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NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

The National Disability Insurance Scheme (NDIS) is a new way of providing support to Australians with disability or a functional impairment, their families and carers.

All Australians who meet the eligibility criteria are legally entitled to NDIS funding for reasonable and necessary support. The NDIS gives all Australians peace of mind that if they, or their child or loved one is born with or acquires a permanent and significant disability they will get the support they need across their lifetime. Further information about access and eligibility can be found at: <https://www.ndis.gov.au/people-disability/access-requirements.html>.

The NDIS gives you choice and control in how and when supports and services are received. With the NDIS, you will receive an individual funding allocation to choose the supports you need to live your life well.

Some people with epilepsy have told us that they do not identify as having a disability, and therefore, believe they are not eligible for supports under the NDIS.

However, epilepsy is a chronic health condition and recognised as a disability under the National Disability Insurance Act (2013), both on its own and as part of other disability types.



Experience from people who are already accessing the NDIS, has shown an important step in the transition to the scheme, is to focus on pre-planning, as this will assist with the planning meeting and ultimately how the NDIS could support people to meet their needs, achieve their goals and enhance their quality of life.

At Epilepsy Queensland, we have listened to this feedback from participants, and stayed abreast of information and updates from the National Disability Insurance Agency (NDIA) and have developed a planning workbook as a way to support you through this pre-planning stage.

This workbook is structured to assist you to document relevant information about you and your support networks, how you live your life, your routines, what is working and not working for you, and ultimately how this information relates to the support required to meet your needs and achieve your goals & ambitions.

We have also provided some examples of goals that are relevant for people with epilepsy, and identified where they fit into the NDIS funding.

(continued on page 2)

Eighth Annual Queensland Epilepsy Symposium

Thinking
outside
the box!

Join us for some stimulating dialogue...

www.epilepsyqueensland.com.au

Bookings essential

Save the date
Thursday 26 October 2017
PA Hospital, Woolloongabba

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



NATIONAL DISABILITY INSURANCE SCHEME (NDIS) (continued)

A few examples are below:

Goal	Support category	Where this fits into NDIS funding	Examples of types of supports that may achieve this goal ...
To increase my independence, safety and inclusion by engaging with a variety of therapies, this may be in relation to: - Memory - Cognitive impairment - Occupational therapy - Speech therapy - Managing behaviours	Capacity building supports	Improved Daily Living - Therapeutic supports Improved Relationships	Therapy services from an Occupational therapist, Speech therapist, Psychologist Behaviour support; social skills development; managing emotions etc.
To access mainstream & other community services, knowing that people around me know how to manage epilepsy and keep me safe	Capacity building	Improved Daily Living - Therapeutic Supports	Development of Epilepsy Management Plan or Emergency Management Plan (Administration of Midazolam)
To attend school/social/sporting activities independently To attend sleep overs (independently and safely) with friends and family	Capacity building supports	Improved Daily Living Improved Relationships Improved Relationships Improved Daily Living Therapeutic supports	Therapy services from an Occupational therapist, Speech therapist Behaviour support; social skills development; managing emotions Aids or equipment in relation to safety and independence

To obtain a copy of the Preparing for your NDIS Planning Conversation Workbook, or if you have any questions about the NDIS, please do not hesitate to contact us on 07 3435 5000 or 1300 852 853 – if outside Brisbane - we are here to help you.

NDIS ROLL OUT ACROSS QUEENSLAND

The National Disability Insurance Scheme (NDIS) will progressively roll out across Queensland over a three year period.

The Bundaberg area is getting ready for an early kick-off of the NDIS as the scheme starts rolling out across the region from 1 September. If you would like more information about whether you or a family member might be eligible or how Epilepsy Queensland can help, please contact us on 1300 852 853 or email NDIS@epilepsyqueensland.com.au.

From 1 July 2016, the NDIS will roll out across the rest of Queensland geographically.

The NDIS will become available;

Brisbane	1 July 2018
Bundaberg	1 September
Gold Coast and Hinterland	1 July 2018
Ipswich	The NDIS is now available
Logan and Redlands	1 July 2018
Moreton Bay	1 January 2019
Sunshine Coast, Noosa and Gympie	1 January 2019
Cairns and Surrounds	1 July 2018
Fraser Coast and Surrounds	1 July 2018
Mackay, Isaac and Whitsundays	The NDIS is now available
Rockhampton	January 2018
Toowoomba and west to the borders	The NDIS is now available
Townsville, Hinchinbrook, Burdekin, west to Mount Isa, and up to the gulf	The NDIS is now available

For more information or assistance with your NDIS Plan please call Epilepsy Queensland on 07 3435 5000 or email NDIS@epilepsyqueensland.com.au

SAFETY: MAKING A SPLASH THIS SUMMER

Many people living with epilepsy will be able to safely enjoy the water. However, it is important to assess each situation individually, taking into consideration the person's epilepsy, their age, abilities, any other disabilities, the location in which they are going to be swimming, and if there are any other supports/people around that may be able to help supervise or provide assistance in the event of an emergency.

Water Safety

Supervision ensures people with epilepsy can participate safely in water activities. Even those with well controlled epilepsy should never swim alone. Important things to consider about supervision include:

- A dedicated 1:1 spotter or swimming companion if possible;
- People with uncontrolled epilepsy should have two people accompany them. One should remain in the pool and one as a spotter outside the pool;
- Companion/spotter to maintain constant supervision, eye contact and/or stay within an arm's reach of you at all times;
- Companion/spotters should be aware of your seizure types & know what to do in the event of a seizure. Other key points:
 - o Always seek advice from your doctor before swimming;
 - o Inform the life guard (if available) of the potential risk of a seizure occurring;
 - o A brightly covered swimming cap or swimming costume can help ensure quick and easy identification;
 - o Avoid resting on the edge of a body of water
 - o If flickering or reflective light is a potential trigger for your seizures, try wearing tinted goggles or sunglasses;
 - o If you have had brain surgery check with your doctor before diving;
 - o Do not swim or continue to swim if fatigued, feeling unwell, having missed medication or experiencing

warning signs of a seizure;

- o Avoid swimming under water for long periods of time as this can cause hyperventilation, a potential trigger for seizures;
- o Swimming programs, both private or school based may require a letter from your doctor (approving participation) & an epilepsy management plan;
- o If a tonic-clonic seizure occurs before/during water activities, the person should not continue swimming or participate in water activities that day, even if they have fully recovered;
- o People with uncontrolled seizures should consider wearing a safety vest that helps keep their head above water. According to Maritime Safety Queensland lifejackets fall into two broad categories:
 - (i) Inflatable (can be either self-inflating or automatic)
 - (ii) Non-inflatable

If a lifejacket is worn it is very important to ensure it is correctly fitted for each individual. Maritime Safety Queensland is currently running the "Life-jacket wear it" campaign which stresses that lifejackets are not an optional safety feature and encourages us to think of lifejackets as the seat belts of the sea.

<https://www.msq.qld.gov.au/About-us/Maritime-safety-campaigns/Life-jacket-wear-it>

If you have any queries about water safety contact the team at Epilepsy Queensland Inc. who will be happy to help you. Call: (07) 3435 5000 or 1300 852 853 (outside Brisbane).

References:

Maritime Safety Queensland
Epilepsy Queensland Inc.

Seizure First Aid in Water

1. Time the Seizure
2. Protect from injury
 - Support the person's head so their face is out of the water
 - Tilt their head back to ensure a clear airway
 - Guide the person away from the edge of the pool or lane ropes to avoid injury
3. Remove from water & gently roll the person onto one side
 - When the seizure ends or when help arrives & it is safe to do so
4. Call for an ambulance - 000
5. Once the seizure ends, check for signs of life, if none, commence CPR immediately
6. Reassure & re-orientate
 - as the seizure ends
7. Stay with the person
 - until the ambulance arrives

ALWAYS CALL AN AMBULANCE for seizures occurring in the water. Even if the breathing seems to have returned to normal and the person appears to have recovered, water may have been inhaled into the lungs.

DO NOT restrain the person's movements
DO NOT put anything in the person's mouth
DO NOT give the person anything to eat or drink until they have fully recovered

+ SEIZURE FIRST AID +

Generalised Tonic-Clonic Seizure

With loss of consciousness, muscle stiffening, falling, followed by jerking movements

1. Time the seizure
2. Protect from injury
3. Gently roll the person onto their side
4. Reassure, re-orientate & stay with the person



Do not restrain the person's movements • **Do not** put anything in the person's mouth • **Do not** give the person anything to eat or drink until fully recovered

Call an Ambulance - 000 if:

- Seizure lasts 5 minutes/ second seizure follows
- Person is non-responsive for 5 minutes post seizure
- Seizure occurs in water/the person is eating or drinking
- Person is pregnant or has diabetes
- Person is not known to you/it's their first seizure
- You feel uncomfortable dealing with the seizure

epilepsyqueensland.com.au | 1300 852 853

THE SEPTEMBER SIZZLE IS UNDER WAY, RAISING MUCH NEEDED FUNDS & AWARENESS FOR SEIZURE FIRST AID. CONTACT US FOR YOUR COPY OF THE LATEST SEIZURE FIRST AID POSTER OR FRIDGE MAGNET.

What's On ...



EPILEPSY QUEENSLAND'S UNDERSTANDING EPILEPSY AND ADMINISTRATION OF MIDAZOLAM TRAINING

'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

Epilepsy Queensland is holding monthly workshops in our Woolloongabba office on:
19 October (9.30am & 5.30pm)
16 November (9.30am)

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

Epilepsy Queensland holds bi-monthly workshops at Benowa:
15 November (11:00am - 1:00pm)

CARER & PARENT SUPPORT GROUPS

Bulimba Library
12 October

EVENTS

26 October Queensland Epilepsy Symposium

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.

Epilepsy Queensland proudly conducts monthly in-house Understanding Epilepsy and Administration of Midazolam workshops at our Woolloongabba office and bi-monthly at the Gold Coast. Did you also know that we frequently deliver these training sessions to a range of different organisations, schools, kindergartens and child care centres around Queensland and northern NSW?

Hint...!

Schools love our 1.5 hour Seizure recognition, first aid and Administration of Midazolam training.

Encourage your school to get in quick as training dates for early 2017 are booking out fast! Contact us for more information.

Come along...

...to our in-house Understanding epilepsy and Administration of Midazolam training at Woolloongabba or the Gold Coast. In 2017 we will also be offering three after hours in-house sessions. These workshops cover -

- seizure first aid
- seizure recognition
- current treatments for epilepsy
- known causes of epilepsy
- seizure triggers
- administration of midazolam

Download a flyer from our website (www.epilepsyqueensland.com.au) or call to register. We would love to see your family, friends and colleagues there or come along to meet new people.

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 date and time.

Need after hours training?

No problem! Contact us to arrange a training package to suit your needs.

Please note, after hours training incurs a 25% surcharge.

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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