living Room

- Use fixed fireguards around a fireplace
- Consider round rather than square or rectangular coffee tables
- Use shatterproof glass for big windows & doors
- For photosensitive seizures reduce the contrast of the television screen by turning on the lights in the room and sit at least 3 metres from the set. A quality TV (with 100hz refresh rate), LCD or plasma screen may also be useful. LCD screens for computers are flicker free and useful for people with photosensitive epilepsy.

Bathroom

- Supervise children at all times in the bath or shower
- Consider a temperature controlled hot water service
- Always turn on cold water first
- Consider shower curtains rather than a glass screen or in the case of a glass screen use reinforced glass
- Consider rubber backed non-slip mats
- Consider the use of a shower chair
- In the toilet, consider an outward opening door & toilet roll holders on the floor beside/behind the toilet, to minimise injury if a seizure occurs while on the toilet.

Bedroom

- Don't sleep on top bunk, use a low bed
- Consider tightly fitted sheets

- Sleep without a pillow or use a firm porous breathable pillow
- Consider bed alarms or other monitoring devices if seizures are frequent during sleep
- And more generally
- Install smoke alarms
- Minimise clutter & consider clearing walkways before going to bed at night
- Consider doors that are outward opening, sliding, half doors or doors that are easily removed. Use security sets for bathrooms and toilets as these can be unlocked from the outside if necessary
- Consider having safety switches in the meter box installed by an electrician
- Minimise sharp edges and corners around the home
- Use safety gates at the top of the stairs
- Keep medications out of reach of children. Store in a cool dry place and do not remove from pillbox or Webster pack ahead of time
- Consider mobility and personal care aids that are appropriate to the requirements of the child?
- Keep a first aid kit that is easily accessible
- Do all members of your family know what to do in an emergency? Consider hanging a seizure First Aid poster in a prominent place within the home (eg. On the fridge)

This is not an exhaustive list, but we encourage you to take the time to walk around the home with a lens of ensuring safety. It may also be helpful to enlist the help of a friend or family member or even an Occupational Therapist who can help you with this. In relation to safety around the home, Occupational Therapists, along with various other professionals, services & equipment may be funded by the **National Disability Insurance Scheme (NDIS)** under various Support Categories, such as:

- ◇ 1.01 Assistance with Daily Life (e.g. Daily tasks and household tasks)
- ◇ 2.05 Assistive Technology
- ◇ 3.11 Improved Relationships – (e.g. Behaviour Support)
- ◇ 3.15 Improved Daily Living – (e.g. Early Intervention Supports for Early Childhood; Selection and/or manufacture of customized or wearable technology; Therapy Services)
- ◇ 2.06 Home Modifications (e.g. equipment or changes to building structures, fixtures or fittings)



For more information, please refer to the 'NDIS Price Guide – VIC/NSW/QLD/TAS Valid from: 1 July 2016 available on the NDIS website – <https://www.ndis.gov.au/providers/pricing-and-payment>. Alternatively, to speak to an Epilepsy Queensland Inc. staff member about safety in your home or how this applies to the NDIS, please call us on 07 3435 5000.

THE TEA ROOM

A Friendly Space for Young People with Epilepsy

www.thetea-room.com





Getting NDIS ready – Where to Start?

In previous editions of LIVEwires we have posted articles on 'Getting NDIS Ready', 'Getting NDIS Ready –Planning' and 'Getting NDIS Ready – Carers.' If you missed these, or would like these factsheets sent out to you by post or email, please contact us.

We understand that for many people, the NDIS seems quite overwhelming and daunting - and people are just not sure where to start or what they should be doing.

However, as the common saying goes – 'a *journey of a thousand miles, starts with the first step*' and we are here to help you on your journey.

In this edition of LIVEwires, we would like to revisit and focus on eligibility – where your NDIS journey will start. The criteria set out by the National Disability Insurance Agency (NDIA), is to be:

- Under 65yrs of age;
- An Australian Citizen, a permanent resident, or New Zealand citizen who is a Protected special Category
- Visa Holder;
- Live in the launch site;
- and meet the NDIA disability or early intervention requirements.

For many, it is the last criteria that will be the most complicated or time consuming to evidence.

More information about access requirements can be found on the NDIS website

<http://www.ndis.gov.au/ndis-access-checklist>, including information on the Access Request Form.

It is important to remember that access to the NDIS is not

based purely on a *diagnosis*, but rather on *functional Impairment*, or in other words, what 'reasonable and necessary' supports do you require to take part in everyday activities and increase your independence and participation in social, work or education pursuits. Consistent with the NDIS being more about functional impairment than a diagnosis, **a person who has epilepsy is not automatically eligible for the scheme.** Therefore, you will be required to evidence the impact that epilepsy has on your life. The types of evidence that the NDIA are seeking include – health professional reports detailing impairments on mobility, communication, social interaction, learning, self management and self-care. These reports may be accessed from your treating GP, neurologist, paediatrician, OT, physio, speech therapist – or a combination of these professionals. Shared stories from families who have accessed the NDIS in other states and territories, stress the importance of being prepared – so we would encourage you to start now – and contact your health professionals to obtain these reports.

Don't forget to ask your GP if you are eligible for the Allied Health Care plan, which may provide subsidised visits for people with chronic health conditions.

Epilepsy Queensland has been focused on NDIS readiness activities, and reviewing business operations and systems to ensure that we are well placed to assist and support you with your NDIS access, planning, implementation and review needs. **So whether the NDIS has already rolled out in your region, or it is yet to come – please feel free to contact us – and we can help you on your unique journey.**

In the near future, we will be hosting informative and interactive NDIS forums and undertaking various community engagement activities to involve people with epilepsy and their families - as you are important to us – so keep any eye out for these fliers.



The National Disability Insurance Agency (NDIA) is aware of a potential scam involving people claiming to be from NDIA attempting to collect personal details via telephone.

The NDIA contacts people by phone for the purpose of completing a verbal access request to become a participant in the NDIS. Where this occurs, the NDIA will ask for certain personal information over the phone, but will only request this information after explaining the purpose of asking for it and seeking your consent to proceed.

If you are already a participant in the NDIS, the NDIA may contact you directly by phone or email to advise you that we require additional information or to update our records. In these instances the NDIA will explain the purpose of

asking for this information and ask that you either, visit your nearest NDIA office or Contact 1800 800 110. The NDIA will never require you to provide personal information or threaten to cancel your NDIS plan unless you provide personal details by phone.

If you are unsure about whether a person calling you is from the NDIA, you can ask for their name and number and call the agency back.

If you believe it is a scam please report it to feedback@ndis.gov.au, your local NDIA contact or call 1800 800 100. They will be able to confirm whether the caller was from the NDIA.

Visit the Privacy section of the NDIS website to find out more about the NDIA's procedures for handling your personal information. You can also find out more about known scams via the Australian Government Scamwatch website. For further information read the media release: Beware of telephone scam – check caller's details Article accessed from <https://www.ndis.gov.au/news/Protecting-your-personal-details.html> on 9th June 2017

What's On . . .



'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

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

20 July (9.30am to 12.00pm)
17 August (9.30am to 12.00pm)
14 September (9.30am to 12.00pm)
*19 October (9.30am to 12.00pm)
(5.30pm to 8.00pm)

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

Epilepsy Queensland is holding monthly workshops at Benowa

6 September (11.00am to 1.00pm)
15 November (11.00am to 1.00pm)

CARER & PARENT SUPPORT GROUPS

Bracken Ridge Library:
1 September 2017

EVENTS

Dalby on 24th and 25th July

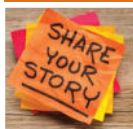
We will be: Delivering training – Understanding Epilepsy and Midazolam Administration as well as Facilitating a Community forum on 'Preparing for the NDIS'

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.

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!



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.

ndis

Ipswich, Bundaberg and Rockhampton get earlier access to the NDIS

The Commonwealth and Queensland Governments recently announced an agreement to bring forward the NDIS start date in the next three Queensland regions to roll out, with Queensland Government disability clients in Ipswich, Bundaberg and Rockhampton gaining early access to the NDIS.

Ipswich State clients can now gain access to the NDIS and other eligible people will begin to enter the scheme from July 2017.

Bundaberg State clients will begin to enter the NDIS from September 2017 and other eligible people will begin to enter the scheme from October 2017.

Rockhampton State clients will begin to enter the NDIS from November 2017 and other eligible people will begin to enter the scheme from January 2018.

Dates for subsequent areas of Queensland remain

What we offer...

Understanding Epilepsy

Administration of Midazolam

Epilepsy awareness (tailored to individual needs)

Length – 1.5 hours to 4 hours

How to organise an education session

It's easy! Simply download a 'training request' form from our website (epilepsyqueensland.com.au) or call us on 07 3435 5000 or 1300 852 853 (toll free) to discuss a training package and a suitable time.

Testimonials

'Trish was an excellent and knowledgeable presenter. She listened to all questions and addressed our concerns kindly and professionally. I now feel confident to administer Midazolam if my daughter has a prolonged seizure.'

'Jenny travelled two hours to train my staff in Epilepsy awareness. The session was engaging and interesting. Our clients will be much better supported. I will be recommending this training to others.'

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