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ROSA THE SURGICAL ROBOT

ROSA is a surgical assistant robot used for stereotactic EEG electrode insertion. It works with the neurosurgeon to ensure accurate and precise placement of depth electrodes used for epilepsy monitoring (invasive stereotactic EEG). ROSA guides the neurosurgeon to the surgical site—the surgeon still creates the opening (drill) and feeds the electrodes in, along the laser-guided pathway created by ROSA.

In 2015, with the opening of the Mater Centre of Neurosciences, the Advanced Epilepsy Unit (under the direction of Epileptologist, Dr Sasha Dionisio, and Neurosurgeon, Dr Jason Papacostas) undertook the first SEEG case in Queensland (September 2015)—becoming one of three centres country-wide credentialed in this procedure. By December 2015, three cases had been successfully implanted and monitored.

The purchase of the robot was to improve surgical times (the time in the operating theatre under general anaesthetic) to reduce clinical risk and to improve on the accuracy of electrode placement.

Now, by April 2016, a further 3 cases have been undertaken and successfully implanted, using the ROSA.

Rosa Robotic Surgical Assistant

The Rosa Robotic Surgical Assistant is the latest generation in robotics to work alongside neurosurgeons to provide guaranteed accuracy that is ergonomically superior to a standard navigation system.

Benefits

- Procedural safety is increased as the instruments are guided into position based on the planned trajectory inputs
- Application accuracy is the best available on the market today. It combines robotic accuracy with patented laser technology.
- Patient comfort is increased



Team photo with the epilepsy service, neurosurgeon, engineers and ROSA staff from France

- Operating time is reduced
- There are no limitations with planned trajectories and they can be easily modified.
- There is a seamless integration between surgical planning and actual execution, thus providing the surgeon with increased confidence in their surgery.

Clinical advantages

- access to a larger area of the brain (including posterior electrodes), allowing for a more detailed and accurate implantation and subsequent diagnosis and treatment (Medtech, 2015)
- the ability to quickly and accurately modify the trajectories intraoperatively to within a fraction of a millimetre, promoting patient safety (Medtech, 2015)
- decreased anaesthesia for the patient with a more rapid recovery
- an increase in clinical confidence in electrode placement.

The Mater Centre for Neurosciences is the only centre in the southern hemisphere with a Rosa Robotic Surgical Assistant.

Story provided by Mater Centre for Neurosciences

GETTING NDIS READY

For some time now we have been hearing about the NDIS and we are soon to see it rolled out for the first time in Queensland (Townsville) next month. For many this is both a scary and overwhelming change. There are questions about how this will affect current supports and concerns about how it will all work.

Whilst these concerns may be valid, at Epilepsy Queensland we are excited at the prospect that some people who have epilepsy, who were previously not eligible, may become eligible for support under the NDIS. Below we have outlined just some of the basics of NDIS and how it may help those living with epilepsy. Over the coming months and as we observe it's rollout in Townsville, we hope to be able to provide more information.

What is NDIS?

NDIS stands for National Disability Insurance Scheme and will be implemented by the National Disability Insurance Agency (NDIA). It is aimed at providing support for people with an impairment or condition that is likely to be permanent, or a developmental delay that affects their ability to take part in everyday activities.

Under the new scheme, individuals will have more control, greater flexibility and the power to choose providers, instead of funding being allocated to specific organisations. If you are eligible for NDIS, you and/or your family/carer (if you wish), will meet with a planner to develop a plan that meets your personal goals and funding will be allocated accordingly. The participant will then be able to choose how, when and where their supports are provided.

What will be funded?

The NDIS will fund “reasonable” and “necessary” supports. This means that the support:

- Increases independence, economic and social participation
- Relates to the person's disability
- Does not include day-to-day living costs that are unrelated to the participant's disability support needs
- Represents value for money and
- Is likely to be effective and beneficial to the participant

As each participant's plan is individualised to meet their needs, NDIS will fund different supports for different people, depending on their goals. Examples of supports include:

- Transport
- Support workers
- Therapy
- Aids and equipment
- Workplace help
- Home and vehicle modifications
- Social participation activities
- Education and training
- Health and wellbeing activities

Who is Eligible for NDIS?

To be eligible for NDIS, you need to be:

- Under 65 years of age
- An Australian Citizen, a permanent resident, or New Zealand citizen who is a Protected special Category Visa Holder
- Live in a launch site
- Meet either the disability or early intervention requirements

More information about access requirements can be found on the NDIS website access checklist www.ndis.gov.au/ndis-access-checklist.

Accessing the Scheme if Epilepsy is Your Primary Diagnosis

To become a participant, you (or your parent, legal guardian or representative) will need to complete the Access Request Form. All participants must complete section A and B.

Part A: General Information for the person accessing NDIS (compulsory)

- including proof of age and residency

Part B: Diagnosis of Conditions (compulsory)

- completed by treating doctor/s
- Includes information about diagnosis and treatment/s

However, if your condition is not on the list of ‘Permanent impairment/functional capacity—no further assessment required’, you must also complete Part C. Whilst many people recognize that Epilepsy can have a profound impact on an individual's ability to function on a daily basis, it is not currently recognized as a condition that allows for a streamlined process when entering the scheme. Therefore, you will be required to complete Part C, providing evidence of the impact of the condition.

Part C: Functional Impairment

- Completed by health professional
- Provides details of impairment on mobility, communication, social interaction, learning, self management and self care.

Epilepsy Considerations when planning for NDIS

In planning for the NDIS, there will be many things to consider:

- Dreams and aspirations
- Goals
- Strengths and abilities
- The type of supports you will need
- What and how much funding (if any) you currently receive

Further to this you will need to think specifically about the impact epilepsy is having on your day to day living and how to plan to support your care needs. Here's a list of just some of things you may wish to consider:

- Is Understanding Epilepsy and Midazolam training required for family, carers, and support workers to provide safe care?
- Do you require an Epilepsy Management Plan or Emergency Plan to be written for school, workplace, support agency etc?
- Are there any aids or supports required to assist in accessing social and educational activities? eg cooling vests, monitoring devices, special needs stroller etc.
- Do you require assistance with transport to be able to improve independence, to access work etc?

Where can I get more information?

Whilst the NDIS may still be a little way off in your area, it's a great idea to start thinking about it and planning ahead! If you require further information:

- www.ndis.gov.au
- www.everyaustraliancounts.com.au
- Or feel free to call Epilepsy Queensland's Services Team on 3435 5000 or 1300 852 853 (outside of Brisbane).

Five things you need to know about the NDIS in Queensland

The National Disability Insurance Scheme (NDIS) is the new way of providing individualised support for people with disability, their families and carers. The NDIS is the insurance that gives us all peace of mind. Disability could affect anyone and having the right support makes a big difference.

The NDIS provides eligible people a flexible, whole-of-life approach to the support needed to pursue their goals and aspirations and participate in daily life.

1. WHAT?

The Commonwealth and Queensland governments have agreed on how the NDIS will be rolled out across Queensland. In Queensland, the NDIS will be operating state-wide by July 2019. The NDIS already has early transition sites in Townsville and Charters Towers for children and young people (0-17 years) and all eligible participants from Palm Island.

2. WHEN?

The NDIS is a big change and will be progressively rolled out in Queensland over three years from 1 July 2016.

People will move to the NDIS at different times depending on where they live. The NDIS will be operating state-wide by July 2019.

3. WHERE?

1 July 2016 - 30 June 2017

Townsville • Mackay • Toowoomba

1 July 2017 - 30 June 2018

Ipswich • Bundaberg • Rockhampton

1 July 2018-30 June 2019

Logan • Cairns • Brisbane (North and South)
Fraser Coast • Caboolture/Strathpine • Maroochydore
Gold Coast • Robina

4. HOW?

The National Disability Insurance Agency is working closely with relevant Commonwealth and Queensland government departments to ensure a smooth transition to the NDIS for people with disability, their families, carers and providers.

5. WHAT CAN I DO TO PREPARE?

If you currently receive disability services you will be contacted before your area transitions. If you are not currently receiving services you will be able to apply to access the Scheme when the NDIS is available in your area.

- Check the information and resources available at www.ndis.gov.au/qld or call 1800 800 110
- Talk to Epilepsy Queensland

Did you know that the UQ Psychology Clinic is currently accepting referrals for both therapy and assessment cases across the lifespan?

Their team of Provisional Psychologists provide high-quality, low-cost psychological services to a diverse range of clients.

"The UQ Psychology Clinic prides itself on being able to provide the stepping stones to a better sense of wellbeing"



Why refer to them?

- Individual, couple and group therapy
- Service across the lifespan (children, adolescents, adults & older adults)
- Cognitive and neuropsychological assessment
- Flexible appointment schedule
- Affordable prices (\$40 Standard, \$25 Concession)
- Medicare healthcare plan not required

How to make a referral

There are two ways you can refer clients to them:

1. Download the digital referral form and email the completed copy to psyclinic@psy.uq.edu.au
2. Call the UQ Psychology Clinic directly on 07 3365 6451

Other useful info

They see patients with the following psychological issues...

anxiety, depression, stress, behavioural problems, sleep issues, chronic pain, grief and loss, caregiving issues, relationship difficulties, significant life transitions, and managing health-related behaviours

Please visit the website for more information
www.clinic.psy.uq.edu.au



UQ Health Clinics

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 July **20 October**
25 August **24 November**
15 September

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:
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:

4 August • Longreach
18 October • Charleville

SUPPORT GROUPS

Brisbane Adult Support Group

9 July • 5 November

Northside Support Group

11 August • 11 November

Parents of Children with Uncontrolled Epilepsy Support Group

5 September • 6 December

EVENTS

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.

Epilepsy in Adolescence Research



Epilepsy Queensland is commencing research into adolescents with epilepsy in Queensland. There will be a number of stages to this research over the coming years.

The first stage of this research will commence in the upcoming months, where Provisional Psychologist Dana Breadsell will be distributing a survey to gather information about the experiences of adolescents with epilepsy. Dana will also be conducting phone interviews and focus groups.

The aim of this research is to improve understanding of the experiences of adolescents with epilepsy, with the ultimate goal of identifying and providing effective support to adolescents in managing life with epilepsy and their transition from child to adult health care teams. If you would like to be notified once the research commences, please email Dana on dbreadsell@epilepsyqueensland.com.au or look for a notice in upcoming newsletters for more details.

Clinical trial for fenfluramine for Dravet syndrome convulsive seizures

Lady Cilento Children's Hospital's Neurosciences is a site for a clinical trial for fenfluramine.

If you have a child with Dravet Syndrome convulsive seizures, and are interested in being considered for the trial, please email services@epilepsyqueensland.com.au. In the subject line say "Interest in the fenfluramine trial" with your contact details in the body of the email.

LCCH cannot discuss inclusion/exclusion criteria otherwise, until a patient has been deemed suitable for screening, and the parents have signed the consent.

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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