

Queensland Paediatric Epilepsy Network

New Diagnosis of Epilepsy Fact Sheet for young people and their families





WELCOME to the Queensland Paediatric Epilepsy Network’s fact sheet on epilepsy to assist you and your family accessing important initial information when dealing with a new diagnosis of epilepsy in a young person. The Queensland Paediatric Epilepsy Network (QPEN) is a sub-network of the Queensland Health State-wide Child and Youth Clinical Network. QPEN is a structure by which professionals from a number of organizations and backgrounds (neurologists, paediatricians, hospital and school-based nurses and community organizations including Epilepsy Action Australia and Epilepsy Queensland) collaborate to improve care for young people with epilepsy in Queensland. QPEN’s goals are to improve equity of access to high quality, family-centred health care; to improve access to high quality, culturally and age-appropriate educational material and to provide expertise on matters related to epilepsy and planning of epilepsy services to the Queensland Health Executive.

This fact sheet is designed to provide a broad range of initial facts and information to assist a family at the time of a new diagnosis of epilepsy in a young person. Whilst comprehensive, it may not be all the information that you may require, for this reason many additional resources are referenced. This fact sheet is current at the time of going to print, however services and resources referenced may change.

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WHAT IS A SEIZURE?

Anyone can have a seizure in the right circumstances, however not everyone who has seizures has epilepsy. A seizure is the result of a sudden, uncontrolled electrical discharge in a group of brain cells (neurons). For a brief period, this abnormal activity in the brain causes varied symptoms: strange sensations, emotions, convulsive movements, uncharacteristic behavior, altered awareness and/or loss of consciousness.

WHAT IS EPILEPSY?

A single seizure does not necessarily mean a person has epilepsy. For example a single seizure can occur if a person has a bang to their head. Epilepsy is a condition whereby an individual has a tendency to have recurrent seizures; the reasons why individuals may have this tendency differ from individual to individual. Epilepsy is a health condition, it is not a disease, it is not contagious and it is not a psychological disorder.

HOW IS EPILEPSY DIAGNOSED?

The diagnosis of epilepsy is based on the doctor clarifying that your young person has epileptic seizures and that these have a tendency to recur. Your doctor will ask questions to determine if your young person is having recurrent epileptic seizures and to obtain information about the detail of the seizures that are occurring. Sometimes this requires information from others who have seen the seizures first hand. The diagnosis is made primarily using the doctor's clinical judgment regarding the information given to them about what has been occurring. If safe to do so (for example if there is a second person present during a seizure), it can be very helpful to take videos of the seizures and show these to the doctor to ensure that they have optimal information for their assessment. Other tests such as EEG or MRI are more helpful to look at the underlying causes of epilepsy, after the diagnosis has been made using the doctor's clinical judgement.

Caution: many different things can look like epileptic seizures and it is common for these to be incorrectly interpreted as epileptic. Examples include:

- Young people can appear to be 'not there' when concentrating, bored, tired or over-stimulated, this 'zoning out' (or daydreaming) can look like an absence seizure. A clue is that 'zoning out' often happens in certain circumstances (when the young person is tired, bored, over-stimulated or relaxed) and you can bring a young person out of a daydream using methods to attract their attention. In contrast to this, absence seizures can occur at any time and typically a young person will suddenly stop an activity that they were involved in when the absence seizure occurs, and resume the activity when it ends (usually 10 seconds or so later).
- Children when asleep can have normal sleep jerks in light sleep, these look like myoclonic jerks but are normal sleep phenomena.
- Children can have 'night terrors' and other sleep events that look like seizures, but are not.
- Children can have movements that are unusual when concentrating or excited, that are not epileptic seizures.
- Faints can look like seizures, and commonly can occur with prominent jerking of the body, these are not seizures. A clue is that the individual often experiences a sick feeling in their

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- tummy, a darkening of their vision and weakness in their legs as the faint starts; and in a faint an individual is often pale. A faint is longer if the person is not laid flat on the ground quickly.
- Young people with panic attacks or other forms of reactions to stressful situations can look as if they are having seizures, but the events are not seizures.

Your doctor will consider all the different types of attacks that can imitate epileptic seizures when considering whether a diagnosis of epilepsy is appropriate.

WHAT CAUSES EPILEPSY?

Epilepsy, having a risk of recurrent seizures, has different causes in different individuals. Broadly the following are possible causes of epilepsy:

- Genetic factors, these are a common causes of epilepsy, many genetic factors are not inherited as they are new genetic changes that occur in the individual with epilepsy, others are ‘susceptibility factors’ meaning that the genetic make-up alone does not definitely mean that seizures will occur in every individual with this genetic make-up in a family, but the genetic factors increase the risk of seizures. Approximately 70% of epilepsies are due to genetic factors. Doctors do not routinely test for many of these genetic factors, as most testing is not available outside of research studies. However, there are recognized patterns of seizures and findings on EEG in epilepsies that are likely to be genetic in their basis and these patterns may allow the doctor to diagnose the epilepsy as genetic. Please check with your doctor if you think the cause of the epilepsy is ‘unknown’ as in many instances, these epilepsies are still understood by doctors as being due to genetic influences.
- Abnormal areas of brain formation (structural malformations), often these are present from when the brain developed during fetal life. Sometimes these areas of abnormal brain may be small or hard to see and high resolution MRI with expert review may be required to detect them. Speak to your doctor if this may be relevant (if there are focal seizures) for your young person.
- Brain injury e.g. trauma, stroke, meningitis
- Immune disorders that cause inflammation in the brain
- Metabolic disorders, resulting in imbalance in chemicals within the brain
- Unknown, despite all tests that are currently available some epilepsies still are not able to linked to an underlying cause.

It is important to know that epilepsies are typically not caused by anything that a parent or carer did or failed to do.

Understanding the underlying cause of the epilepsy will give your doctor a better idea as to whether or not your young person might grow out of their epilepsy. This can happen for some epilepsies, but not for all of them.



Tests that are commonly used to help understand the cause of epilepsy in your young person include:

EEG

An EEG measures the electrical activity in the brain. During an EEG, electrodes (small metal recording disks) are applied to specific locations on the scalp and record this activity. An EEG is a painless procedure. Epilepsies with different causes have different patterns on EEG. For example epilepsies that are genetic generalized epilepsies typically have generalized spike-and-wave patterns, epilepsies that start in one part of the brain (focal) have localized abnormalities seen in electrodes over that part of the brain. An EEG is not typically used to diagnose epilepsy; this is because some EEG abnormalities can be seen in healthy members of the population without epilepsy. But looking at the EEG patterns in an individual with epilepsy can be helpful in understanding which cause of epilepsy they are likely to have. An EEG can only diagnose epilepsy if a seizure occurs during the EEG recording.

MRI

An MRI is a scan that uses magnetic fields instead of radiation to obtain high quality images of the brain. It is not always necessary, especially if the epilepsy is thought to be due to a genetic condition.

Other tests

Other tests may be required, such as blood tests. These may be done to exclude other conditions or for specific epilepsies e.g. genetic epilepsies.

WHAT ARE THE DIFFERENT TYPES OF SEIZURES?

Generally, seizures fall into two broad categories: focal seizures and generalized seizures. The difference between these types is how they begin in the brain.

Focal Seizures

Focal seizures (previously known as partial seizures) start in one part of the brain. The symptoms or signs the person experiences will depend on the function which that region of the brain controls. The seizure may involve uncontrolled movement or stiffening or localized jerking/twitching of a part of the body, or can involve sensations or experiences such as feelings of *déjà vu*, an unpleasant smell or taste, or sensations in the stomach such as ‘butterflies’ or nausea. Focal seizures that predominantly have sensations or experiences that may only be evident to the individual experiencing them may be known as auras (or ‘warnings’). People can have different levels of awareness during focal seizures ranging from the person remaining alert throughout the seizure, or the person may lose awareness of what is happening at the time of the seizure, and appear confused.

When a person is alert during a seizure they can describe the experience (although they are unable to control it) during the seizure. They may not be able to do this immediately during the seizure, but can do so afterwards. When a person loses awareness, this is called a focal dyscognitive seizure. In this state, the person may often appear confused and dazed and may do strange and repetitive actions like fiddling with their clothes, chewing or swallowing or uttering unusual sounds. They may appear to have a vacant expression. When a person has had a dyscognitive seizure they can be sleepy, tired or have resolving confusion after the seizure terminates, which can last for minutes to hours.



Some focal seizures with initial awareness can evolve into a phase where there is later loss of awareness. Focal seizures can also evolve into a phase where there is a generalized seizure.

Generalized Seizures

Generalized seizures typically involve electrical activity that is widespread in brain, the activity can be very brief or more prolonged. There are many types of generalized seizures – some convulsive, others non-convulsive. Not all generalized seizures are associated with loss of consciousness.

- **Absence seizures [previously called petit mal seizures]**

These are brief, non-convulsive events, usually occurring in young school-aged children. With this type of seizure, the person's awareness and responsiveness is briefly impaired. Children stare vacantly and their eyes may roll upwards or their eyelids may flutter. Sometimes they may drop their head forwards or backwards. There may be some fumbling movements of the hands or mouthing movements.

It can be difficult to tell the difference between absence seizures and daydreaming. However, absence seizures start suddenly, interrupt the young person's activity, typically last a few seconds, and then stop suddenly with the person resuming what they were doing previously. Although these seizures are brief, they can occur many times daily, and thus be disruptive to learning. Daydreaming, by contrast, typically occurs when a young person is tired and quiet e.g. watching TV, or in the evenings. The young person stares and may show signs of tiredness. The staring usually occurs whilst the rest of the young person's body is quiet. Children who are daydreaming can be brought out of their staring events through the use of voice, touch and other stimulation.

- **Myoclonic seizures**

Myoclonic seizures are brief, shock-like jerks of a muscle or a group of muscles, usually lasting for a split second. Sometimes this can result in a fall or in a young person dropping what they were holding. There can be just one myoclonic jerk, but sometimes these can occur as a series of jerks. In some types of epilepsy they are seen more commonly in the morning on waking.

In sleep, it is common for children to have non-epileptic myoclonic-like jerks as a usual sleep phenomenon. These are called hypnic jerks and are more prominent in lighter stages of sleep and should not be confused with epileptic myoclonic jerks.

- **Atonic seizures**

Atonic seizures cause a sudden loss of or decrease in normal muscle tone and the person often falls to the ground. These are brief events and are often called 'drop attacks', these seizures can cause head or facial injury. Wearing protective headwear may avoid injury.

- **Tonic seizures**

Tonic seizures greatly increase normal muscle tone and the body, arms, or legs stiffen. If the person is standing, they may fall.

- **Tonic-clonic seizures [previously called grand mal seizures]**

During a tonic-clonic seizure a person loses consciousness, their body stiffens (tonic phase), air is forced past the vocal cords causing a cry or groan, and they can fall if standing. Their limbs then begin to jerk rhythmically (clonic phase). The person may produce excess saliva, may change color, or lose control of their bladder and/or bowel as the body relaxes.



As consciousness returns, the person may be confused, drowsy or agitated. They may have a headache and want to sleep. This drowsiness can last for a number of hours.

Although this type of seizure can be frightening to watch, a brief tonic-clonic seizure is unlikely to seriously harm the person having the seizure if they are correctly attended to (see seizure first aid to view the correct positioning of the person to ensure safety of airway and breathing, do not place anything in the mouth). They may, however, vomit or bite their tongue and can sometimes injure themselves if they hit nearby objects as they fall or convulse.

Focal or Generalized seizures

- **Epileptic spasms**

These are seizures, which are seen more commonly in infants than in older children, and are characterized by brief movements that tend to occur in a cluster when the young person first awakes.

The movements involve the head dropping down and the arms elevating, there may be abdominal ‘crunches’ that also occur. Subtle forms may only involve a jerk/drop of the chin. These are important to distinguish early as they may be associated with regression in development.

WHAT MIGHT TRIGGER A SEIZURE?

There are some things that increase the likelihood of having a seizure for most kinds of epilepsy, and some epilepsies that have additional specific triggers. Speak to your doctor about what the triggers might be for the specific epilepsy that your young person has. Young people with epilepsy are more likely to have a seizure (have a lower seizure threshold) when they have viral illnesses (whether or not there is a temperature). Sleep deprivation is another common trigger for many epilepsy types. Seizure triggers may include any/all of the following:

- Forgetting/unable to take medication (e.g. vomiting)
- Sleep deprivation / fatigue
- Emotional stress
- Alcohol or drugs
- Infections, viruses
- Extreme temperatures, particularly heat or fever
- Flashing lights (e.g. from video games, strobe lights), this is an uncommon trigger and only applies to a small proportion of people with epilepsy, typically those with a genetic epilepsy. This can be identified during EEG testing (as light testing is performed to check if there is light sensitivity). Speak to your doctor and ask him/her if any sensitivity to light was demonstrated on EEG. Even if it was, the level of light stimulation used in the EEG lab is higher than that experienced in day to day life so it may not mean that light-induced seizures are seen.

SEIZURE FIRST AID

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| Step 1 | Note the time the seizure starts and remember to note the details of exactly what happens to the person during the seizure. |
| Step 2 | Protect the person from injury. |
| Step 3 | If mobility is compromised and/or the person is confused encourage them away from danger. |
| Step 4 | Call for assistance; follow instructions in any emergency medication plan. |
| Step 5 | If unconscious, place in the recovery position when possible, to maintain a clear and open airway. |
| Step 6 | Do not restrain the person, place anything in the mouth or give food or drink. |
| Step 7 | Do not leave unattended. |
| Step 8 | Note the time when the seizure ends, reorientate the person to their surroundings as they recover. |

RECOVERY POSITION



WHEN TO CALL AN AMBULANCE – 000

A prolonged seizure (continuing for 5 minutes or more), or a series of shorter seizures in quick succession (both known as status epilepticus) are indications for taking emergency action.

For some patients, a doctor may prescribe home rescue medication and if a family member has been trained and is competent in home rescue medication administration, this may be given and may terminate the seizure emergency.

If you **DO NOT** have home rescue medication, you might need to call for ambulance support in the following situations (check with your doctor):

- If a seizure occurs and you are not familiar with managing it yet (in the new diagnosis period)
- If the seizure continues for more **than 5 minutes**
- If seizures occur in close proximity (typically **if seizures are < 20 minutes apart**)
- If your young person has an unusual seizure or fails to follow their usual recovery pattern
- If your young person is injured, goes blue in the face or has swallowed/inhaled water



If you **DO** have home rescue medication, administer it and call for ambulance support as instructed in your emergency plan.

HOW TO BEST RECORD SEIZURES?

Keeping a record of seizures is important. Few doctors ever see their patients with epilepsy having a seizure and they rely heavily on accurate descriptions of events, which can be forgotten if not recorded soon after the seizure. Doctors also use information on the frequency and severity of seizures to guide treatment decisions they make. In some cases, the detailed description of seizures helps the doctor find the cause of the epilepsy. Seizure recording may also be a useful way for you to identify seizure triggers, for example you may identify that you see a pattern of seizures during school holidays when your young person stays up late at night.

Tips for recording seizures:

- The key things that the doctor will be interested in will be what exactly occurred from the start of the first sign of the seizure to the end of the post-ictal stage (the post-ictal stage is the period after the seizure ends until the person is back to their normal self). Think through each thing that you saw in a step-by-step fashion. What movements of the body were seen – describe each part of the body and whether moving to the persons right or left or staying midline? Was the movement stiffening, jerking, or a loss of control? What direction did the head turn to, what direction did the eyes move in? Did the person report any experiences before the seizure started? How aware were they during and after the seizure? What was their color? How long did the seizure last? How long was the post-ictal phase (after the seizure ceased, how long did it take for the person to return to normal)?
- As you become used to the types of seizures that are occurring, you will identify that your young person may only have one or a few type(s) of seizure. Assigning a name to these different types will help you record these. The name is not important, it can be the name that your doctor calls them (see section on seizure types) or it can be the name(s) you/your young person call them, so long as your doctor has a detailed description of what occurs he/she will still understand what seizure type it is.
- There are very simple ways to record seizures, such as using a calendar with large boxes for each day of the month (e.g. calendars with one month on each page), so long as you have space to write the seizure type (the name you have decided to call the seizure type), together with the duration of the seizure and post-ictal stage and whether rescue medication was required (see rescue medication). A range of seizure diaries are available from a number of sources including community support organizations or online (see community support section below).
- Use video; if safe to do so, to record the detail of what is occurring during the seizure. If there is uncertainty for your doctor in assigning a seizure type, one or two typical videos of that seizure type may be helpful.
- If your young person is in school, ensure that you provide information to school staff so that they can record seizures in the same consistent way as you do.

THE ROLE OF YOUR USUAL DOCTOR AND EMERGENCY SERVICES?

While your usual doctor is able to provide support for non-urgent issues, urgent support is accessed through your local ambulance service and emergency department.

When your young person first starts having seizures, some seizures may be frightening. Families require time to build up confidence in managing seizures. It is therefore not uncommon for families, when the diagnosis of epilepsy is new, to seek the support of ambulance and local emergency department services when a seizure occurs. These services are there to provide support and care until the young person has recovered, at which time he/she is usually able to go home. After time has passed, families often recognize what is usual for their young person's seizures and are confident enough to manage straight-forward seizures and the young person's recovery at home, without the need to call an ambulance.

If, however, a seizure is prolonged (5 minutes or more) or there are a series of seizures without sufficient time for the individual to recover in between (typically 3 or more seizures an hour, although check if this is appropriate for your young person), then it is important to act and seek support from emergency services as such seizures typically require emergency medications and care.

After any seizures that have required intervention from emergency services it is important to notify your usual doctor. He/she may not receive communication about this from anyone other than you and he/she is better placed to advise on any changes to usual medications that may be required.

THE ROLE OF HOME EMERGENCY (RESCUE) MEDICATION?

For young people who have seizures that are likely to frequently require emergency treatment, your doctor can prescribe a home rescue medication that a suitably trained family member can administer. The home rescue medication that is commonly used is midazolam, and this can be squirted into the inside of the cheek or sprayed up the nose. Your doctor will consider if this is required and if it is will provide you with a prescription and specific training. If a young person is in school and midazolam is part of their emergency treatment plan, then the school should be informed and teachers can be trained to administer it (training is available for teachers from Education Queensland Nursing Service and from community support organizations such as Epilepsy Queensland or Epilepsy Action Australia).

Typical indications for home midazolam:

- A young person has demonstrated that they have a tendency to have prolonged seizures (seizure > 5 minutes)
- A young person has demonstrated that they have a tendency to have seizures that are close together (typically seizures less than 20 minutes apart)
- A young person with epilepsy lives remote from emergency services
- Other indications may apply in specific cases

THE ROLE OF WRITTEN EPILEPSY MANAGEMENT PLANS?

As your young person may experience a seizure in unpredictable locations, it is important that your doctor provides you with a written epilepsy management plan so that this can be with your young person, for example at school, in the event that a seizure emergency occurs. This will ensure that emergency service staff (and other persons e.g. school staff) have rapid access to important information to treat your young person. There are a range of different written epilepsy management plans available from different sources e.g. from certain Queensland Health or other hospitals, and from community organizations such as Epilepsy Action Australia and Epilepsy Queensland. It does not matter which one you use, so long as key elements are included, including a brief description of your young person's seizure types in easily understood terms (so that the seizure can be recognized by people who do not know him/her), their epilepsy cause (if known), their usual medications, their emergency management (seizure first aid, rescue medications if prescribed), and the people to contact in an emergency. In the section dealing with emergency medications, clear instructions (when to give, how much to give, how to give) should be included for the administration of emergency medications, so that people who do not know your young person well will still be able to follow the plan. It is recommended that such plans are in writing, signed off by your usual doctor and reviewed annually (or if emergency medications are changed) to ensure doses and instructions are current.

It is always helpful to ask your usual doctor to send you copies of his/her clinic letters and to keep these in a folder so they can be accessed if you need to attend hospital, as your young person's medical records may not always be accessible quickly (or at all, e.g. if you are away from home and your young person is brought to a different hospital by ambulance).

EPILEPSY AND YOUR CHILD'S LEARNING?

Like all children, many children with epilepsy will be high achievers or will be within the average range. However, some children with epilepsy may have difficulties learning. Such difficulties may be due to a number of different factors including direct effects of the underlying cause of the epilepsy, different expectations of their ability because of their epilepsy, the additional impact of seizures, and side-effects of medication.

The underlying cause of the epilepsy and learning

Some causes of epilepsy have no effect on brain functioning, other causes (such as a previous brain injury) can have direct consequences on brain functioning. Ask your doctor about the likely effects of any known brain problem in your young person on their learning. If there is an area of previous injury or an area where the brain is abnormal, then your doctor may be able to predict likely effects on learning. This is because different learning functions are carried out in different parts of the brain. For example memory for things that we see (pictures, graphs, maps) is a function in the non-dominant temporal lobe, whereas memory for things that we hear (the teacher reading a story) is a function in the dominant temporal lobe. Structures in the front of the brain (in the frontal lobes) help control attention and concentration as well as helping us plan and organise ourselves. They also help us to manage our emotional responses to situations. If abnormality or damage occurs in the frontal part of the brain a young person may have difficulties with attention or concentration or become impulsive and find it difficult to think through their behaviour before acting.

Seizures and learning

It goes without saying that if a young person has a tonic clonic seizure during a lesson, then that seizure will obviously affect what is learnt during that lesson. However, some seizures will lead to problems with learning in less obvious ways. For example, absence seizures may be difficult to spot and may occur for only a few seconds at a time. However, during these seizures, a young person will be unable to take in any information. Sometimes absence seizures occur many times over the course of a day and this will affect how much information a young person can absorb in the school environment. Temporal lobe seizures occur in close proximity to important memory structures in the brain, and after a temporal lobe seizure these memory areas need to recover before the brain is able to absorb new learning. Seizures that happen out of the school environment can still affect learning, particularly if they are numerous or frequent and are reasonably severe or affect important activities like sleeping.

Medications and learning

The goal of medical treatment of epilepsy is to reduce the number of seizures without causing significant side effects. However many medications have side effects that can reduce how alert or how awake a young person feels and can cause problems with concentration. Learning and memory problems as well as behaviour difficulties such as irritability have all been linked to different types of medication that are sometimes used to treat epilepsy. Side effects are more common if the young person is taking more than one medication or if they require higher doses of medication to control seizures. So it's always important to keep doses of medication to the lowest dose that gives seizure control. Specific drugs can have specific impacts on learning so read the product information and ask your doctor about what you should look out for.

Psychological impact of epilepsy and learning

A diagnosis of epilepsy can bring difficulty adjusting to the unpredictable nature of the condition, and can bring emotional changes including feelings of anxiety and low mood. At times, family, peers and teachers can lower their expectation of the abilities of person with epilepsy. It is important for learning confidence that these issues are proactively tackled, that there is a positive 'can do' attitude otherwise these issues can result in loss of confidence, self-esteem, motivation and school attendance and these factors can impact more negatively on learning than the direct effects of the seizures or medication.

What to do

If you are concerned that your young person is having problems at school or has difficulties with memory or concentration, you should speak to your doctor and your school. Some issues can be improved by reviewing medications and optimizing seizure control. Some issues can be mitigated through having a good understanding of the specific learning profile that your young person has, and accessing specific educational programs. Ask your teacher and doctor about the roles of speech and language and occupational therapy assessments, early intervention programs (and funding) and the roles of guidance officers or neuropsychology assessments to obtain a better profile of the learning needs of your young person.

It is important that you tell school staff if your young person has epilepsy, so that staff are adequately prepared in the event that a seizure occurs at school (even if the risk is low). Be mindful in your communication to also consider and respect your young person's privacy and seek their involvement in this process.

WHAT INFORMATION TO TELL SCHOOLS?

Tips for working collaboratively with your school to support your young person:

- Provide practical and factual information about epilepsy, including your young person's particular type of epilepsy, his/her current seizure description(s) and their current treatment.
- Provide information on whether there are any expected impacts on your young person's educational progress.
- Work collaboratively with the school to develop school epilepsy management plans and to ensure that staff have appropriate education and access to additional resources and information as required. This may include additional training e.g available from Epilepsy Queensland, Epilepsy Action Australia or from Education Queensland Nursing Service.
- Whilst it is important to advocate proactively for your young person, remember to be positive, calm and solution-orientated in your approach at all times.
- Discuss strategies with school staff to provide factual information to other school children, with a focus on dispelling myths and improving understanding.
- Ask to be involved in camp and excursion planning for your young person.
- Provide clear instructions on your young person's medication. Schools have policies for managing medications; please consult with school staff in relation to their policy for storage and administration. Schools also have policies for when they call the ambulance, again ask for this information.
- If there are any changes to your young person's treatment, ensure that you inform the school as soon as possible.

Education Queensland Registered Nurses (EQRNs) are based at state schools/units in most regions of Queensland. EQRNs provide services in response to referrals from school principals (or delegated officers) to support students with epilepsy, and the school staff that care for them during the school day. Such services include the development of health and emergency care plans for the student with epilepsy and the provision of information and education to school staff around the students needs. For more information about these services talk to your young person's school staff and/or visit:

http://learningplace.com.au/default_community.asp?orgid=77&suborgid=756

HOW ARE SEIZURES CONTROLLED?

There are a number of strategies that are used to reduce the risk of seizures occurring:

- Reducing/avoiding seizure triggers - for some people this alone is enough to reduce seizure frequency.
- Medications, taken regularly. There are a number of different medications available and your doctor will chose the best medication that he/she thinks is suitable for your young person's epilepsy.
- Specialized diets (the modified Atkins diet, the ketogenic diet) can in selected young people reduce seizures. Not all young people are suitable for a trial of these diets, and the diet is reasonably restrictive so not all young people will be able to comply and remain on the diet. As the diet is restrictive, it should only be performed under the supervision of a specialist dietician



who is experienced with it and under the supervision of a Paediatric Neurologist, as such if your young person is to be considered for the diet they should be referred to a Paediatric Neurologist with dietary therapy experience.

- Vagal nerve stimulator (VNS) therapy is a therapy requiring insertion of a pacemaker that stimulates the vagus nerve in the neck, with impulses travelling to the brain and reducing seizures. VNS is available in only a few centers in Queensland and for this treatment your young person would need to be referred to a centre that provides VNS therapy.
- Epilepsy surgery is where the area of the brain causing seizures is removed. Not all people with epilepsy are suitable for epilepsy surgery, however if this is possible it stands a high chance of curing seizures that have failed to respond to medication. To determine if surgery is a possible treatment for your young person, assessments need to take place under the care of a Paediatric Neurologist with expertise in epilepsy surgery.

Tips for your young person regarding their medication:

- Always take medications on time and as prescribed. If it is a struggle to remember to take medications on time, speak to your pharmacist about things that are available to help, people use alarms on their mobile phones, or fridge magnet alarms, but there are also ways of packaging medication so that you can see if you have taken your dose or not.
- Note that some drugs can actually aggravate seizures in certain epilepsies, for example carbamazepine can aggravate some epilepsies (those with prominent fever-induced seizures, and absence or myoclonic seizures) but can work very well for others. It is important that the medication selected is the right one for your young person's type of epilepsy, speak to your doctor if you are concerned about seizure aggravation.
- Side-effects are common with medications. Educate yourself about what to expect, speak to your pharmacist and read the product information that should be in your medication box. If your young person experiences side-effects, discuss these with your usual doctor so he/she can advise how to minimize these.
- Medications are always started slowly and increased gradually until they control seizures so as to avoid side-effects.
- For most medications (including carbamazepine and valproate), testing of blood levels is not required as the levels in the blood stream are not reliable as an indicator of seizure control or side-effect risk. This can be better assessed clinically. Some people have very low levels of medication in their blood but this is enough to stop their seizures. For most drugs, decisions about what dose to use can be made without blood tests, on the basis of whether your young person is having seizures or side-effects, as assessed clinically.
- Medications should always be weaned off gradually, otherwise a longer or more serious seizure can occur.
- It is always a good idea to keep a record of all the medications that have been tried, the highest dose given (dose and the young person's weight at that time) and the reason it was ceased. This record is helpful to have for the future, if your young person is seen by different doctors in different places.
- Check that any other treatments that are taken including over the counter preparations, herbal/natural remedies etc do not interact with the prescribed anti-convulsant medication, note however that even if there are minor interaction possibilities that it is still important to take medication to reduce temperatures if a fever is present, or to control any pain.

- It is generally not recommended that you switch from named brands to generic supplies of your anti-convulsant medication without consulting with your doctor as seizure control can vary between named and generic forms of the same medication.

WHAT IF SEIZURES ARE NOT CONTROLLED?

If your seizures are not controlled then it is reasonable to consider asking your doctor to see a neurologist.

Examples of situations where it is important for your young person to see a neurologist include:

- when there is diagnostic uncertainty in relation to the diagnosis of epilepsy or in relation to the underlying cause of the epilepsy
- when seizures fail to be controlled by appropriate trials of ≥ 2 consecutive anti-convulsant medications or within 2 years from diagnosis
- when there are significant side-effects from anti-convulsant medications
- when seizures occur in young people < 2 years of age
- when seizures are accompanied by developmental delay, learning impairment or decline in functioning or significant psychiatric or psychological issues
- when seizures might be controlled by epilepsy surgery, examples include when epilepsy is associated with a hemiplegia, or with a brain abnormality on MRI, or with certain conditions such as Tuberous Sclerosis or Sturge-Weber syndrome, or if seizures are focal

The Queensland Paediatric Epilepsy Network have endorsed the **NICE guidelines for the management of epilepsy in children and young people** as defining an appropriate standard of care for young people with epilepsy in Queensland. These guidelines provide further information on referral and testing and can be accessed on the following link (referral guidance on p40) if you need to show them to your doctor:

<http://www.nice.org.uk/nicemedia/live/13635/57779/57779.pdf>

KEEPING YOUR YOUNG PERSON SAFE?

The unpredictable nature of seizures means that they can occur without warning. Depending on the type of seizure the individual experiences (e.g. seizures with loss of awareness), the onset of a seizure can place the individual at risk. Whilst it is important that individuals with epilepsy have a normal life, some sensible precautions are required to reduce the risk of harm or injury from a seizure.

Around water:

A person with epilepsy can swim, but it is important that they are supervised so that if a seizure occurs this can be identified early and the person's head lifted above the water followed by their being removed from the water. All relevant personnel should be informed that the person has epilepsy. When swimming at a beach, it is advisable the person swims within their depth, and with a buddy at all times.



At home it is advisable that a person with epilepsy takes showers rather than baths, or that they are fully supervised whilst in a bath and bath water levels are kept low. A seizure in a bath can result in immersion and drowning if the person is not immediately assisted. If a person is showering, advise them to turn the cold water on first and then turn the hot water on to bring the water temperature up to the required heat, this minimizes the risk of scalding if a seizure occurs and the hot water has been turned on first.

Activities:

Young people with epilepsy should participate fully in all activities if possible. This is healthy for their social and emotional well-being. Activities that involve climbing high apparatus without restraint should be avoided. Cycling on busy open roads may also pose a risk if an unexpected seizure occurs. All other activities should be reviewed, and pursued with sensible planning around what to do if a seizure occurs.

Around the house:

Young people sometimes feel unwell before a seizure starts and may go to the bathroom, make sure that they do not lock the door and it is better if your bathroom door opens outwards rather than inwards (to reduce the risk of the young person falling down in a seizure against the door which would then not be able to be opened). It is also sensible to review the placement of objects and furniture around the house so that if your young person has a seizure and falls that the risk of injury is reduced.

Out and about:

Young people often have to balance their developing independence together with the risk of a possible seizure. When out and about they could consider going out with a friend who knows they have epilepsy. There are ways in which they can carry medical information and alerts (medi-alert bracelets, necklaces and wallet cards) that will alert others to the fact that they have epilepsy in emergencies.

Driving:

There are specific laws around the requirement to report medical conditions to transport authorities. Please check relevant websites and with your doctor for more information. There are situations where people with epilepsy can drive, however certain criteria must be met and a medical report supplied.

Night time and SUDEP (sudden unexpected death in epilepsy):

Night-time is the time that a person with epilepsy is most likely to be at risk, as a seizure can occur without anyone knowing, and therefore the person is not assisted during their seizure. Consider the bedroom environment – remove dangerous objects or furniture near the bed, have a bed that is low and check pillows and bedclothes – choosing breathable fabrics.

It is recognized that there is a small risk of sudden death in epilepsy, this is known as SUDEP (sudden unexpected death in epilepsy). The majority of these deaths occur overnight, with the person being found dead, suddenly and unexpectedly in the morning, often with signs of a seizure having occurred that had not been identified through the night. There is still a lot of research to be done to understand more about SUDEP, why it occurs and how it can be prevented. There may be different factors that lead to SUDEP in different individuals. An unattended night-time seizure is not the only cause, as some people are also at risk of SUDEP at other times of the day.



There are factors that may increase the risk of SUDEP:

- seizures that are poorly controlled
- not taking medications as prescribed, suddenly stopping medications
- generalized tonic-clonic seizures or seizures often in sleep, especially if frequent > 1 / month
- in young children, a co-existent learning disability or a neurological disability such as cerebral palsy can increase the risk
- in childhood SUDEP affects males and females equally, in adulthood there are more SUDEP deaths in males and young adult males appear to be at increased risk

Although there is a lack of research around effectiveness of different measures in reducing SUDEP, it is still reasonable to consider practical ways in which you might increase the likelihood of being alerted to your young person having a seizure through the night. In addition, if your young person has any of the above risk factors, it is important that you seek specialized advice in relation to how they can optimally control their seizures. Eliminating seizures virtually eliminates the risk of SUDEP.

Reducing the risk of missing a night-time seizure

There is no one method that is guaranteed to ensure that you will be alerted to your young person having a night-time seizure. In addition, nocturnal surveillance has to be balanced with the importance of allowing your young person a level of healthy independence. However considering some of the following options may reduce the number of seizures that you miss, the options that you chose will depend on your individual circumstances, in many instances families rely on more than one option as no individual option is completely reliable:

- There is evidence to show that having an older young person (e.g. >12 years) sleeping in the same room as the person with epilepsy reduces SUDEP, presumably through alerting others to a seizure in the night.
- Consider having the bedroom of the person with epilepsy close to that of adults in the home, this again increases the likelihood of being alerted to a seizure.
- Consider available forms of nocturnal seizure alert options:
 - A simple baby audio/video monitor can alert you to the noise of a seizure when your young person is asleep in another room.
 - Commercially available seizure mattresses may detect abnormally sustained rhythmic body movement and alarm, some also monitor heart rate and breathing and can alarm if the person leaves (or falls out of) the bed.
 - Newer technologies including wearable wrist devices that detect movement and heart rate variability, and wearable audio monitors are in development, so continue to seek updates at intervals from Epilepsy Action Australia or Epilepsy Queensland.

ADJUSTING TO THE DIAGNOSIS

Research has shown that one of the greatest variables that determine social adjustment, academic success and the psychological well-being of children with epilepsy is the response of their family and friends. How a family copes with the diagnosis can have a greater effect on the young person than the severity and frequency of seizures. Although epilepsy is a complex condition, it is manageable and there are several things you can do to improve your young person's adjustment.

- **Educate yourself**

To enable your young person to be well-adjusted following an epilepsy diagnosis, it is important for you to be well-informed, as your thoughts, feelings and behaviour can be apparent to your young person. If you are anxious, they will be too. You can improve your knowledge through researching epilepsy, asking questions and seeking advice. There are many different types of epilepsy and one person's experience may differ from another's. Learn about the particular type of epilepsy your young person has so you have a good knowledge and can educate your young person. Understand what your young person's diagnosis is and what it is not.

- **Educate your young person**

Provide your young person with open and honest information about their epilepsy and try to answer questions they may have. This will decrease feelings of anxiety, fear, anger, loss or low self-esteem. It will also avoid confusion and help them feel empowered. Use age appropriate language to help your young person understand that epilepsy is not contagious and that there is no-one to blame. Help your young person prepare for their consultation with their doctor and encourage them to ask questions and seek information.

- **Present epilepsy in a matter-of-fact manner**

To avoid creating fear, talk about epilepsy in a balanced and matter of fact manner. Use language that prevents your young person from viewing epilepsy in a negative way. Make it comparable to other health conditions such as asthma or food allergies. For example, some children may have asthma attacks from time to time and need a puffer. After they have had the puffer, they recover. Seizures are typically brief episodes and after your young person has a seizure they will recover too.

- **Epilepsy is only a small part of your young person's identity**

Epilepsy is a condition your young person has which does not define them. Just as a young person with the flu is not known as 'a young person with the flu', your young person should not be defined as 'a young person with epilepsy' or an 'epileptic'. Epilepsy is part of your young person's life and can be managed, but the impact of it does not need to be exaggerated. Your young person should have the opportunity to develop and experience the world the same way as other children do. Emphasizing and reminding them of their talents and interests will increase motivation and promote a sense of belonging.

- **Promote cautionary behavior only when necessary**

For anyone diagnosed with epilepsy, caution is sometimes warranted. However, this should not be exaggerated as it can stifle independence and may result in behavioural and emotional difficulties. Expect the same level of responsibility and discipline from your young person as you



would from any young person their age. Let your young person swim, ride bikes and play sports if they are able to do so. Inclusion in age appropriate behaviour and activities is vital for the development of a healthy and happy young person.

- **Socialise with others who have epilepsy**

Just as your family is a great support for your young person, it is extremely beneficial for them to share their knowledge and experiences with other children who have epilepsy. Organisations such as Epilepsy Queensland and Epilepsy Action Australia provide support programs and services aimed at helping people with epilepsy adjust to their new diagnosis.

- **Adjustment**

The impact of a new diagnosis of epilepsy can vary from family to family and depends on many factors including the family's previous experiences and resilience, the frequency and severity of seizures and the change that the health condition brings. It can be very normal to have heightened emotion, sadness and anxiety for a period of time. For some individuals this period of time can be prolonged and the experience can be more difficult resulting in delayed psychological adjustment to the epilepsy diagnosis. It is important to know that there is help available, speak to your usual doctor or to your general practitioner who can assist in directing you to appropriate health professionals.

MORE INFORMATION, RESOURCES AND SUPPORT?

Epilepsy is a very common condition, many people have it, and as a consequence you are not alone. The more you fully inform yourself about this condition the better you will be able to advocate for you/ your young person's health. There are a number of organizations in the community who have been established to specifically provide information, services and support to people with epilepsy and their families. There are also a range of other agencies that can provide information, financial assistance and other services to support people with epilepsy. Here we have listed the important ones, please note that services and supports may change from time to time.

Community epilepsy organizations

In Queensland, there are two organizations (Epilepsy Queensland and Epilepsy Action Australia) who provide services to people with epilepsy, their family and carers. While some services overlap, each organization provides different services, therefore it is often useful to access both organizations.

Services provided include:

- Information sheets and booklets on all aspects of epilepsy
- Seizure diaries
- Help over the phone with advice and support
- Support at hospital visits
- Internet resources, including specific resources for children and adolescents
- On line support groups/forums
- Information for schools and day-care centres, seizure first aid and midazolam education for teachers, support with providing information to class-mates, assistance with plans for school trips/excursions

- Family workshops and support, family retreats
- Assistance with epilepsy management plans
- Information on navigation through available services and organizations, relevant for you
- Education sessions for families including training on midazolam administration and seminars and workshops

Contact information:

Epilepsy Queensland

Ph: (07) 3435 5000

Ph: 1300 852 853 (outside Brisbane)

Email: epilepsy@epilepsyqueensland.com.au

Website: www.epilepsyqueensland.com.au

Epilepsy Action Australia

Ph: 1300 (Epilepsy)

Ph: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

Website: www.epilepsy.org.au

Other organizations

There are a number of organizations that provide information, education and support to people with epilepsy and their families, carers and schools (often depending on need). It is not possible for all these organizations to be listed in this document, and some services may change over time, therefore always speak to your GP or usual doctor and ask what services might be relevant to you and your young person.

Centrelink

For: healthcare card, carer allowance and carer payment, carer adjustment payment and mobility allowance.

Phone: 13 2850

www.centrelink.gov.au

Department of communities

For: community access to respite services, early intervention services, aids and equipment, funding assistance, home and vehicle modifications, continence aids, companion cards, medical cooling and heating electricity concessions.

Phone: 1800 177 120

www.disability.qld.gov.au

Department of Families, Housing, Community Services and Indigenous Affairs (FaCSIA)

For: Better Start Funding for children with disability, autism package funding.

Phone: 1800 079 098

www.FaHCSIA.gov.au

Commonwealth Respite and Carelink Centre

For: emergency/time-limited assistance for people with disabilities and their family and carers including respite and household help.

Phone: 1800 052 222

<http://www9.health.gov.au/ccsd/>

Carers Queensland

For: information, education, training, advocacy, counselling and other support services to assist people in the caring role.

Phone: 1800 242 636

www.carersqld.asn.au

Patient Travel Subsidy Scheme

For: patients who need access to essential specialist medical services which are not available within their local area (50kms). Further information is available from your local Queensland Health public hospital.

www.health.qld.gov.au/ptss

WHAT TO BRING TO YOUR USUAL DOCTORS APPOINTMENT?

Plan your time with your doctor well so that you ensure you get the most out of your appointment. Here is a list of some tips and things that you need to remember to bring:

- seizure diaries - have a think in advance about seizure control and any triggers you have identified
- seizure videos
- a list of all your questions
- your prescriptions and your medication bottles so your doctor can check these and write new prescriptions
- travel forms if you are traveling from a distance and wish to seek reimbursement (see Patient Travel Subsidy Scheme in the Other Organizations section above)
- any other medical reports or forms that you need completed
- your current emergency plans, especially if these are due for review
- referrals from your GP or referring doctor if required
- any recent blood test results, scans, EEG reports
- don't forget to ask if you need a medical certificate for your time off work/school

USUAL DOCTORS CONTACT INFORMATION?

Ask your doctor for his/her contact details and their usual day-time hours of operation. This ensures that you have a way of contacting him/her if your young person has side-effects from medication or if their seizures increase and you need advice about what to do with their medications. It is always useful to ask your doctor to give you a written 'escalation plan' i.e. a plan to follow if seizures get worse before the next usual appointment in the clinic.

Usual doctors name: _____

Address for correspondence: _____

_____ State _____ Postcode: _____

Contact details: Phone: _____ Fax: _____

Doctors usual working days/times: _____

DISCLAIMER

This factsheet has been put together with the aim of improving the information available to families facing a new diagnosis of epilepsy in their young person. We hope that the information is accurate, but things change – if you note that any of the information provided is no longer current, please do not hesitate to let us know (**email: Statewide_Child_&_Youth_Network@health.qld.gov.au**)