

## Feature 1: Landau Kleffner Syndrome

### What is Landau-Kleffner syndrome?

Landau-Kleffner syndrome (LKS) is a rare childhood disorder and is most often diagnosed in normally developing children who are between 3 and 7 years of age. It can also be seen as early as 18 months of age or as late as 13-14 years. It affects boys two to three times more than girls. LKS may also be called *infantile acquired aphasia*, *acquired epileptic aphasia* or *aphasia with convulsive disorder* (aphasia meaning inability to understand or produce speech).



A major characteristic of LKS is the gradual or sudden loss of the ability to understand and use spoken language. For no apparent reason, these children begin having trouble understanding what is said to them. Doctors often refer to this problem as auditory agnosia or "word deafness." The auditory agnosia may happen slowly or very quickly. Parents often think that their child is developing a hearing problem or has become suddenly deaf, but hearing tests show normal hearing.

These symptoms emerge in association with [epileptiform](#) EEG abnormalities. All children diagnosed with LKS appear to be normal before their first seizure or the onset of language problems.

### Other signs

A total of 70–80% of children with LKS demonstrate evidence of seizures at some point during the development of the syndrome. About fifty percent of children with LKS develop [electrical status](#)

[epilepticus during sleep \(ESES\)/continuous spike wave during sleep \(CSWS\)](#). This leads to memory disorders because the nearly continuous [epileptiform](#) discharges in sleep do not allow for the memory consolidation that also occurs during sleep. The loss of language may occur after an epileptic seizure that usually occurs at night. Speech problems can range from mild to severe. The inability to understand language eventually affects the child's spoken language which may progress to a complete loss of the ability to speak. Children who can read and write before the onset of LKS can often continue communicating through written language. Some children may develop a type of gestural communication or sign-like language. Intelligence usually appears to be unaffected but communication problems may lead to behavioural or psychological problems.

Approximately eighty percent of the children with LKS have one or more epileptic seizures that usually occur at night. All children with LKS have abnormal electrical brain activity in both hemispheres of the brain. Seizures usually stop by the teenage years. Behavioural disturbances are apparent in more than two-thirds of children with LKS. By far the most frequently observed behavioural problems are attentional deficits, impulsivity, distractibility, and hyperactivity. Aggressiveness and depression can also be seen with this syndrome. Children may also appear developmentally delayed or show traits on the autism spectrum, so this can cloud the picture making diagnosis difficult.

### How common is Landau-Kleffner syndrome?

LKS is rare. True prevalence is unclear but globally more than 300 cases have been described in literature.

### What causes Landau-Kleffner syndrome?

The cause of LKS is unknown. Some experts think there is more than one cause for this disorder. There have been no reports of children who have a family history of LKS. Therefore, LKS is not likely to be an inherited disorder.

### What treatments are available?

Landau-Kleffner is rare and often difficult to diagnose, but an accurate diagnosis is critical for treatment to be effective. Early speech and language intervention is critical. The earlier and more intense the intervention, the greater the chances of regaining spoken communication. [Corticosteroid](#) therapy improves the language skills of some children. For those children who do not regain spoken communication, other forms of communication need to be considered. For example, sign language benefits some children. Medication to control the seizures and abnormal brain wave activity (antiepileptic drugs) usually have very little effect on language ability, but seizures tend to be easy to control. On rare occasions, a surgical treatment, [multiple subpial transection](#), is considered if the corticosteroids are ineffective or cause unacceptable side effects.

### What is the outcome of Landau-Kleffner syndrome?

The long term prognosis for LKS varies considerably, and is not always completely clear. Seizures and EEG abnormalities tend to disappear during adolescence, but not always. Some children experience a permanent severe language disorder, while others regain much of their language skills. The time it takes to regain language skills can vary from months to years. Some children may experience remission and relapse. Generally, the prognosis is better when the onset is after age 6 and speech and language therapy is started early. The number of people with LKS is very small and there have not been many long-term follow-up studies of children with LKS. This lack of evidence, along with the wide range of differences among the affected children, makes it difficult to predict the outcome of this disorder. Complete language

recovery has been reported; however, language problems usually continue into adulthood. The continued language problems can range from difficulty following simple commands to no verbal communication. If recovery takes place, it can occur within days or years. So far, no relationship has been found between the extent of the language impairment, the presence or absence of seizures and the amount of language recovery. Generally, the earlier the disorder begins, the poorer the language recovery.

Language disturbances tend to persist in most people. People with LKS have an overall poorer quality of life, mostly due to language difficulties.



### Conclusion

LKS is a perplexing disorder involving of two main symptoms: 1) acquired aphasia and 2) [epileptiform](#) EEG abnormalities, and at least two accessory symptoms: 1) behavioural disturbances and 2) an easily controlled seizure disorder. The long-term outcome of people with LKS shows that epilepsy and EEG abnormalities do not always disappear and language disturbances tend to persist in most people. The duration of epilepsy interferes in the outcome of speech difficulties and psychosocial aspects of the disease and contributes to a poorer prognosis with regards to both.

### Where can I get more information?

Landau-Kleffner Syndrome  
[http://www.medicinenet.com/landau-kleffner\\_syndrome/article.htm](http://www.medicinenet.com/landau-kleffner_syndrome/article.htm)  
 LKS, early speech and language interventions.  
<http://speech-language-pathology-audiology.advanceweb.com/Features/Articles/Landau-Kleffner-Syndrome.aspx>  
<http://www.noahsark.net.au/> - search Landau-Kleffner for the factsheet  
 What every educator should know about Landau-Kleffner Syndrome  
<http://trainland.tripod.com/whatever.pdf>

## References

[http://www.epilepsybehavior.com/article/S1525-5050\(10\)00662-1/abstract](http://www.epilepsybehavior.com/article/S1525-5050(10)00662-1/abstract)  
[http://www.brainanddevelopment.com/article/S0387-7604\(08\)00237-4/pdf](http://www.brainanddevelopment.com/article/S0387-7604(08)00237-4/pdf)  
<http://www.tandfonline.com/doi/abs/10.1080/13854046.2011.614779#.V2tEsLt96M8>

## Glossary

**Corticosteroid:** Any class of steroid

**Epileptiform:** pertaining to epilepsy and its symptoms

**Electrical status epilepticus during sleep (ESES)/continuous spike wave during sleep (CSWS):** Where the EEG shows continuous spike and wave epileptiform activity during sleep, particularly deep sleep, with no outward signs of seizures.

**Multiple Subpial Transection** is a relatively new surgical epilepsy treatment. MST stops the seizure impulses by cutting nerve fibres in the outer layers of the brain (gray matter), sparing the vital functions concentrated in the deeper layers of brain tissue (white matter).

## Leonardo's journey with LKS – A mothers diary

Leonardo was born July 2008. He went full term and weighed 4.1 kg, started walking at 11 months and talking at 18 months.

### Feb 2012

At 3 ½ years, Leonardo begins his epilepsy journey with a 30 minute seizure at day care. Little did we know what was ahead. Nine ambulance calls accompanied by nine hospitalisations in this short period.

### Mid May 2012

Antiepileptic drugs Epilim and Frisium were introduced and things were improving.

### November 2012

We notice that Leonardo's language is disappearing and by the end of December 2012 all language was completely erased.

### 2013

Mid-January 2013 Leonardo is admitted into hospital where he has many tests and scans concluding that he has a Landau-Kleffner Syndrome.

### A very tough and gruelling year!

Leonardo begins his LKS journey with three regressions in six months. These regressions leave him with no words incontinence, minimal food intake, minimal mobility and uncontrollable behaviour. Between each regression he is given six weeks of steroids and then weaned off steroids for six weeks - hence the regression, improvement, then regression again.

I also learn that fatigue increases epileptic activity so I start a mandatory midday sleep for Leonardo. We have not seen a regression like those since.

### 2014

#### Landau-Kleffner is "managed".

Leonardo is now in his second year of the "active phase" of LKS. We are told that it is expected to "burn out" anytime between now and puberty. However the epileptic activity is now sub-clinical (no obvious seizures). Night-time is when Leonardo experiences more epileptic activity which causes daytime fatigue, and still does today.

Leonardo attended the first 6 months of school for only an hour each day. During this time we came close to severe regressions again, but every time this happened we slowed everything down and rested him, which kept things reasonably under control. With the help of an executive member of staff at school, and Leonardo's neurologist, Leonardo slowly managed to increase his time at school.

What made a difference for us was when we introduced a radical neuroscience chiropractor Dr Randy Beck who managed to stabilise his health considerably. In September 2014 we started the [Institute of Functional Neuroscience](#) program under

his direction three treatments a week. We noticed huge improvements in things like language, immunity, diet, stability of his feet and sleep. We still attend this clinic but due to time restraints only once a week.

Along with daily exercises plus vitamin supplements Leonardo is moving forward. The epileptic activity is still there and is the basis of Leonardo's health issues, so there is no denying that he is still sick.

## 2015

### Continued "management " of LKS.

Leonardo really spent the whole of 2014 "transitioning" into big school as he was so unwell. Now we are focused on learning. LKS has deleted three years of Leonardo's development so it's catch up time.

Is he learning and can he learn? The answer is *yes*. Leonardo had huge improvements in language which we attributed to neuroscience clinic, mainstream education exposure, a new speech therapist and new tutor. It is slow because the epileptic activity is in the way, but it is happening. We are not giving up!

## 2016.

### Leonardo now

Leonardo is 7 1/2 years old. Diagnosis ....Landau-Kleffner Variant (epilepsy syndrome).

**February.** We have recently taken Leonardo to Boston Children's Hospital in USA for five weeks. This was helpful as they are world leaders in the management of LKS. The neurologist there informed us that the epilepsy is burning out, which is great news.



The neuropsychologist at Boston explained the best therapies for recovery. We are following this plan - two occupational therapy and one speech therapy

sessions a week - plus the speech therapist has coordinated a programme for teacher aides to follow at school.

The team in Boston were very positive about the prospect of Leonardo recovering. Keeping in mind that 50 percent of LKS kids do recover. For me, I have no idea what Leonardo will be like in 10 years' time.

What I do know is that it's been extremely tough so far. We are currently spending lots of money on therapy plus now looking at [ABA therapy](#) because Boston has also insisted on mainstream education. The benefits are that he is with other kids who are verbal and [neurotypical](#). He is "modelling" good behaviour and picking up *so* much language. As for education, that is something I have to fight for and something I slave over!

### The main gist of this disease and how it manifests in Leonardo specifically.

Leonardo experiences sub-clinical epileptic activity 24/7. This is like a pendulum. Sometimes it's worse than other times which means Leonardo misses things, so we need to reinforce things learnt throughout the day.

Leonardo has not had a clinical seizure since 2012. You may see a blank stare, which could be a super quick clinical seizure but that is the extent of it. A drop seizure or a seizure that lasts for 5 mins or more hasn't happened since 2012. In moments of higher epileptic activity Leonardo's brain simply does not work to full capacity and this creates a host of problems. Let me paint a picture of a moment where Leonardo experiences high epileptic activity – his behaviours include:

- complete defiance...refusing to do as his told
- excessive drooling
- excessive whinging or stubbornness, only wanting things his way
- wobbly on his feet
- inability to eat food and behaviour escalates as yes he *is* hungry but he cannot swallow as the epileptic activity affects that part of his body
- aggression....lashing out, hitting, swearing, loads of screaming

- extremely active. Running around uncontrollably at serious risk of injury
- looking "glazed over" looking "out of it" no eye contact
- almost non-verbal in the sense that he cannot say anything coherent
- appearing to be in another world - autistic like.

The *bottom line* is Leonardo's subclinical epileptic activity is *still* happening and he is still at risk of hurting himself and others. This subclinical activity impedes his ability to take things in and remember. Therefore over time, do we run the risk of Leonardo being left behind mentally? Hopefully that won't happen as I feel his triggers for his epileptic activity are being completely "contained".

### Expectations – Moving Forward

- 1) Leonardo responds well to compliments and praise. Leonardo is completely aware of his inability to speak properly so he feels inadequate.
- 2) Occasional trips to the park are great. We stand back and give him his space, help him converse with kids *only if required*. We want to get him to be more independent socially.
- 3) He needs daily vitamins and I try my best to make daily fruit/veggie juice.
- 4) One needs to reinforce work from school - revise work sheets and school work, readers and story books.
- 5) Try to build up life skills... The epileptic activity is in the region of the brain that affects fine motor skills. Encourage Leonardo to dress and feed himself without making *so* much mess. Doing up buttons on a school shirt or on pants is quite difficult for Leonardo, and he makes a lot of mess when eating.
- 6) We are saturating Leonardo in a main stream lifestyle. The idea is that he will over time with a lot of guidance "blend into the social landscape".
- 7) If Leonardo has an "autistic type" meltdown he needs time to self-regulate. If you are familiar with sensory overload or sensory

processing disorder then you will understand my reasoning for this. Lately I've tried to hug it out! Give him a hug and sometimes this works as he feels disorientated.

- 8) We now have two therapists which the school has *finally* accepted and allowed to come into the class after years of advocating! Leonardo has a scrap book with his daily work pasted in and a daily report card is filled out by me, therapist and teacher aides. The only therapy missing is the ABA, which is going to start soon. As for methods of teaching it is multi-faceted...apps, speech therapy programme, OT input to maximise his learning capabilities.
- 9) I also wanted to mention that I'm currently pursuing mercury testing at <http://interclinical.com.au/contact.php>. If I can confirm that Leonardo has mercury poisoning then my next step is to find a highly reputable doctor who works in the area of chelation.

Leonardo requires mostly one-on-one assistance. But the main thing is he is improving. Life is mostly go, go, go, but I am so glad for his sake that he can participate in events with family and friends. Leonardo's favourite thing to do is going to the beach especially at my parents holiday home where he gets to have holidays with his cousins and grandparents.

### Final note

I would say that I am dedicating my entire life to this. I have given up my job as a high school music teacher and my 13 year old twin daughters have struggled with Leonardo's behaviour and mood swings and have had to learn to do a lot of things independently. The girls catch public transport everywhere even for their outings unless they are at night. I have to utilise respite services so I can spend quality time with our girls.

### My philosophy on raising happy kids .....

My belief is and always will be "that kids need *love, patience, time* and lots of *fun* experiences". Having

things to look forward to is *essential*. This is why I try very hard to give my kids fun times as opposed to material possessions. I also avoid at all costs comparing them to each other and their peers.

*Note: This article contains a number of treatments and methods used by the family to manage LKS. Management of this condition may vary for each individual. This article is not intended to provide medical or health advice, and if you have any specific questions about any of these or other treatments, you should consult your doctor or other appropriate professional healthcare provider.*

### Glossary

**ABA:** (*Applied Behaviour Analysis*) is a behaviour modification program that use techniques and principles to bring about meaningful and positive change in behaviour.

[http://raisingchildren.net.au/articles/applied\\_behaviour\\_analysis\\_th.html](http://raisingchildren.net.au/articles/applied_behaviour_analysis_th.html)

**Neurotypical:** showing typical neurological behaviour and development

## Feature 2: Discharge Planning for people with epilepsy

Whether you have just been diagnosed, or visiting hospital because of seizures or potential epilepsy surgery, when you go home, it is important to have the right documentation, information and advice to help you manage as best you can.

### In Hospital

Many peoples first hospital experience is the emergency department. It is usually a chaotic and overwhelming experience and if you are discharged from the emergency department, often it is difficult to remember everything you have been told.



Likewise, many people with epilepsy have hospital admissions outside of the initial seizure or diagnosis. This can be related to seizures, seizure emergencies, medication, or epilepsy surgery. For some people, hospital admissions can be quite intimidating, and the focus is mostly on your seizures and treatment. You may not give much thought to what happens at home after your discharge.

### Going home – Discharge Planning

Medicare states that discharge planning is "A process used to decide what a patient needs for a smooth move from one level of care to another." When you are going home, good discharge planning by hospital staff can dramatically improve your coping in the community. However, every hospital is different and there is a surprising lack of consistency in both the process and quality of discharge planning across the healthcare system.

Only a doctor can authorise a patient's release from the hospital, but the actual process of discharge planning can be completed by a social worker, nurse, case manager or other person. Ideally, and especially for complicated medical conditions, discharge planning is done with a team approach.

In general, the basics of a discharge plan are:

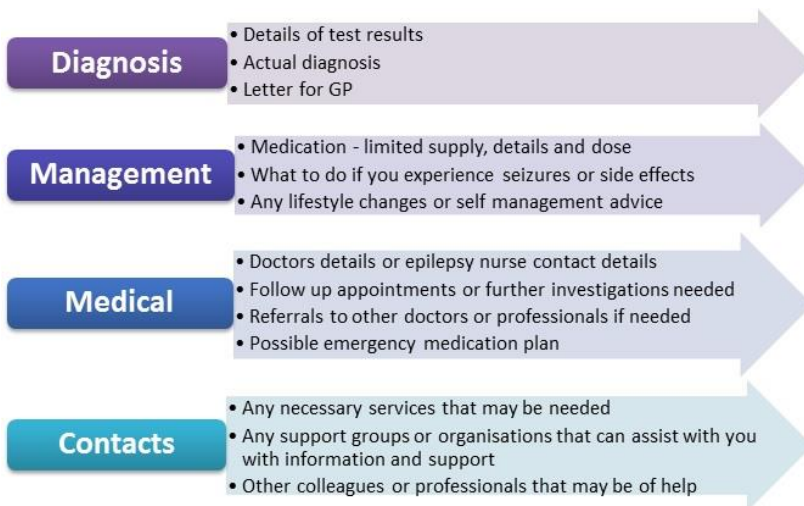
- Assessment of the patient by qualified personnel
- Discussion with the patient and/or family/carer
- Planning for going home or transfer to another care facility
- Determining if caregiver training or other support is needed
- Referral to home care agency and/or appropriate support organisations in the community if needed
- Ensuring the patient goes home with enough medication and any other supplies
- Arranging for follow-up appointments or tests.

The discussion needs to include the persons health details both before and after hospitalisation; details

of the types of care that may be needed; medication changes that need to be made at home (such as reducing or increasing dose); what to do in the case of seizures; and whether discharge will be to a facility or home. It should also include information on whether the condition is likely to improve; what activities the person might need help with, avoid or to be cautious of; information on medications and lifestyle; and changes needed around the home or environment; and transportation and safety considerations.

One thing that many people with epilepsy find useful is **Seizure Management Plans**. These can be used at home, in the workplace, at school, aged care or disability centres. We will discuss these later.

### A discharge plan should include:



### Things you should think about

If you've been in hospital for seizures or prolonged video EEG monitoring, there are safety concerns to consider if your medications were changed in hospital, if you've had more seizures than usual or if you've had epilepsy surgery.

Here are some things to think about and questions to ask before going home.

1. **Seizures:** When did you last have a seizure? Were your seizures different or

more severe in hospital? Are your seizures back to your typical frequency or pattern? If you feel your seizures aren't stable, then you should take extra safety precautions particularly during the first week or two at home.

2. **Diagnosis:** You should be aware of the initial test findings and what they mean. Did you get a diagnosis and do you understand it? Was your diagnosis changed during the hospitalisation? A final diagnosis and plan for changes may not be completely organised when you first go home. Your neurologist will give you some advice, but a lot of information is usually collected during monitoring and the epilepsy team will need time to review it.

3. **Medications:** Were there medication changes made during admission? Do you know which medications were stopped or reduced and if they were returned back to usual doses or stopped altogether? Will more changes be needed after discharge?

Sometimes medication changes are made slowly and you will be told when to increase a dose at home. Make sure you know how much to take, when to make a change and what to do if you aren't feeling well as changes are made. Return any unwanted medication to the pharmacy.

Do you need a new prescription? Make sure you have this before discharge. If it's a new medication or different formulation (generic, brand, long-acting), speak to your doctor or pharmacist for information regarding that medication. Ask if a new seizure medication will affect other medication you are taking.

4. Do you have **emergency medication** prescribed? Generally, these are prescribed only to be used for prolonged seizures or clusters of seizures. Make sure you have all

the appropriate paperwork for this medication – prescription and emergency medication orders for the people in the community who may need to give it.

5. **Safety:** What safety precautions might be needed at home? Ask when you can return to your usual activities, for example, school, work, sport or other activities. Ask about driving regulations if that is relevant for you. If your seizures aren't controlled, think about a safety plan or any changes that you might need to make at home or work.
6. **Know when to call for help:** Ask your neurologist, epilepsy nurse, or other health providers when an ambulance may need to be called.
7. **Seizure Management Plans (SMP):** Do you have or need a SMP? Create a SMP or update your current SMP with any changes: Know what to do when you have a seizure or if seizures change after admission. Know exactly when and how to take any emergency medicines. Know about possible side effects: Get a list of what to look for, when to call your epilepsy team, and when to be seen urgently.

Don't be afraid to ask questions and get these concerns addressed before, during or after hospital. You have a captive audience in hospital, so make the most of it. Don't wait until the last day or until you get home.

### **Seizure Management Planning**

A seizure management plan (SMP) is a document providing essential information to persons who may be in a position to help someone having a seizure - whether that be family, friends, carers, teachers, colleagues or other involved parties. SMP's are a practical tool that can be used by all caregivers in a variety of settings to manage seizures, seizure emergencies, treatments and safety. They can help reduce both the impact of seizures on the person's

daily life and the risk of injury in the event of a seizure.

### **A SMP is intended to provide:**

1. Clear instructions on the roles of the family, primary care provider or specialist in a variety of possible situations when and where a seizure could happen.
2. Information on what to do in case of a seizure, including details such as when to give emergency medication, how long any medication might take to work, and any other action needed such as when to call an ambulance.
3. A strategy outlining who should be contacted for what, as well as first steps to take in common scenarios that might occur.
4. Each person's seizures will be different and the SMP will require tailoring to each person's needs and circumstances.

SMP's may be called other names, however they essentially contain the same information with the aim to provide anyone who may be present during a seizure with enough information to enable them to know what to do and how to best assist and keep the person safe.

Sometimes seizure management planning involves developing a similar plan for administration of emergency medication. These are called **Emergency Medication Plans.**

### **Emergency Medication Plans – What are they?**

People who have had seizure emergencies such as prolonged seizures, clusters of seizures or status epilepticus, may be prescribed an emergency medication to be administered outside of the hospital setting. This requires the use of an Emergency Medication Plan (EMP).

The neurologist will complete the emergency medication order and specify what situation(s) the medication is to be given. An EMP is then completed by the health team, often the GP or a trained registered nurse, in collaboration with the



person, their carers/family/guardians, or anyone else involved in looking after the person on a day to day basis such as teachers.

The use of emergency medications in seizure emergency situations is considered a first aid intervention. An emergency medication order consists of:

- personal information;
- emergency contacts;
- description of seizure requiring emergency medication;
- when the medication is to be given, or not to be given;
- dose and route of medication;
- when to call an ambulance; and
- doctors details, signature and date for review.



As a general rule, SMP's and EMP's are kept together.

### **Organising a Seizure Management Plan (SMP) or Emergency Medication Plan (EMP):**

#### **Why is it important to have a SMP?**

- Part of managing epilepsy and seizures depends on being prepared to tackle whatever comes your way – from understanding your epilepsy, maintaining seizure control, responding to seizures, and managing safety.
- SMP can help you organise your seizure information to be available to the appropriate people when and where you need it. This may be at home, in the workplace, school or sporting facility.
- It can help you and others know what to do to prevent an emergency or inform others what to do in case a seizure or emergency situations. You can also adapt these plans to different situations in your life.

- By helping you be prepared, it lessens anxiety about having seizures and enables you to be a more active or confident participant or employee in whatever your role may be.
- The person with epilepsy is an integral part of the development of the SMP.

#### **Why develop a SMP?**

Seizures are often unpredictable and because epilepsy varies so much between individuals, it is crucial that everyone understands how to support the person having a seizure. A SMP has crucial information that can assist the person attending the seizure to respond appropriately and safely.

#### **Who may need to use a SMP?**

The plan is intended for use by the person with epilepsy, their family and any other person who has a role in caring for or supporting the person with epilepsy, either in a paid or unpaid capacity, including:

- Childcare and early childhood staff
- Teachers, aides, other school and Out-of-School Hours Care program staff
- Disability workers
- Medical practitioners
- Hospital accident, emergency and nursing staff
- Aged care, Home and Community Care (HACC) and disability support workers
- Employers or any other place where the person with epilepsy or their family believes this would be useful.
- Sports, Scouts, Girl Guides and other recreation staff

#### **Follow-up**

What you can do:

- Think about safety issues: Having unpredictable seizures means there is a potential safety risk. Think about your seizure type and when you are most likely to have seizures. Take sensible safety precautions but don't restrict your activities to a point where your interests and fun are

excluded. See our website for more help with safety issues

<http://www.epilepsy.org.au/about-epilepsy/living-with-epilepsy/safety>

- SMP: You are able to do this yourself, or with an epilepsy nurse at EAA, then have it signed off by your doctor and other relevant persons once you discuss it with them. Alternatively you can sit down together and work out your plan as a team. Register for free access via the Epilepsy Action Online Academy [www.epilepsy.org.au/node/383](http://www.epilepsy.org.au/node/383)
- Lifestyle changes: Some simple lifestyle changes and self-management techniques can influence and reduce or prevent seizures. Have a look at these suggestions <http://www.epilepsy.org.au/about-epilepsy/living-with-epilepsy>
- Informing others: It's your decision, whether you tell the people about your epilepsy. But if you do, particularly those who you spend a lot of time with or people who may be present if you have a seizure, it will give them confidence about helping you if you have a seizure.

### References and further reading

<http://www.epilepsy.com/article/2014/10/safety-concerns-discharge-epilepsy-monitoring-unit>  
<http://www.drugs.com/cg/epilepsy-discharge-care.html>

<https://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000128.htm>

<https://www.uichildrens.org/Adam/?/HIE%20Multimedia/60/000128>

[http://www.summitmedicalgroup.com/library/adult\\_care/ac-seizure\\_dc/](http://www.summitmedicalgroup.com/library/adult_care/ac-seizure_dc/)

Discharge planning template

<http://hosppeds.aappublications.org/content/4/6/366>

## In the News – The latest on epilepsy



### **New guidelines for pregnant women with epilepsy in the UK.**

Pregnant women with epilepsy should be treated by a specialist healthcare team to prevent unnecessary risks, according to new national UK guidelines. The guidelines recommend women seek advice well before pregnancy on their care. Read more <http://www.bbc.com/news/health-36559424>

### **New comic book about a boy with epilepsy**

Eight year old Jonty Stickland has become a comic book hero, his life with epilepsy forming the story behind a new book. The book Medikidz Explain Epilepsy is available free of charge and can be requested by calling 1300 37 45 37 or emailing [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au) For more information go to <http://www.sbs.com.au/news/article/2016/06/11/schoolboy-takes-lead-role-comic-about-life-epilepsy>

### **Impact of epilepsy on sexual function**

People with epilepsy can suffer from sexual problems but tend to be reluctant to discuss these problems with their neurologist and will instead seek advice from other healthcare professionals who may not have the knowledge to recognise and deal with the problem. Read more <https://www.epilepsysociety.org.uk/discussing-impact-epilepsy-sexual-function#.V3sylvb96M9>



### **Why stress can lead to seizures**

For people with epilepsy, stress and anxiety can increase the frequency and severity of seizures. Until now, it was unclear why this happened and

what could be done to prevent it. Recently researchers have shown that epilepsy actually

changes the way the brain reacts to stress, and have used these findings to point to new drugs that may prevent stress-induced seizures. Read more <http://medicalxpress.com/news/2016-06-stress-seizures-epilepsy-patients.html>

### Medicinal cannabis access for children with epilepsy

In an Australian first, NSW children with severe treatment-resistant epilepsy will be provided with compassionate access to Epidiolex<sup>®</sup>, a GW Pharmaceuticals cannabis-based medicine. NSW Premier Mike Baird and Minister for Medical Research Pru Goward met with clinicians, who will be prescribing Epidiolex<sup>®</sup>, at Sydney Children's Hospital, Randwick.

*"We will be able to deliver access to Epidiolex<sup>®</sup> to allow some of our most vulnerable children to use a standardised pharmaceutical cannabis-based medicine under medical supervision," Mr Baird said. "Parents have told us they do not want to play pharmacist – they want nothing but the best for their children and we are driven by this same purpose."*

Specialist paediatric neurologists who practice in NSW public hospitals have been authorised by the Therapeutic Goods Administration to prescribe Epidiolex<sup>®</sup>. Clinicians, who will monitor the children receiving the medicine, will contact eligible families in the coming weeks with further details. View the SBS news story here <http://www.sbs.com.au/ondemand/video/718519363957/epileptic-nsw-children-to-trial-cannabis>

## Q&As – Our service providers answer your questions



***Q. I've heard that there are some tinted glasses you can buy that might help people with photosensitive seizures. Is this true? [i]***

A: Medical management for *photosensitive epilepsy* may not always be 100% effective. Non-pharmacologic approaches have included the use of sunglasses of various types. We often recommend trying polarised sunglasses. The effectiveness of glasses (and contact) lenses for managing photosensitivity depends on both the lens colour and transmittance. Some studies in the epilepsy literature have shown that blue-tinted lenses may help people with epilepsy that have a *\*photoparoxysmal* response (on *EEG*) and seizures. Blue lenses have been shown to suppress the abnormal *EEG* response photic stimulations more effectively than lenses of other colours with similar overall transmittances.

One study, Capovilla et al (2006), showed that a particular blue spectacle lens (Z1 from Zeiss) was highly effective in controlling the *\*photoparoxysmal* EEG response in a large number of people with *photosensitive epilepsy*. When these people were wearing the glasses and exposed with photic stimulation, the lenses made the response disappear in 76 percent of people, and the response was reduced in an additional 18 percent. Therefore, the overwhelming majority benefited from blue-tinted spectacle lens use.

These glasses aren't available in Australia, so before investing in them, you might want to just try polarised sunglasses to see how helpful they are first. For some people the polarised glasses are good enough protection.

For more information regarding blue lenses and purchase options follow the links below <http://www.ncbi.nlm.nih.gov/pubmed/16529617> <https://videogame seizures.net/2012/03/11/life-with-zeiss-z1-f133-protective-lenses/> <http://www.clspectrum.com/articleviewer.aspx?articleID=107722>

*\* the abnormal occurrence of epileptiform discharges on electroencephalogram (EEG) in response to intermittent light stimulation*

[i] <http://www.ncbi.nlm.nih.gov/pubmed/16529617>  
<https://videogame seizures.net/2012/03/11/life-with-zeiss-z1-f133-protective-lenses/>  
<http://www.clspectrum.com/articleviewer.aspx?articleID=107722>

**Q: I have been diagnosed with epilepsy but I'm not sure. I have had 2 seizures, both in situations where I have fainted. How can I get it checked?**

A: Fainting can be commonly confused with epilepsy because sometimes you can experience brief jerks, twitching or convulsive movements during a faint. The most important part of making a *diagnosis* is to have a clear description of what happened. This is both from you and, if possible, from an eye-witness. Fainting has many known *triggers*, and a good history of the episode can often help to differentiate between a faint and a seizure.

When someone has a seizure immediately following a faint, it is known as a convulsive syncope.

It can be difficult for a doctor to say definitely that you have had a seizure if the description is not typical or clear. For example, a faint can sometimes cause brief stiffening of the body followed by a few jerks of the arms and legs. This may appear to an onlooker to be a short seizure; however, it is not a seizure. A doctor may ask questions to try to find the cause of what happened. If your doctor is unsure about the cause of the event, you may be referred to a specialist for further testing.

I think it is important you speak to your *neurologist* to ask why you have an epilepsy diagnosis. There may have been some abnormalities on EEG that lead to this conclusion. If the diagnosis is based purely on the event history and description, then I would encourage you to pursue further testing or seeking a second opinion.

**Q: My doctor said my seizures are intractable. What does this mean? [1]**

A: People with epilepsy whose seizures do not successfully respond to *antiepileptic drugs* are considered to have *intractable* epilepsy. In other words, it means your seizures are poorly controlled or not fully controlled despite trialling a number of different medications. This can also be referred to

as drug-resistant, medically refractory, or pharmaco-resistant epilepsy.

Approximately thirty percent of people with epilepsy are likely to have intractable epilepsy. There are other forms of treatment and management that may help, and this depends on the type of epilepsy but they can include surgery, *ketogenic diet*, vagus nerve stimulation and lifestyle changes, so it may be worth asking your *neurologist* if you are suitable for other forms of management.

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[1] <http://www.uptodate.com/contents/evaluation-and-management-of-drug-resistant-epilepsy>

**Q: My child has autism spectrum disorder, and has recently had an abnormal EEG. Does this mean he will have seizures? [1]**

A: There is a definite and well documented association between *autism spectrum disorder (ASD)* and epilepsy, with approximately one third of children with ASD developing epilepsy. However, an even higher number of people, up to eighty percent, with ASD have abnormal EEGs with no sign or evidence of seizures.

It also depends on what sort of abnormalities were found in your child's EEG, as some abnormalities can be "epileptiform" - indicating there are features seen that resemble a tendency towards epilepsy, whilst others can be non-specific or have a completely different interpretation. So to answer your question, essentially people with ASD can have abnormal EEGs and it does not necessarily mean they have or will develop seizures or epilepsy. I suggest you speak to the specialist who referred you for an EEG and try to clarify the meaning of the abnormality.

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[1] <https://npejournal.biomedcentral.com/articles/10.1186/s40810-014-0001-5>  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3847481/>  
<http://www.sciencedirect.com/science/article/pii/S0387760410002184>

## Taking Action – What’s happening at Epilepsy Action

### Connect with us and keep up to date!

Have you joined us on social media? It's the best way to stay connected and keep up to date with upcoming events and programs. It is also a good way to interact with other people who are living with the experience of epilepsy, either through a personal diagnosis or that of a friend or family member. So join today by clicking on the icons and we look forward to connecting with you.



<https://www.facebook.com/epilepsyactionaustralia>



<https://twitter.com/action4epilepsy>



<https://www.instagram.com/epilepsyactionaustralia/>



<https://www.youtube.com/user/EPILEPSYTV>



<https://au.pinterest.com/epactionaus/>

### City2Surf: There’s still time to join in the fun!

Join our Epilepsy Action team in the iconic 14km race from Sydney city to Bondi on 14 August 2016. Sign up and raise over \$250 by race day and we'll send you an Epilepsy Action goodie pack! Visit



[https://city2surf2016.everydayhero.com/au/sign-up to register.](https://city2surf2016.everydayhero.com/au/sign-up-to-register)

### Adventure Fundraising: Take your fundraising to the next level!

Do you dream of trekking Mount Everest? Cycling Cambodia? Walking the Great Wall of China? Or exploring Kakadu? Then Adventure Fundraising is for you!

We’ve partnered with Huma Charity Challenge to offer you the opportunity to choose a destination that most interests you, at a time that works best for you, with a minimum fundraising target of just \$1,000, allowing you to create your ultimate adventure with ease, and still make a positive impact on the world.

Visit <http://www.epilepsy.org.au/support-us/fundraise-for-us/adventure-fundraising> to see the destinations on offer.

