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EPILEPSY QUEENSLAND IS HERE TO HELP YOU ON YOUR NDIS JOURNEY



Are you wondering if you are eligible for the National Disability Insurance Scheme (NDIS)?

Are you wanting to know what evidence to collate for access and eligibility assessment or help with preparing for your NDIS planning meeting with the National Disability Insurance Agency (NDIA)?

Then please give us a call. We have many practical resources that can help through this process.

Did you know that Epilepsy Queensland is a Registered Provider under the NDIS?

We are registered to provide a range of supports and services including:

- In home support;
- Accessing community activities;
- Developing an Epilepsy Management plan (inc. Midazolam plan if required);
- Delivering training for support workers/teachers/ family & carers and;
- Completing an Epilepsy Assessment which will identify relevant assistive technologies and supports in relation to safety and independence.

We are committed to making sure that there is a good match between the person providing the services, and what the person receiving and their loved ones want and need. Therefore, we actively involve the family in the recruitment and decision making about their support team.

For more information on how we can assist you, please contact us on 07 3435 5000.

Your feedback is important to our future: Epilepsy Queensland survey



We want to hear from you about what we are doing well and what we can do better to ensure a more valuable service to those impacted by epilepsy. A copy of the survey and a reply paid envelope is included in this edition of Livewires.

This survey is seeking the views of:

- People living with epilepsy
- Family, carers and friends
- Support workers
- Organisations that have used our training

The continued rollout of the National Disability Insurance Scheme will have implications for Epilepsy Queensland, our members and supporters. Feedback provided will help to identify how we can support our members in the best way possible now and into the future.

We would really appreciate you taking the time to complete the survey and posting it back to us. If you have any queries or would like to do the survey over the phone, please call Epilepsy Queensland on (07) 3435 5000 or 1300 852 853 (outside Brisbane)

NDIS - TIPS AND HINTS

Many people have asked about the interface between Medicare services, private health and NDIS funding. Similarly, as the initial information provided from the NDIA was incorrect, in this edition, please find below the updated information from the NDIA, posted on 12th February 2018 in their Q and A segment.

Q - Can I use my NDIS funds to pay the gap for Medicare services?

A - No. The NDIS is not designed to fund supports more appropriate funded or provided by the health system. You cannot use your NDIS funds to pay Medicare gap fees. As an NDIS participant, you cannot claim under both systems for the same support. The NDIS Act and Rules provide guidance for what is funded under the Scheme. Basically, a support the NDIS pays for is not claimable against any other Commonwealth Program such as Medicare.

Q - I was told I must use the 10 free Medicare psychologist sessions in the mental health plan my GP created for me before I can access my NDIS funded supports to see a psychologist. Is this correct?

A - No. That is not correct. The NDIA develops and approves plan budgets to cover the full cost of supports, for example, psychology services, where they are considered reasonable and necessary for a participant.

The decision as to what capacity building supports or therapy would be deemed reasonable and necessary

takes into account the responsibilities of the health system and services already available to the participant.

Once plan supports are approved, the participant can use those supports as described in the plan. Therapy may be described generally (e.g. "Therapy up to the value of \$x") in a budget so it can be used flexibly within that budget or it may be described specifically (for example, 1 session of psychology/therapy per week.)

Q - Can I claim the gap from private health insurance for allied health services from my plan?

A - NDIA plan budgets are developed to cover the full cost of supports (e.g. physiotherapy or OT services to build function) where these are considered reasonable and necessary for the participant. As a result, you should not have to pay a 'gap' fee.

Participants should not make claims under private health insurance policies for 'reasonable and necessary' supports in their plan they intend to claim from the NDIS. Participants may choose to use private health insurance to fund services and treatments not funded in their NDIS plan.

In rare cases, where a support being delivered may be claimable under either the participant's plan or private health insurance, the participant may choose whether to use NDIS funds or to make a claim under their private health insurance but they cannot make a claim under both in respect to the same support.

For a personalised conversation about how we can support you and your family, please contact us on 07 3435 5000.



Safety – Alerting Others

Epilepsy is an unpredictable condition, with seizures happening at unknown times and places, often without any warning at all. As a result, there are a number of safety considerations and devices available for people living with epilepsy, to help minimise the risks associated with seizures.

Despite being easily accessible and relatively inexpensive, personal medical alerts are a basic first line safety measure, which often get overlooked. Personal medical alerts can be worn on or near the body (e.g. in wallets and handbags etc.) to make others aware of your condition in the event of a medical emergency.

Alerts may include jewellery, tattoos, wallet cards & covers or tags that can be attached to seatbelts/backpacks and can provide varying levels of personal medical information. On the more basic front, they may simply alert others to a diagnosis of epilepsy, with more detailed versions providing diagnosis, treatment, allergies, next of kin and doctors' details.

Importantly, they provide vital information, particularly to first responders, like the Queensland Ambulance Service, to help guide emergency care. If you have overlooked personal alerts in the past, now might be the time to consider them.

For more information on options and considerations specific to your needs, including potential eligibility under NDIS, contact our Services team on 07 3435 5000 or 1300 852 852 (outside Brisbane).



MYTIME - SUPPORT GROUP FOR PARENTS/CARERS

Epilepsy Queensland has partnered with Playgroup Queensland and is now able to offer the MyTime program designed to support parents and carers of children with disabilities or chronic medical conditions.



What is the MyTime program?

If you're a mum, dad, grandparent or anyone caring for a child up to the age of 18 years with a disability, developmental delay or chronic medical condition, then MyTime is a wonderful program designed to help and support you.

MyTime is unique because it is focused on the carer. It gives them time to look after their own needs, build confidence and form friendships and is a place for both giving and receiving.

These peer support groups provide the opportunity to socialise, share ideas and information with others who understand the rewards and intensity of caring for a child with special needs.

The MyTime program also has a strong parent education component. It is intended that the program will build skills, foster shared responsibilities and strengthen the capacity of the whole community to support parents of children with disabilities.

What happens at MyTime?

Skilled facilitators will guide and support each group, bringing people together and ensuring the topics and activities are relevant for the group. By attending the group parents and carers become invaluable supports to each other, building on their social networks and often sharing information and experiences about the range of services available in their local area.

The activities are designed with the group to ensure they are relevant and engaging. A Play Helper is available to keep young children – including under school aged siblings busy with activities so members can spend time catching up with one another.

There is no cost to join a MyTime group. The Epilepsy Queensland MyTime group meets fortnightly during school terms at St Paul's Anglican Church, 554 Vulture Street, East Brisbane. This venue may change so please contact us for up to date information. For further information or to RSVP please call Leonie Hogarth on 07 3435 5000 or email: lhogarth@epilepsyqueensland.com.au

New Funding Arrangements for VNS Therapy

Vagus Nerve Stimulation Therapy (VNS Therapy®) is a treatment for epilepsy that involves a small device (similar to a pacemaker) which is implanted under the skin of the chest. The device sends regular, mild electrical impulses to the brain through a nerve in the neck called the vagus nerve. The aim of this treatment is to reduce the number of seizures patients have and make them less severe¹.

VNS Therapy is a treatment for people with epilepsy whose seizures are not controlled with medication, referred to as drug-resistant epilepsy. The definition of drug-resistant epilepsy according to the International League Against Epilepsy (ILAE) is the 'failure of adequate trials of two tolerated and appropriately chosen and used anti-epileptic drug (AED) schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom'². Patients who have tried two or more AED's and are unable to fully control seizures can be considered for VNS Therapy.

Until recently, VNS Therapy has had no public funding in Australia. However in November 2017, the Australian government approved the subsidisation of VNS Therapy through Medicare Services, improving patient access to VNS Therapy in public hospitals. It means that all patients considered for VNS Therapy are now government funded for both implanting and programming of their device.

Patients with private health insurance can also access VNS Therapy through their health fund. All VNS Therapy generator models are now included on a list of implantable prostheses that private health insurers must pay benefits for when they are provided to patients with appropriate health insurance cover.

For further information on VNS Therapy, please contact your health care provider or LivaNova Australia Customer Service on 1800 452 650.

References 1 .What is VNS therapy for epilepsy? Retrieved from <https://www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation> 2 .Kwan P, et al. Epilepsia 2010;51:1060-1077



What's On ...



'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

monthly workshops at the Woolloongabba office on:

19 APRIL (9.30am - 12:00pm)
17 MAY (9.30am - 12:00pm)
14 JUNE (9.30am & 6.00pm)

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

16 MAY (11:00am - 1:00pm)
25 JULY (11:00am - 1:00pm)

MyTime Support Group

9:00am - 12:00pm Every 2nd Tuesday within school term
starting 22 January 2018

SAVE THE DATE

Little Poss Birthday June 9

contact Epilepsy Queensland on 07 3435 5000 or
1300 852 853 (Regional Queensland)
or email epilepsy@epilepsyqueensland.com.au for more
information on support groups in your area.



MS Queensland



FREE NeuroPhysio Information Sessions
Dutton Park and Chermside during April and
May. To find out more information and secure
your place, call 1800 177 591 or email
info@msqld.org.au

Do you know a Support Worker?

Please let them know that Epilepsy
Queensland is seeking the help of support
workers to improve our services.
The information provided will help us to ensure
we are delivering services which meet the
needs of support workers in Queensland
Please go online to complete our survey.
Follow the link below.

Computer and mobile phone friendly.
www.surveymonkey.com/r/dswepilepsy
For further information contact:
services@epilepsyqueensland.com.au

or
P: 07 3435 5000

**G E N E T I C E P I L E P S Y
F A M I L Y C O N F E R E N C E**

**25th and 26th MAY 2018
MELBOURNE - REGISTER NOW**

GETA: GET A TEAM, GET A TARGET, GET A CURE

FOR MORE INFORMATION - [HTTP://GENETICEPILEPSYTEAM.COM.AU/](http://GENETICEPILEPSYTEAM.COM.AU/)

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condition, its treatment and management should be directed to
your doctor.*

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