EPILEPSY
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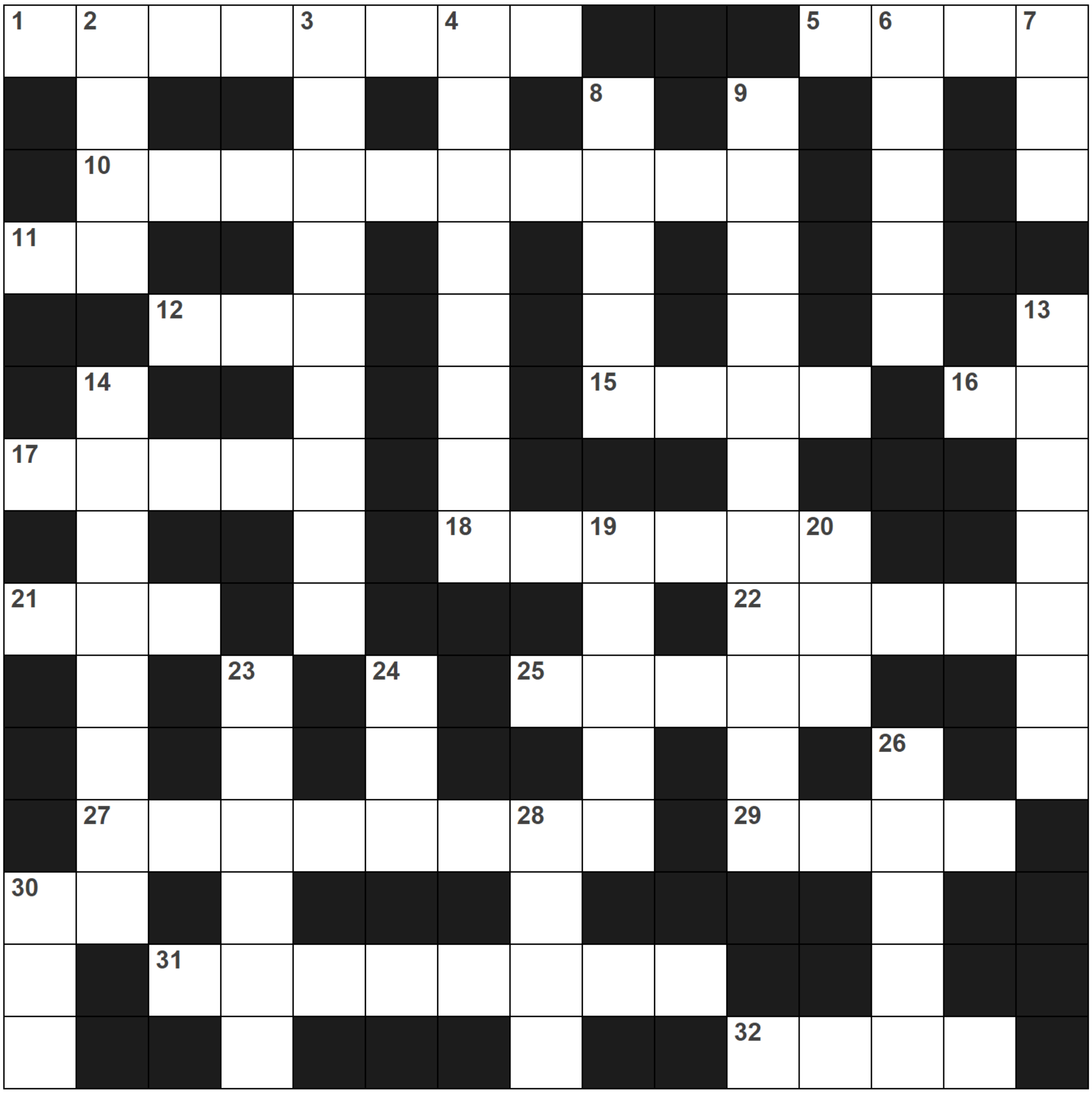
Fact Sheet 1

What is epilepsy?

Epilepsy is:

- A tendency to experience recurrent, unprovoked seizures.
- A seizure occurs when neurons send abnormal electrochemical signals to the brain; such signals result in an alteration in sensation, behaviour, and consciousness.
- One of the most common neurological conditions, affecting one in 100 people.
- Can affect anyone regardless of age, ethnicity, or social economic status.
- Commonly found in children under 2 years old and in the elderly (over the age of 65) around 70 million people globally are affected with epilepsy.
- Its causes include genetic influences, medical disorders, head trauma, meningitis, lead and alcohol poisoning, and chemical and hormonal imbalance; in many cases the cause of epilepsy is unknown.
- Most people become seizure-free by using anti-epileptic medication.
- A spectrum disorder.
- Encompasses > 25 syndromes, many types of seizures, seizures vary in severity, affects wide range of people, impacts on health/quality of life differ widely.

Epilepsy Crossword



Answers:

angst, empirical, ok, complex, cure, EEG, primal, epilepsy, level, toxicity, to, simple ECT, air, diet, seizures, under, ictal, compliance, minus, big, die, triggers, by, ruin, caffeine, help, aura, pack, tonic, intra, generalized, but

Across

1. This is a common neurological disorder characterised by reccurring spontaneous seizures.

5. Medication does not ___ epilepsy but controls it. About 50% of people with epilepsy will achieve total seizure control using drugs. A further 20-30% will achieve very good control.

10. ___with taking anti-epileptic drugs reduces the risk of uncontrolled seizures and possible death.

11. It is ______ to be open about epilepsy as openness reduces stigma.

12. Placing a person in the recovery position ensures that the ____ way is clear and open.

15. A peculiar sensation (or simple partial seizure) which often precedes a complex partial or generalized seizure.

16. During a complex partial seizure a person's consciousness is impaired for 5 __ 10 minutes, during which time the rest of the brain functions well

17. In the _____ phase of the tonic clonic seizure, the limbs are rigidly extended for up to a minute or so, and there may be an "epileptic cry". It does not mean that the person is in pain.

18. A ____ partial seizure is one in which the patient is conscious and so can describe what's happening to their body (e.g. a jerking limb).

21. People with epilepsy can unfortunately ___ with this condition. When this occurs, the term used is SUDEP (sudden unexpected death in epilepsy). It is estimated that one in 2500 people with epilepsy die from SUDEP annually. The main cause of this is suddenly stopping medication which frequently results in status epilepticus.

22. Latin word for "stroke" or "event" when it is actually occurring.

25. There can be a lot of ____ with people when epilepsy has been diagnosed, but epilepsy can go away. A person taking AEDs, seizure free, and whose medication is gradually withdrawn, can have a 30-50% chance of permanent remission. For children, the figures are 60-80%.

27. ______ are certain factors that seem to be associated with a greater likelihood of seizures developing. Recognizing these _______ allows people to make adjustments in their life-style so that they can control their seizures.

29. A ketogenic _______ is high in fat, adequate in protein and low in carbohydrates. Any person considering this diet must do so in consultation with a medical specialist and dietician.

30. "The only thing we have to fear is fear itself'. It is important for people with epilepsy to try to live day ____ day with courage.

31. _________ is a well known trigger in epilepsy. Epileptic seizures are caused by a burst of uncontrolled firing of brain cells in part of or throughout the whole brain. Adenosine, a chemical in the brain, assists in stopping this uncontrolled brain activity. Caffeine taken into the body enters the brain which identifies its structure as being similar to that of adenosine. In some people this misleads the brain into thinking the caffeine is adenosine and that sufficient adenosine has been produced.

The brain then stops producing adenosine. Hence it appears that when the adenosine levels are low it becomes easier for seizures to occur, and more difficult for the brain to stop seizures.

32. It is always good to ________ those in need.

Down

2. A blister ____ is a useful medicine dispenser available from the pharmacy.

3. A neurologist uses an _______ approach to treating epilepsy. It may take time to find the right medication and right dosage for each individual.

4. These are temporary bursts of uncontrolled electro-chemical activities in the brain.

6. Newly diagnosed clients with epilepsy can be _____ severe stress. They could be fearful of their seizures, drugs and of the social stigma.

7. An ______ (electro-encephalogram) is a painless device placed on the head to record electrical activity close to the brain's surface.

8. Most anti-epileptic drugs are taken orally but some can be taken ______ -venously as well.

9. A primary _____ seizure is one where there is an instant onset of confused electrical activity throughout the brain.

13. _______ partial seizures are mostly located in the temporal lobe. This is the site of the hippocampus, which is the control 'switchboard' for memory.

14. When taking new medication it is important to recognize signs of _______.

19. An ideal therapeutic range is excellent seizure control _____ side effects.

20. Epilepsy is not a mental health issue, therefore ____ (electro-convulsive therapy) will not cure it.

23. In ancient times people had a ____ fear of epilepsy. This was because the condition was not understood.

24. Seizures were once commonly known as grand and petite mals ("____ and small sickness").

26. The key to successful control of seizures with minimum side effects is finding and maintaining the right blood _____ (i.e. the right concentration of the anti-convulsant drug in the blood-stream).

28. No-one should let epilepsy _____ their lives. It is only part of their lives - the rest of the time should be in living life to the full.

30. Many people experience a single seizure during their lives, ___ this does not constitute epilepsy.

Fact Sheet 2

Epilepsy Types

There are different types of seizures. Some affect a part of the brain (focal seizures) and others affect the whole brain (generalized seizures). The first aid required for each seizure type is dependent on what is happening in the brain at the time of a seizure.

Focal Seizures (Affecting a specific part of the brain)

Do not try to stop the seizure. Guide the person away from danger.
Talk quietly to reassure. Confusion is common.

Temporal Lobes

Simple focal (small part of temporal lobe)

- A person will remain conscious

- Hearing speech, memory and emotions can be affected
- Experience deja vu, jamais vu, hallucinations, depression
- Smell and taste changes
- Abdominal/chest discomfort, altered heart and breathing rates, sweating

Complex focal (larger part of the lobe)

- A person's consciousness is affected

- The person can appear confused, drunk, distracted and is unresponsive
- Behaviours can include lip smacking, chewing, swallowing, fumbling, picking, grunting, screaming, undressing, repeating a word
- Wandering off

Be prepared for a generalised seizure

Frontal Lobes

In a simple focal seizure (small part of the lobe) consciousness is not affected

In a complex focal seizure (larger part of the lobe) a person's consciousness is altered.

Unusual behaviours become apparent and can be considered emotional or psychological in origin.

Seizures can involve:

- cycling movements
- turning the head to one side
- thrashing of arms
- carrying out strange body movements
- screaming, laughing, shouting or crying
- becoming incontinent
- experiencing sexual feelings and behaviour

Be prepared for a generalised seizure

Parietal Lobes

These seizures are uncommon.

Typically cause sensations in the skin such as:

- Tingling, numbness or pain (rarely)
- Can be felt on one side of the body
- Sensation can spread from a finger and upwards to the whole hand and arm (Jacksonian seizures)

Be prepared for a generalised seizure

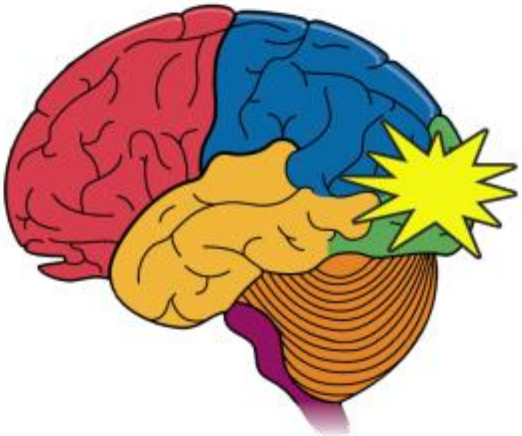
Occipital Lobes

These seizures are uncommon.

Can experience visual changes incl. flashes of light, colour, and patterns and even temporary blindness.

Seizures can spread to the temporal or frontal lobes

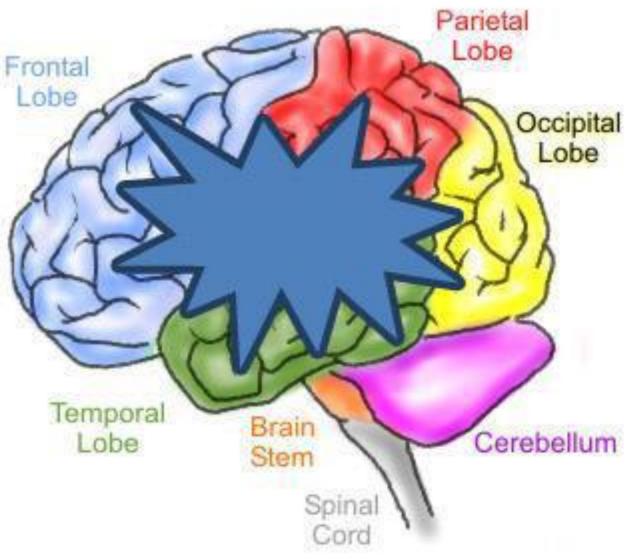
Be prepared for a generalised seizure



Generalised Seizures (Affecting the whole brain)

Absence, myoclonic, tonic, myoclonic, atonic, tonic clonic

Do not try to stop the seizure. Guide the person away from danger.
Talk quietly to reassure. Confusion is common.



- **Absence** – Brief staring spells and brief loss of consciousness (3 to 20 seconds)
  - – No warning before seizure and immediately afterwards the person is alert.
  - – Eyelids may twitch, flutter or blink.
  - – Brief automatic mouth or hand movements
  - – Can have 100, or more, absence seizures a day

Be reassuring. Guide the person away from any danger.

- **Myoclonic** – Jerking movements of the body or limbs
  - – Benign myoclonus occurs in healthy people, e.g. a 'jumping' sensation whilst falling asleep

Stay with the person to reassure them.

- **Tonic** – Brief loss of consciousness
  - – Body will stiffen
  - – Breathing becomes irregular or stops
  - – May lead the person to fall

Observe person's breathing and colour. Stay with him/her until he/she has recovered.

- **Atonic** – Brief loss of consciousness
  - – Muscles slacken
  - – Can lead to severe falls and injuries
  - – Recovery is quick
  - – Helmets are often worn to prevent facial injuries

Observe the person. Attend to any injuries

- **Tonic clonic** – Loss of consciousness
  - – May cry out, stare
  - – Stiffening of the body and a fall
  - – Difficulty in breathing
  - – May be froth or saliva at the mouth
  - – Blue colour
  - – Convulsions
  - – Can become incontinent
  - – Gradually returns to normal
  - – Can become confused and sleepy

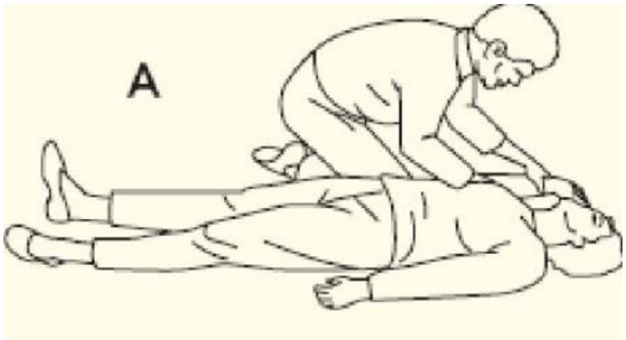
Stay calm!

Make the person safe
Cushion the head
Time the seizure
Look for ID on the person
Don't hold down
Put nothing in the mouth
When the seizure ends, place the person in the recovery position
Stay with the person until he/she has fully recovered.

There is no need to call an ambulance (111) *unless*:
The seizure lasts longer than 5 minutes
The seizure is closely followed by another
The person is pregnant or has diabetes
The person has suffered an injury
The person has swallowed water

Status epilepticus or non-stop seizures. It is serious and requires immediate medical attention. Phone 111 and ask for assistance.

How to put a person in the recovery position



Sit close to the person. Place his/her nearest arm to you at right angles.

Place the furthest arm to you across the person's chest and next to his/her cheek. Hold the arm in place.

Using your other hand, grab the far leg and lift it, making sure that the foot remains on the ground.

Gently roll the person onto his/her side.

Adjust the position of the arms and legs to ensure that the person is in a stable position for recovery

Make sure that you tilt the head slightly.

Stay with the person until full consciousness returns .

Images accessed 21/4/13 from www.oxfordmedicine.com

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

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Fact Sheet 3

Our Brain

- The brain is the key part of the central nervous system that controls our entire body. It controls our breathing, our beating heart, our ability to use our senses, how we receive and gather information, and even our behaviour and personality.

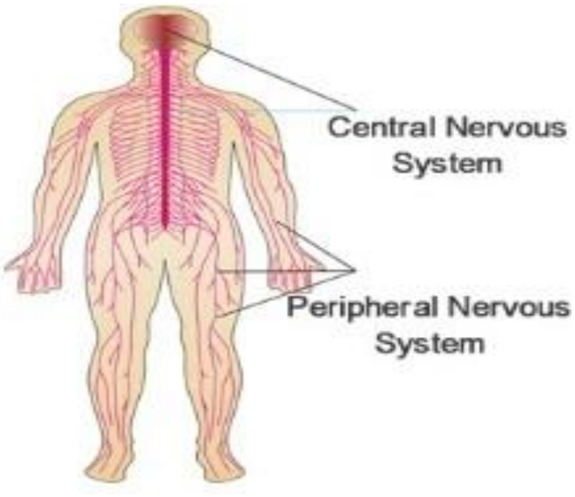
- The brain has 100 billion brain nerve cells (neurons). These cells communicate with one another and to other parts of the body by sending out messages.

- The messages are sent by electrical and chemical activity.

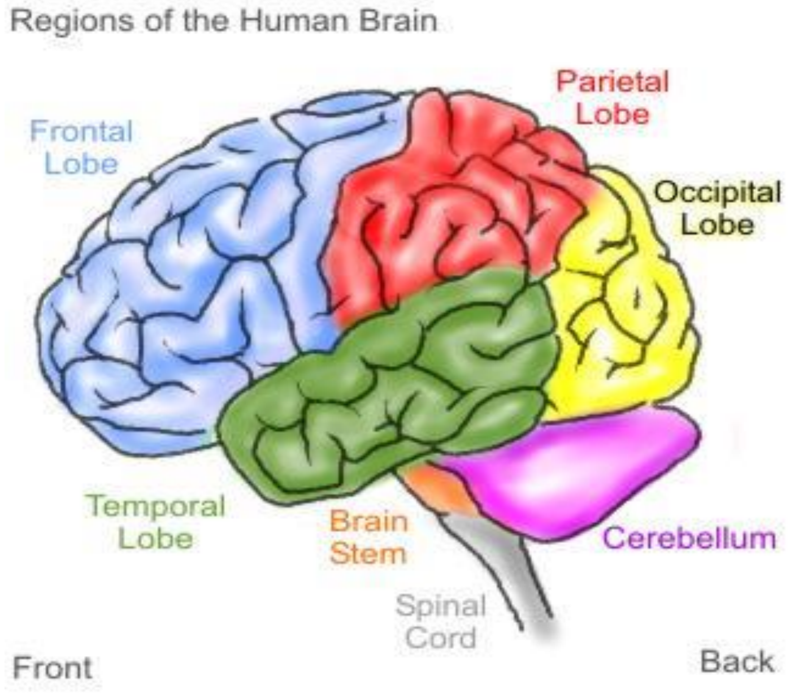
- Seizures are caused when the brain cells (neurons) have an uncontrolled burst of electrical/chemical activity. The type of seizure displayed depends on which part of the brain is affected. It could be a partial seizure (involving part of the brain) or generalized seizure (involving the whole brain).

- Neurology is the study of the human nervous system (brain and spinal cord and peripheral nerves).

- A neurologist is a specialist who treats people who have neurological diseases such as epilepsy.



- The brain is divided into six main regions: the frontal lobe, parietal lobe, occipital lobe, temporal lobe, cerebellum and brain stem.



The frontal lobe: regulates decision making, our ability to solve problems, controls our behaviour, emotions and directs our personality

The parietal lobe: receives and processes sensory information such as touch, pressure, temperature, and pain. It is also involved with language comprehension

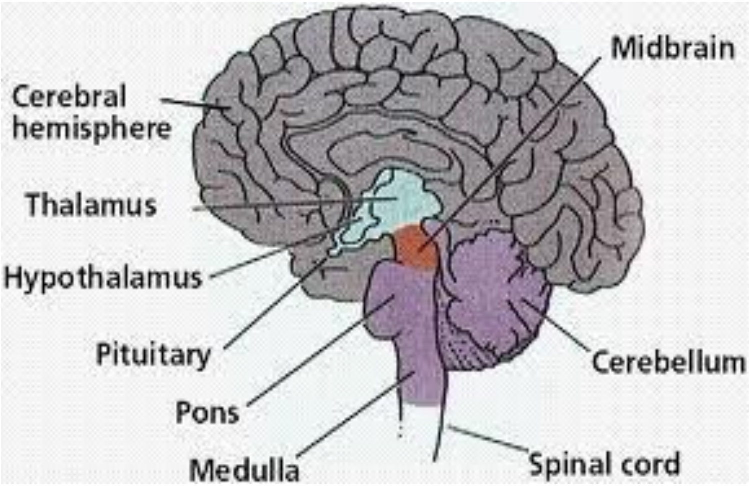
Temporal lobe: regulates memory, hearing, language/ learning and speech comprehension.

The cerebellum: controls our balance, movement, and coordination

Occipital lobe: controls visual perception and processes visual information

Brain stem: is made up of the midbrain, pons, and medulla. The brain stem is responsible for all involuntary actions that keep us alive, for example our breathing, food digestion, our heart beat, and circulation of our blood. The brain stem connects the brain to the rest of the body through the central nervous system.

- Deep within in the brain are the thalamus, corpus callosum, the hypothalamus, and pituitary gland.



Thalamus: relays sensory information to other parts of the brain.

Corpus callosum: connects the right and left sides of the brain and ensures communication between the two sides.

Hypothalamus: Controls body temperature, thirst, hunger, and emotions

Pituitary gland: controls hormone levels

Fact Sheet 4

What to do if someone is having a convulsive seizure

Stay calm!

1. Make the person safe
2. Cushion the head
3. Time the seizure
4. Look for ID on the person
5. Don't hold down
6. Put nothing in the mouth
7. When the seizure ends, place the person in the recovery position (see below)
8. Stay with the person until he/she has fully recovered.

There is no need to call an ambulance (111) *unless*:

- The seizure lasts longer than 5 minutes
- The seizure is closely followed by another
- The person is pregnant or has diabetes
- The person has suffered an injury
- The person has swallowed water

Status epilepticus or non-stop seizures, is serious and requires immediate medical attention. Phone 111 and ask for assistance.

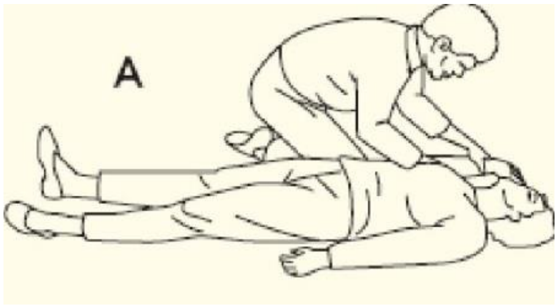
What to do if a seizure occurs whilst a person is in a wheelchair

– Don’t remove them from the wheelchair
– Make sure that the wheelchair is secure
– Support the person’s head
– If the airway is blocked, take the person out of the wheelchair **after** the seizure and place him/her in the recovery position

What to do if a seizure occurs whilst the person is in water

– Stay calm
– Swim to the person
– Keep the person’s face above water by supporting their head and shoulders
– Do not restrain the person’s movements
– Do not force anything into the mouth
– Guide the person away from the edge of the pool to avoid injury
– Once the seizure has stopped, move the person out of the water
– Place the person in the recovery position
– Check the person’s airwave and pulse
– Commence resuscitation if needed
– Stay with the person until consciousness returns and offer reassurance.
– Dial 111. The person may have inhaled water into his/her lungs

How to put a person in the recovery position



Sit close to the person. Place his/her nearest arm to you at right angles.

Place the furthest arm to you across the person’s chest and next to his/her cheek. Hold the arm in place.

Using your other hand, grab the far leg and lift it, making sure that the foot remains on the ground.

Gently roll the person onto his/her side.

Adjust the position of the arms and legs to ensure that the person is in a stable position for recovery.

Make sure that you tilt the head slightly.

Stay with the person until full consciousness returns.

Images accessed 21/4/13 from www.oxfordmedicine.com

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Fact Sheet 5

Children and Epilepsy

- Epilepsy affects 1 in 100 people, and most have their first seizure in childhood. The largest group of people with epilepsy is children under the age of five (see “What is epilepsy?” fact sheet).

- There are many types of seizures with varying degrees of severity. Some types of childhood seizures are benign (the child grows out of them and their development and intellect are usually normal). Some types are more serious and are associated with other problems.

- Some children are diagnosed with a syndrome. Here is the list of syndromes. These syndromes are age-related and may have different causes. The diagnosis of a likely syndrome will guide the pediatrician in choosing the best treatment plan possible.

  Aicardi syndrome
  Angelman syndrome (AS)
  Benign myoclonic epilepsy in infancy
  Childhood absence epilepsy (CAE)
  Childhood epilepsy with centro-temporal spikes (CECTS)
  Dravet syndrome
  Electrical status epilepticus during slow wave sleep
  Early myoclonic encephalopathy
  Epilepsy and limbic encephalitis (LE)
  Epilepsy of infancy with migrating focal seizures
  Epilepsy with myoclonic absences
  Eyelid myoclonia with absences
  Generalised epilepsy with febrile seizures
  GLUT1 deficiency syndrome
  Gelastic epilepsy
  Juvenile absence epilepsy
  Juvenile myoconic epilepsy
  Landau Kleffner syndrome
  Lennox Gastaut
  Mitochondrial disorders
  Myoclonic astatic epilepsy (Doose syndrome)
  Ohtahara syndrome
  Panayiotopoulos syndrome

Rasmussen syndrome
Rett syndrome
Ring syndrome
Self-limited neonatal convulsions
Self-limiting and pharmacoresponsive focal epilepsy in infancy
Self-limiting late-onset occipital epilepsy
Sturge-Weber syndrome
Unverricht-Lunborg syndrome
West syndrome

For more information on these syndromes visit www.epilepsy.org.uk/info/syndromes

- Children with epilepsy have a wide range of learning abilities. Epilepsy does not necessarily hinder learning and skill development, but many children do experience learning issues which may include ongoing motor skills or cognitive functions, as well as a difficulty acquiring new skills or knowledge.

  Some children have problems with global delay, adaptive behaviours, such as learning to walk, talk or getting dressed, etc, and they will have significant problems in sleep. They may also have significant difficulties with social and emotional development as featured in ADHD and autism.

  Seizures are common in children with ASD (Autism spectrum disorder) and ADHD (Attention deficit hyperactivity disorder). Both are neurodevelopmental condition and have a range of symptoms: www.understood.org/articles/en/the-difference-between-adhd-and-autism

- Anti-seizure medications (ASMs) are commonly used for the treatment of epilepsy and most children’s seizures are controlled with their use. The choice of ASM depends on the individual child and the epilepsy diagnosis, particularly if there is a likely syndrome. A pediatrician or pediatric neurologist should always start this medication process.

  ASMs are designed to stop seizures from happening rather than treat any underlying cause.

  All medication needs to be taken regularly every day, and compliance in taking them is essential in maintaining seizure control.

- All ASMs can cause unwanted side effects and a pediatrician will work to alleviate them where possible (see “Epilepsy Medication” fact sheet). Report all side effects, especially if there is an accompanying rash or significant mood change, to your pediatrician. It is important that your child remains on their medication at all times unless directed otherwise.

  Your pediatrician should prepare a comprehensive care plan for your child. You should be given information on your child’s seizure type and if there is a possible epilepsy syndrome.

You should receive treatment and emergency management plans which may include the use of midazolam.

For those children with uncontrolled seizures, the ketogenic diet (which is high fat, adequate protein, low carbohydrate) can been used to treat seizures once a child has been trialled on two or more medications.

Whilst on the ketogenic diet, the body burns fat, not sugar, for energy (ketosis). The ketogenic diet is rigid, and strictly calculated, and requires commitment by both the parent and child.

Children on this diet cannot deviate from it. Specialist advice and support are essential before starting on this diet with your child.

There are a number of reputable websites that help with up-to-date information, and Ketogenic diet recipes:

The Daisy Garland - www.thedaisygarland.org.uk/Pages/FAQs/Category/what-we-do
Matthews Friends - www.matthewsfriends.org
Atkins for Seizures - atkinsforseizures.com/how-to-start/

- Some children with uncontrolled seizures may be candidates for surgery, or the use of a vagal nerve stimulator. Your epilepsy professional can advise about these options.

- Some children living with epilepsy will experience depression or anxiety, and some of these children will have suicidal thoughts. Mood disorder symptoms may look different from child to child. Many will have low self-esteem and negative thinking but some will show irritability and disruptive behaviours, poor school performance, changes in sleep patterns or appetite.

  Parents and teachers are to be aware of mood changes in children especially if seizures worsen, or after a medication change. Medical help and mental health support will be needed.

  For more information on epilepsy and mood changes please visit our Epilepsy and Mood Disorders fact sheet: ewct.org.nz/epilepsy-and-mood-disorders/

- Safety in the home (see “Safety in the home” fact sheet) and at school is important for all children with epilepsy. A risk management plan should be formulated with your child’s classroom teacher and school (see “Risk management” fact sheet). There should always be direct supervision by an adult around water activities including bathing and eating. Children should avoid biking in any traffic and climbing to heights greater than one metre, with the exception being playgrounds with safety mats.

- Ask for information, help and support from your EWCT epilepsy advisor. Your epilepsy advisor will explain the following:

  - What is epilepsy?
  - What are the different types of seizures?
  - Explain the difference between epilepsy and non-epileptic seizures
  - Discuss medications and how they work
  - Explain seizure triggers and how to manage them
  - Show you how to fill out a free EWCT seizure diary
  - Create an epilepsy action plan so you know what to do in the event of aseizure. It can be shared at schools/residential homes, etc
  - Discuss lifestyle issues and how to overcome them
  - Explain what happens in an EEG
  - Connect you with other social services
  - Explain what benefits you can receive and information on Ministry of Health funding
  - Give epilepsy-awareness talks to schools etc.
  - Give you children's books on epilepsy
  - Advocate on your behalf

  By becoming informed you will feel empowered to manage your child's epilepsy.

- Many children with epilepsy can lead a good life and many will outgrow their condition. Ensure positive social interactions at home, at school and with family and friends. Please remember that having epilepsy is only a small part of who your child is.

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My name is..

I have epilepsy. Please contact...

Phone..

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Only call an ambulance (111) if, after my seizure
I have hurt myself
I have problems breathing
My seizure lasts longer than 5 minutes
I have one seizure after another and I don't recover
PLEASE STAY CALM!

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I have one seizure after another and I don't recover
PLEASE STAY CALM!

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Only call an ambulance (111) if, after my seizure
I have hurt myself
I have problems breathing
My seizure lasts longer than 5 minutes
I have one seizure after another and I don't recover
PLEASE STAY CALM!

EPILEPSY
WAIKATO
CHARITABLE TRUST
Leading the way *He arahanga whakamua*

Only call an ambulance (111) if, after my seizure
I have hurt myself
I have problems breathing
My seizure lasts longer than 5 minutes
I have one seizure after another and I don't recover
PLEASE STAY CALM!

EPILEPSY
WAIKATO
CHARITABLE TRUST
Leading the way *He arahanga whakamua*

Only call an ambulance (111) if, after my seizure
I have hurt myself
I have problems breathing
My seizure lasts longer than 5 minutes
I have one seizure after another and I don't recover
PLEASE STAY CALM!

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My name is ....

I have epilepsy. Please contact ....

Phone...

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When I have a seizure this is what usually happens to me

....

....

My seizure lasts for...minutes

It takes me some time to recover, typically...minutes

Please help me by...

....

....

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Only call an ambulance (111) if, after my seizure

I have hurt myself

I have problems breathing

My seizure lasts longer than 5 minutes

I have one seizure after another and I don’t recover

PLEASE STAY CALM!

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Epilepsy first aid during and after a convulsive seizure

1. Make the area safe
2. Place something soft under my head
3. DO NOT put anything in my mouth
4. If my seizure lasts longer than 5 minutes dial 111
5. After my seizure roll me into a recovery position on my side
6. Check my breathing
7. Minimise my embarrassment. I may have lost bladder and bowel control
8. Please stay with me until I recover. I may be confused or really tired

Fact Sheet 7

Epilepsy and Medication

- Epilepsy seizures can be controlled (but not cured) by the use of anti-epileptic drugs (AEDs). Around 70% of people become seizure-free, or have the number of their seizures decreased, with AED use. Most people find the right AED fairly quickly once newly diagnosed.

- These drugs calm the over-excited brain cells by affecting the levels of 'neurotransmitter' chemicals in the brain. They do not work at the time of the seizure.

- Neurologists choose the best AED for you based on your age, type, sex, side effects, and optimum control. Their aim in treatment is to stop seizures with the lowest dosage of AED and with the fewest side effects. Usually treatment involves the use of only one AED (monotherapy), but sometimes two or more AEDs are added to gain best control (polytherapy).

- Once an AED has been decided for you, it is best to strictly follow the directions of its use. Many AEDS are taken once a day, but others are taken two or three times a day. Know your drug regime and stick to it.

– You usually start off your AED on a low dose, and this is increased slowly until the most effective dose is found for you, i.e. no/or few seizures with no/or few side effects.

"Start low and go slow"

– It is important that the AED is taken regularly to ensure that there is a 'steady level' of medication in your blood at all times. This near-constant level enables good seizure control. Use an alarm on your watch, a phone message, a daily pill box, or some way of remembering when to take your AEDs regularly.

– If you forget to take your medication, take it as soon as you remember unless it is near to your next dose. **Do not double dose to make up for the one that you forgot to take.**

– It is important to never stop taking your prescribed medication because this could result in an increase in seizures or **status epilepticus** (non-stop seizures), which are life-threatening. Other withdrawal symptoms could include psychosis, hallucinations, behavioural disorders, tremors, or anxiety.

– If the AED chosen for you is unsuitable, the neurologist will prescribe another one, or add to the one you are already taking. This process is done slowly so that you experience few or no side effects. Your neurologist will guide you in what to do. Follow his/her instructions carefully.

– Record your seizures in a ‘Seizure Diary’, noting where, when, seizure type, and medication dosage to enable your neurologist to adjust your medication regime if necessary. Only a true record will indicate how best to control your seizures.

– How long you remain on medication is up to you and your neurologist. Some people may need to take AEDs indefinitely, but sometimes epilepsy goes into spontaneous remission, and seizures stop happening. Discontinuing medication after a seizure-free period of about two years may be an option, but the successful withdrawal of AEDs is a slow process and must be medically supervised to reduce the likelihood of seizures occurring.

DO not adjust or stop your medication except on the advice of your specialist.

- All AEDs have a list of possible side effects. “Start low and go slow” helps to minimize the effect of AEDs on your body.

– Look for unusual signs or symptoms in your behaviour and/or on your body. A rash is a significant side effect that requires immediate medical attention. Some rashes can be life-threatening. Warning signs of a serious rash are raised lumps, flaky skin, a swollen face, painful skin, purple blotches, and sores on the lips or around the mouth, and asthma symptoms.

– Other symptoms to watch for include swollen gums, acne, feeling drowsy/dizzy/tired, weight-gain, feeling moody, nauseous, or having problems with memory and concentration. Take note of these side effects and, if they become difficult to cope with, discuss them with your neurologist or GP.

– Some AEDs may cause your bones to become thinner and more brittle (osteoporosis), which means that you are at greater risk of breaking them.

– Some AEDs interfere with the contraceptive pill and some women may fall pregnant as a result of this interference. At other times the contraceptive pill may interact with the AEDs by reducing the amount of AED in the blood, therefore resulting in more seizures. Professional advice on AEDs and contraceptive use is important.

– Some AEDs can affect the development of the unborn baby and so specialist advice and support are essential at least 3-6 months before starting a family. Most babies are born healthy to mothers who are taking AEDs. AEDs affect your body’s ability to absorb folic acid and so it is advisable that you take higher-than-usual doses to prevent nervous system defects such as spina bifida in your developing baby. Your specialist will prescribe an AED that gives you best seizure control whilst protecting your baby from its side effects. Any risks will be kept to a minimum.

- Consult your neurologist before taking herbal medicines, homeopathic substances or supplements (e.g. ginko biloba, St John's wort, and evening primrose oil) as these may interfere with your AED and affect seizure control.

- Vomiting, diarrhea, and dehydration may increase seizure activity because of an insufficient amount of your AED being absorbed into your blood stream.

- Stay on the AED that was prescribed to you by your neurologist. The differences between a brand named AED and a generic one, no matter how small, can be enough to cause break-through seizures or result in different side effects. Ask your pharmacist to give you the drug that you were initially prescribed.

- Avoid consuming grapefruit juice if you are taking Tegretol. Grapefruit can interfere with the way your body is able to absorb and break down this AED by increasing or decreasing its levels in the bloodstream.

- Here is a list of common AEDs that are available to neurologists in New Zealand:

– Carbamazepine (Tegretol, Carbatrol)
– Clobazem (Frisium)
– Clonazepam (Rivotril, Paxam)
– Ethosuximide (Zarontin)
– Gabapentin (Neurontin)
– Lamotrogine (Lamictal, Arrow-Lamotrogine, Mogine, Logem)
–Levetiracetem (Keppra)
– Phenobarbitone, Primodone
– Phenytoin (Dilantin)
– Sodium valproate (Epilim)

For information on these AEDs contact:

° Medsafe consumer medicine information: http://www.medsafe.govt.nz/consumers/cmi/cmiform.asp

° Best Health website http://besthealth.bmj.com/x/index.html

How Does Anti-Epileptic Medication Get to the Brain?

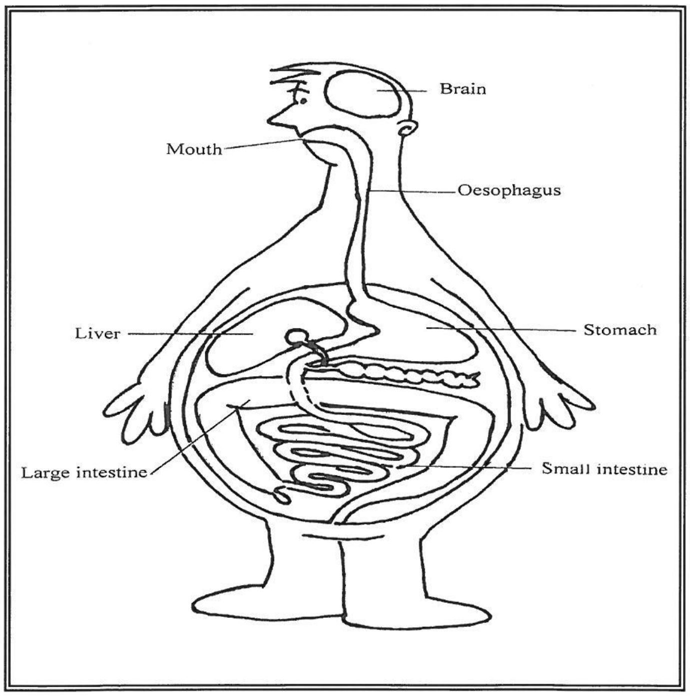
1. AEDs come in many forms. Most are tablets, others are capsules and some are liquid. Your medication is swallowed and follows the oesophagus down to the stomach.

2. Once the medication reaches your stomach and intestines it is absorbed before passing into the portal vein and onto the liver.

3. The liver, which is the largest organ in the body and acts like a chemical factory, processes the medication further before passing it into the bloodstream to be taken by the heart to all parts of your body, including your brain.

4. About 20% of all the blood pumped by the heart goes to the brain. Once the AED is in the brain it slowly re-enters the blood stream, back to the heart and then onto the liver which metabolises more of the drug. This cycle is continuous and requires regular dosing of the AED in the brain to prevent seizure activity.

5. Missed medication can cause major unexpected seizures. Some of these may develop into repeated seizures (status epilepticus) and can be fatal. It is advisable not to take extra medication to avoid seizures – always consult your doctor about aspects of your medication regime.



Is your epilepsy medication right for you?

c	o	n	c	e	n	t	r	a	t	i	o	n	w
s	t	s	w	o	l	l	e	n	g	u	m	s	x
d	r	o	w	s	y	q	m	m	n	x	a	h	z
p	d	y	g	r	e	n	e	f	o	k	c	a	l
n	a	u	s	e	a	w	m	v	p	d	n	k	p
m	e	c	n	a	l	a	b	o	k	u	e	i	d
o	s	s	e	n	i	p	e	e	l	s	j	n	i
o	n	o	i	s	s	e	r	p	e	d	o	g	z
d	o	u	b	l	e	v	i	s	i	o	n	q	z
y	r	a	s	h	f	u	n	s	t	e	a	d	y
c	w	e	i	g	h	t	g	a	i	n	u	q	r
h	e	a	d	a	c	h	e	u	g	i	t	a	f

Some of these side effects happen at the start of taking anti-epileptic drugs whilst the body is adjusting to them.

Concentration
lack of energy
depression
weight gain
dizzy
moody
remembering
shaking
double vision
unsteady
headache
balance
swollen gums
rash
acne
drowsy
fatigue
nausea

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

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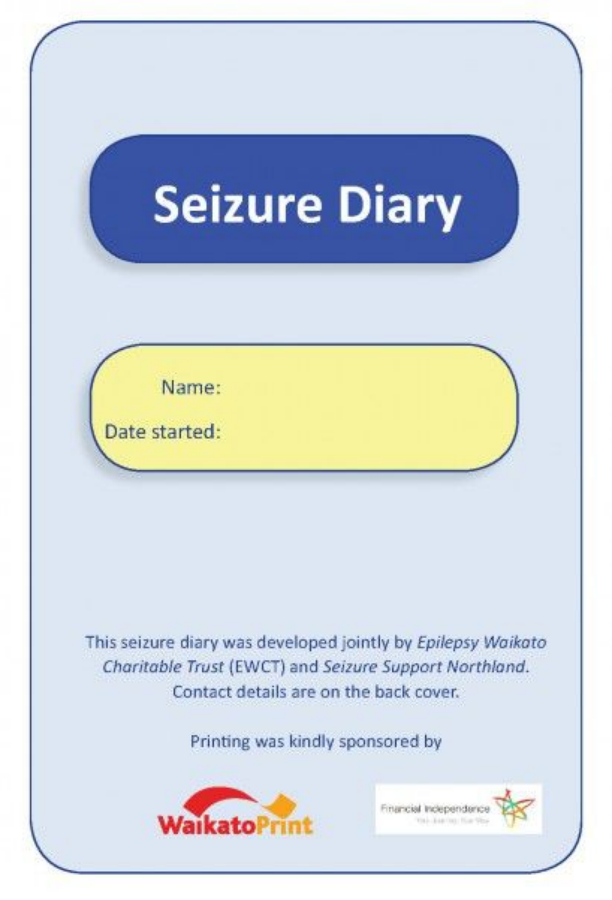
Fact Sheet 8

My Seizure Diary

A seizure diary is an important tool to manage, record and keep track of seizures and epilepsy. It can be used to keep track of medications, side effects, seizure frequency and for help in identifying potential triggers.

We worked together with Seizure Support Northland to develop an easy to use and in depth seizure diary. Please contact us if you would like to receive a free copy.



Seizure Diary

Name:
Date started:

This seizure diary was developed jointly by *Epilepsy Waikato Charitable Trust* (EWCT) and *Seizure Support Northland*. Contact details are on the back cover.

Printing was kindly sponsored by

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

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Fact Sheet 9

Keeping Safe – Living With Epilepsy

The home is the most common place for seizure-related accidents, followed by street and workplace accidents.

The following information is designed to help identify the most appropriate safety measures for you.

In the bedroom

- Have a low bed
- Don’t place the bed against the wall or near other furniture
- Place protective cushions around the bed
- Pad sharp-edged furniture

  These measures are suitable for people with nocturnal seizures or for children with epilepsy.

In the bathroom

- Have someone near you to help
- Hinge the door outwards
- Shower if possible, sit on a seat
- Shower screens should be made of safety glass, or use a curtain
- Preferably no shower tray
- Don’t lock the door, hang up an “Occupied” sign
- Reduce the water temperature
- Only have a shallow bath

In the lounge

- Avoid hard floor surfaces
- Place fire guards around open fires and heaters
- Pad hard-edged surfaces
- Avoid having trailing flexes
- Use toughened glass on doors and window

In the kitchen

- Microwaves are safer than stoves/ovens
- Turn pot handles away from stove edge
- Carry plates to the stove, not hot pots to the table
- Use a toaster, not a grill
- Install smoke detectors
- Visit “Life Unlimited” for safety aids

But accidents do happen

- Do the best you can to avoid injuries in and around the home
- Use an alarm if worried about personal safety

NOTE: People can die from epilepsy, but uncommonly. The occurrence is typically referred to as SUDEP (Sudden unexpected death by epilepsy).

Fact Sheet 10

Be Empowered

When a person is newly diagnosed with epilepsy there is an adjustment period. Questions are asked, “Why me?”, and a whole range of emotions can be displayed from denial, sadness, grief, or anger. These in turn can affect self-esteem: a person can become fearful of his/her condition, anxious, embarrassed, or even angry. Relationships can suffer, employment potential can be compromised and a person’s ability to drive a car or to be ‘normal’ becomes an issue. But it doesn’t have to be like this. Managing your epilepsy can be a positive experience, although it may take a while for you to come to that conclusion, and that is okay too. People react differently to their diagnosis and it does take time to feel comfortable about being a new you!

Epilepsy is a neurological condition. You are still the same person but you have a condition that is beyond your control. A neurologist will help you to control your seizures, and then it is up to you to do the rest. Don’t be controlled by your seizures but be in control of them and your life.

Here is what you can do.

- Gain as much information on your condition as you can. Web-based learning is great. There is a lot of information that is easily accessible these days, and from all around the world. You will come to realize that you are not alone; in fact, there are 50 million people out there with epilepsy, just like you!

- Knowledge is power. Information can help you to reduce your anxiety by gaining an insight into your condition. Ask yourself some questions and find out the answers. The brain likes to be exercised after all. By educating yourself you can educate others

- Become a detective and work out what your seizure triggers are. This may take some time and so keep an accurate seizure diary. Over time you may understand what is triggering your seizures. Avoid drinking caffeine and alcohol because these are well known seizure triggers, as are missing your meals, stress, and not taking your medication. Your seizure trigger may show something quite different (see seizure triggers in “My Seizure Diary”).

- Manage your seizures by taking your prescribed medication accurately. The brain likes to be given the same amount of your medication at the same time each day. Remind yourself, with an alarm call, when another dose of medication is required.

- We all like to stay up late but it is important that you get enough sleep each day. Aim for eight hours of sleep a night. Wouldn’t that be great?

- Recognise and respond to your stress because your brain doesn’t like being stressed out. Learn relaxation techniques: perhaps take up yoga or tai chi, or something similar.

- Be a winner in the “confidence contest”. By meeting the world positively means that you can cope with your epilepsy. Play an active role, rather than a passive one. You will feel so much better about yourself.

- Know that you can do almost anything within reason. Go on a ‘journey of self-discovery’. Life is an adventure after all.

- Become an epilepsy ambassador. Help to knock down those prejudices and myths. Be open about your epilepsy and show people who you really are.

- Join an epilepsy social group. You could go and discuss your epilepsy, or just simply enjoy being amongst friends who happen to have … epilepsy!

- Remember that you are not alone. We are here for you and we will help you to discover how you can live life to the full and to become empowered. Epilepsy is, after all, just a tiny part of who you are. Don’t let the idea of having epilepsy dominate your thoughts and feelings. Embrace life and enjoy it. Be empowered!

Famous People with Epilepsy

“There have always been people with epilepsy. Since the dawn of time, epilepsy has affected millions of people from beggars to kings. It is one of the oldest conditions of the human race.”

The names of 32 famous people are hidden in this word find.

Do not try to find the names in brackets ( ), they are there to identify the person only. If you google “famous people with epilepsy” you will find out more information on these characters.

Bumper Word Find

M	I	C	H	E	L	A	N	G	E	L	O	T	W	U	S	V	X	T	R
A	N	Y	A	L	E	W	I	S	C	A	R	R	O	L	L	O	P	A	I
R	I	T	N	N	O	T	W	E	N	C	A	A	S	I	R	I	S	L	C
G	N	H	N	E	N	C	H	A	C	F	M	B	K	U	W	X	T	A	H
A	A	A	I	I	A	H	U	L	P	N	C	A	E	S	A	R	B	L	A
U	G	G	B	L	R	A	G	F	D	A	N	N	Y	G	L	O	V	E	R
X	A	O	A	Y	D	I	O	R	L	C	H	R	I	S	T	I	E	X	D
H	P	R	L	O	O	K	W	E	B	A	H	A	N	D	E	L	T	A	B
E	O	A	T	U	D	O	E	D	W	A	R	D	G	B	R	F	B	N	U
M	L	S	E	N	A	V	A	S	O	C	R	A	T	E	S	S	U	D	R
I	O	E	N	G	V	S	V	V	S	E	L	R	A	H	C	Z	U	E	T
N	C	J	N	H	I	K	I	L	O	Q	U	S	I	U	O	L	T	R	O
G	I	W	Y	X	N	Y	N	N	Z	B	A	M	A	R	T	I	N	T	N
W	N	D	S	F	C	H	G	J	Z	Y	P	B	O	I	T	G	E	H	C
A	Z	R	O	T	I	E	O	P	N	E	L	L	A	R	A	G	D	E	R
Y	V	I	N	C	E	N	T	V	A	N	G	O	G	H	B	L	A	G	T
N	A	P	O	L	E	O	N	B	O	N	A	P	A	R	T	E	Q	R	O
S	C	H	U	M	A	N	N	L	A	L	F	R	E	D	N	O	B	E	L
K	M	D	J	S	N	E	K	C	I	D	S	E	L	R	A	H	C	A	R
S	J	T	H	E	O	D	O	R	E	R	O	O	S	E	V	E	L	T	M

Michelangelo
Leonardo da Vinci
Sir Isaac Newton
Sir Walter Scott
Danny Glover
Pythagoras
Alfred Noble
Charles V (of Spain)
Neil Young
Martin (Luther)
(Robert) Schumann

Margaux Hemingway
Lewis Carroll
Hannibal
Nicolo Paganini
Alexander (the Great)
Hugo Weaving
Edgar Allen Poe
Richard Burton
Theodore Roosevelt
Louis (X111 of France)
(George Frederick) Handel

Caesar (Julius)
Tchaikovsky (Peter)
(Agatha) Christie
Edward (Lear)
Socrates
(Alfred Lord) Tennyson
Charles Dickens
Vincent van Gogh
Napoleon Bonaparte
Alfred (the Great)

Fact Sheet 11

Epilepsy and Driving

Driving requires a complex array of neurological functions and skills that involve vision, thinking, attention and judgement, co-ordination, reaction time and motor control. Any of these can be impaired by epilepsy and seizures. People who drive vehicles may present safety concerns for themselves, their passengers and the public.

Despite having epilepsy, many people are still able to drive and hold a driver's licence, but conditions do apply. It is necessary to be assessed and advised by your neurologist to determine your eligibility to hold a driver's licence. If break-through seizures occur, it is important for your safety, and that of other road users, to stop driving immediately. It may mean that there is a seizure-free period of a year before you are potentially able to hold a driver's licence again. In some cases the stand-down period could be six months, but this is at the discretion of the New Zealand Transport Authority in consultation with your neurologist.

To drive a vehicle whilst experiencing uncontrolled seizures means that:

(a) your seizures could be affecting your ability to drive;
(b) you are breaking the law;
(c) your car insurance may not cover you.

For more information on epilepsy and seizures in New Zealand, please go to the website below:

https://www.nzta.govt.nz/driver-licences/getting-a-licence/medical-requirements/epilepsyseizures-and-driving/

Topics covered are:
- Am I legally allowed to drive?
- Guidelines for private drivers
- Controlled epilepsy
- Uncontrolled epilepsy
- Driving for work
- P,V, I or O endorsements and heavy vehicle licence classes
- Precautions while driving

When you have been suspended from driving by a neurologist or GP because of a seizure, they will write a letter to the NZTA letting them know of that fact. This information is then relayed to the police who will keep it on record. You may be asked to hand in your driver's licence to the AA for the period of your suspension and you will possibly face criminal charges if you are caught driving a vehicle during this time. It would also be against the law if you drove a mobility scooter if your neurologist or GP deemed you unfit to drive.

If you are caught driving whilst being disqualified or suspended, the vehicle that you are driving will be seized and impounded for 28 days.

Most people with epilepsy take medications to control seizures and that is perfectly legal. However, it is illegal to drive if your medications have caused your body or emotions to be affected in a way that makes you an unsafe driver. Some medications can affect your cognitive ability, your reaction times and perception of reality. It may even make you feel more tired. If you are impaired by your anti-seizure medications then you risk causing death or serious injury to yourself and other people.

Please consult your medical professional about your medication side effects that are causing issues with your driving. It may only be a temporary problem.

In New Zealand a person with a disability is not generally entitled to subsidised public transport costs, but a taxi voucher scheme does operate in some areas.

To inquire as to whether or not you qualify for subsidised taxi cover in Hamilton, you can contact Maria on maria@ewct.org.nz or 021 888 293.

In Hamilton people with epilepsy are able to be assessed for an Accessibility Concession card which means FREE bus travel within Hamilton and on buses coming from Huntly, Pukekohe, Raglan, Paeroa, Cambridge and Te Awamutu.

Total Mobility Scheme
https://busit.co.nz/travelling-with-us/total-mobility/

Accessibility and Buses
https://busit.co.nz/travelling-with-us/accessibility/

There are Workbridge support funds available to help with transport costs to and from work. Conditions apply.

Fact Sheet 12

Epilepsy Risk Management Planning for Teachers

Epilepsy is a complex condition with many different types of seizures possible. Each individual responds differently to the condition and so it is not possible to provide specific risk management guidelines applicable to all children within a school. Each school therefore needs to develop a series of risk management plans that are suitable for individual children with epilepsy, i.e. each child will likely need to have a different plan. These plans may be developed in consultation with the child concerned, his/her family or carers, an epilepsy advisor, and an epilepsy specialist.

The welfare and safety of all children in a school are paramount and so a number of factors need to be considered in developing risk management plans for individuals with epilepsy. Factors to be considered are:

Do you have sufficient information regarding the child's type of epilepsy and seizure patterns?

Ask the family/carers to complete details using a 'Child's epilepsy information record' form. The school's information form could include information on the following:

- the type of seizure and how it affects the child
- the frequency of the seizures (children or parents/carers need to keep a seizure diary)
- is the child newly diagnosed with epilepsy? In this case, an epilepsy specialist would have putin place a care plan; this care plan must be followed in the school's risk management plan
- is there a change in medication or has it been stopped? These changes can cause so-called break-through seizures, i.e. seizures that start suddenly after a seizure-free period
- what are the seizure triggers?

Create a risk management plan with the information that you have, in consultation with the parent/carer, epilepsy specialist, and epilepsy advisor. See 'Management plan for children'.

First Aid knowledge

- are all staff trained in first aid and CPR?
- have the staff been trained to recognize seizure types and know what to do when one occurs?
- do staff members know what to do when convulsive seizures occur with a child in a wheelchair or in water?
- are relief teachers informed about a child's epilepsy condition and needs, and know how to take appropriate first aid action if necessary?

Do the staff know when a seizure becomes a medical emergency?
Staff must:

- follow the child's risk management plan and follow the emergency steps
- have two or more staff trained to administer medication (rectal diazepam/buccal midazolam) if required
- take steps to maintain a child's privacy and dignity whilst administering diazepam
- have someone phone 111 and ask for immediate help and state that the seizure is a medical emergency

Are the staff aware of anti-epileptic medication?

- that medication is taken regularly as prescribed
- that all medication can cause possible side effects
- that many of these side effects can cause behavioural/emotional changes, hyperactivity, irritability, drowsiness, dizziness, tiredness, concentration difficulties, speech disturbances, depression, confusion
- that rectal diazepam or buccal midazolam should not be administered after its use-by-date has expired
- that all medication must be stored carefully and out of the reach of children

Are the staff aware that children with epilepsy may have:

- attention and concentration problems
- memory problems whereby storing, retrieving, and encoding information are difficult; children with epilepsy may even have problems following instructions
- difficulties understanding and interpreting information and therefore need more time to process it
- impaired reasoning which can affect relationships with friends/classmates, and the child's ability to solve problems
- a fear of having a seizure in front of their peers because seizures are unpredictable
- experienced social stigma associated with their epilepsy
- developed poor self-esteem which, if left unchecked, can lead to depression

Are the other children prepared?

- have the children been given a lesson by your local epilepsy advisor on epilepsy?
- do the children know how to give first aid if necessary in the classroom/playground?
- are the children taught to be respectful of a child with epilepsy?
- does the class use a buddy system?

Child's epilepsy information record (*example only*)

Confidential

Name of child……

Name of parent/carer 1………………………………………………………………………………………………………

Relationship to child………

Contact details……

………

Name of parent/carer 2 ……………………………………………………………………………………………………

Relationship to child………

Contact details……

………

Emergency contact name and details………………………………………………………………………………

………

What types of epilepsy does your child have? …………………………………………… …………………

………

……… ……………………

Describe the seizures that your child has. Are these seizures frequent?

1………

………

………

2………

………

………

3………

………

………

Are the seizures likely to happen at school? Yes/ No

Does your child usually know when he/she is going to have a seizure? (aura) Yes/ No

What does he/she experience? ……………………………………………………………………………………

………

Does your child have triggers that start seizures? Yes/ No

What are those triggers? ………………………………………………………………………………………………

How long does the seizure usually last? .... minutes

What happens to your child after a seizure?...

………

What medication is your child taking for epilepsy? …………………………………………………………….

………

………

Will you child need to take his/her medication at school? Yes/ No

When? ……..

Does your child have any side effects related to the medication? Yes/ No

What are those side effects? ……………………………………………………………………………………………..

……

In the event of your child having a seizure at school how would you like us to respond?

1 ……

2 ………

3 ………

4 ………

5 ………

6 ………

When should we call an ambulance for your child?

……

……

Do you have any other concerns or comments to make?

……

……

……

……

Parent’s signature……………………………………………………. Date……………………………………………..

Management plan for ……………………………………………………………………………… (*example only*)

Seizure type				
Description of Seizures				
Known triggers				
What to do				

Emergency Plan

1 ……

2 ……

3 ……

4 ……

5 ……

6 ……

The staff member responsible for your child's care is
………

General comments made about your child on the day of the seizure…………………………………….

………

………

………

………

………

This epilepsy risk management plan was written in consultation with…………………………………

………

……………………………………………………………………………………… Date…………………………………

Seizure action plan

Cushion the head

Make the person safe

Find an adult

Give the person time to recover

Time the seizure

Roll the person into the recovery position after the seizure has stopped

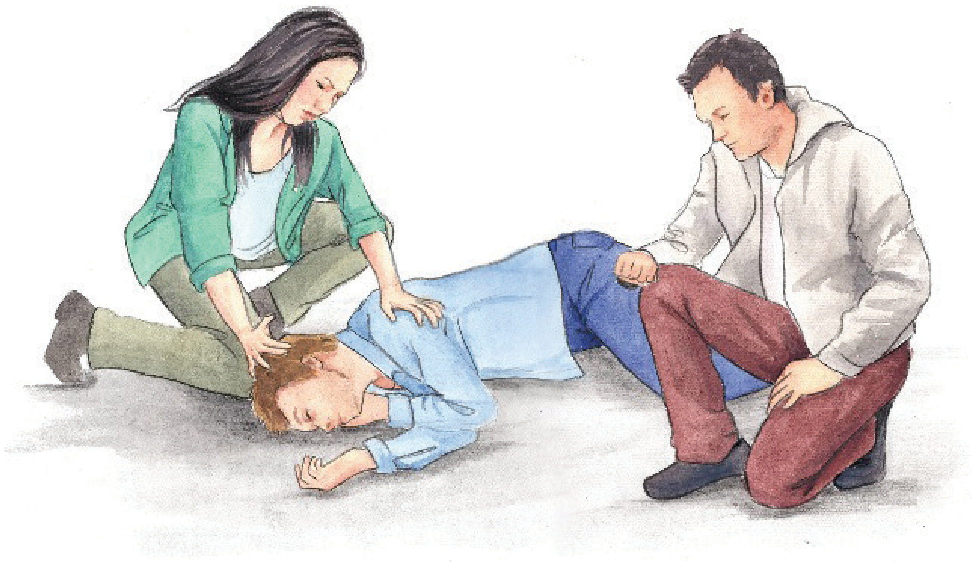
First aid poster for use in the classroom

EPILEPSY WAIKATO
CHARITABLE TRUST
Leading the way *He arahanga whakamua*

from the Epilepsy Waikato Charitable Trust

Act now: First Aid For Tonic Clonic Seizures

In the tonic (stiff) phase, people suddenly become unconscious, the body stiffens, and they will fall if standing. A person may cry out as air is forced out through the lungs and over the vocal cords, and there may be froth or excess saliva (which could be pink if the tongue is bitten). The clonic (jerking) phase begins and the body and limbs jerk rhythmically. A person may develop shallow or noisy breathing, and possibly experience a loss of bladder or bowel control. This seizure generally lasts less than five minutes and a person's awareness gradually returns.



Act:

Stay calm

Create a safe space — remove obstacles

Time the seizure

Cushion the head

Do not restrain the person

Do not put anything in the person's mouth

Put the person in recovery position after the seizure has stopped

Look for personal ID

Comfort:

Provide support and reassurance until the person has fully recovered

A person may ask for help to get home safely — you may need to phone a family member or friend

Time to call 111?

- **If you are unsure how to help**
- **If you know that this is a person's first seizure**
- **If the seizure lasts longer than 5 minutes**
- **If one seizure closely follows another**
- **If the person has difficulty breathing**
- **If the person is injured or has swallowed water**
- **If the person is pregnant**
- **If the person has another health issue**

Act now: First Aid For Focal Impaired-awareness Seizures

People having a focal impaired-awareness seizure will become unresponsive and display some unusual behaviours such as staring blankly, appearing confused, drunk, or distracted, appearing to be swallowing, or smacking their lips or picking at things in the air or around them. They may be repeating a word, crying, screaming, undressing, or carrying out strange body movements.

Whilst a person is having this seizure, a risk of injury is possible.

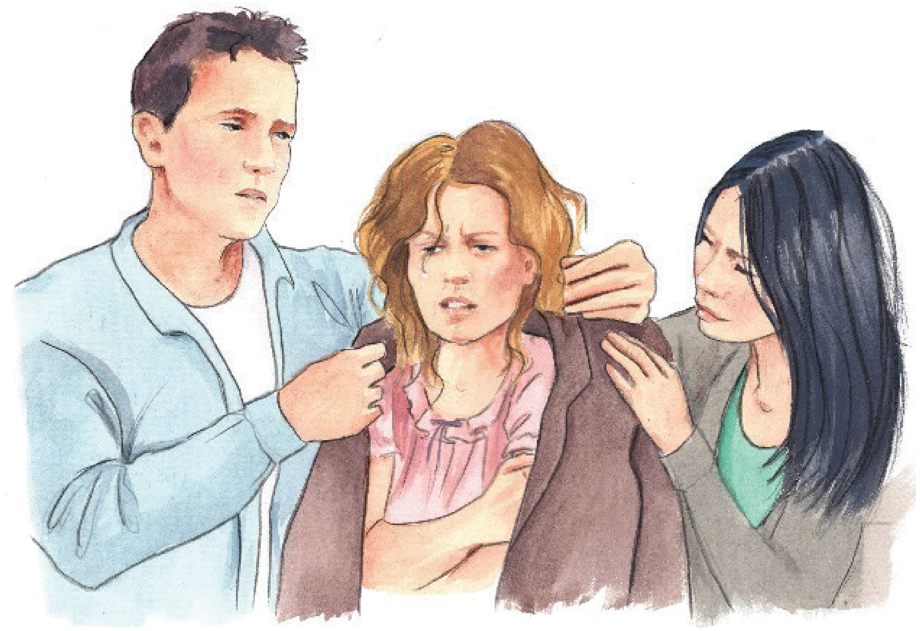
Act:

Stay calm

Make sure that the person is safe.

Guide the person away from any danger

Do not restrain or shout at the person



Comfort:

Reassure the person

Stay with the person until fully recovered

Offer to help. The person may be confused and tired and need further support from a family member or friend

Time to call 111?

- **If you are unsure how to help**
- **If the person continues to have a seizure after 5 minutes**
- **If the person has been hurt**

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WAIKATO
CHARITABLE TRUST
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Fact Sheet 14

Safe Cooking Strategies for People with Epilepsy

by Stephanie Hunter

Safety while cooking

The kitchen, with its ovens, burners, and sharp knives is a potentially hazardous area. Adjustments in methods of food preparation, cooking, and clean-up will make the kitchen safer for people with seizures. For example, some people with occasional complex partial seizures choose to complete all their food preparation with food processors and choppers instead of knives, or purchase pre-cut or already prepared meals or meal components. The microwave oven and slow cookers are chosen as safe and efficient methods of cooking insteadof using the oven or stove top.

Tips for ease of cooking

- Fresh vegetables pre-cut in packs
- Ask the butcher at the supermarket for meat or fish to be cut to your requirements
- Use an electric steamer for rice and vegetables
- Sauces in packets, cans and jars
- Sit down while doing food preparation
- Use a rubber mat under plates, bowls, chopping boards
- Wear an apron when cooking
- Don't cook when you're tired. Have pre-made meals in the freezer.
- Use plastic utensils and containers when preparing food
- Slide hot food containers along the bench rather than pick them up.
- Make the most of slow cookers
- Consider using an electric frying pan, which is more stable, rather than a frying pan on the stove
- Consider using a smaller bench top oven. These have a timer which will turn the oven off after a pre-set time.

Using a microwave

- Microwave ovens can be safer than conventional ovens as they turn off automatically after the cooking time has ended. This means there is less chance of food burning or a fire starting if you leave it unattended. Microwaves don't get hot, which means they are less likely to cause burns if touched.

- Special microwave-safe dishes and containers should not get too hot to the touch so you are less likely to burn yourself when taking food out of the microwave.
- Drinks can also be heated in a microwave. Stirring the drink will disperse any uneven ‘hot spots’ which could burn your mouth.

Making hot drinks

- Cordless kettles that switch off automatically and have a lid that ‘locks’ shut can help prevent scalds.
- Using a kettle cradle means you don’t have to lift the kettle to pour the water.
- Cups with plastic lids (commuter mugs) can protect you if you spill a hot drink during a seizure

Cooking on the stove top and in the oven

- Using a cooking basket inside a pot means you can lift the basket out after cooking and the hot water drains back into the pan. Then you can turn off the element and empty the pot later when the liquid is cool.
- Using a trolley to transfer food from the oven or cook top to the table means that you don’t have to carry hot or heavy dishes
- Always wear oven mitts - the longer the better - when removing hot items from the microwave or oven
- Turning saucepan handles to the side can help prevent pans being knocked off the cooker
- Using rings or burners at the back of the hob or grilling food rather than frying it can be safer. Use long tongs to stay back from the heat.
- Using a gas or ceramic hob means that heat can be turned off quickly
- Fitting a cooker guard around the front of the stove top means that the rings or burners are harder to touch by accident.
- Using a low-level grill instead of an eye level grill can help reduce the risk of injuring your face if you have a seizure
- Having a heat-resistant work surface means you can slide heavy pans across the work surface rather than lifting them

Safeguard your kitchen

- Use oven mitts and cook only on rear burners
- If possible, use an electric stove, so there is no open flame
- Cooking in a microwave or slow cooker can be the safest options
- Ensure that your hot water is at an suitable temperature
- Wear rubber gloves when washing the dishes
- Use plastic containers rather than glass when possible

Safety while eating

- Make sure that friends, family, caregivers know basic first-aid such as the Heimlich manoeuvre to assist someone who is choking
- Always eat sitting upright
- Use chairs with arm-rests to prevent falls
- Use nonskid surfaces under plates and cups to avoid spills
- Use a bowl or dish if coordination is a problem
- Use a cup with a lid and spout (e.g. commuter cup) for warm liquids

We thank Stephanie Hunter for providing this fact sheet.

Fact Sheet 15

Epilepsy and Memory

Dealing with memory issues is challenging for most people at some point in their lives, and for people with epilepsy it is not unusual. Memory loss can occur because of seizure activity within the brain, which disrupts memory processes, and sometimes because of the use of anti-epileptic drugs (AEDs) which can cause drowsiness or attention problems. In most cases AEDs control seizures, which helps improve memory.

Any type of epileptic seizure could potentially affect memory during and after a seizure, but the most common reason for memory loss is abnormalities in the temporal and frontal lobes. The length of time it takes to regain memory after a seizure varies from person to person, and in some cases the memory can be permanently affected.

Memory allows us to retain things that we have learnt, selecting the relevant information we need, discarding that which is irrelevant and encoding the information in categories. We are then able to store that information and retrieve it when needed. However, during an epileptic seizure that natural process of inputting and retrieving information is interfered with. The more seizure activity a person has means that he or she is likely to experience more memory issues. The use of AEDs helps to minimise that memory disruption by controlling seizure activity.

Practical tips for managing memory problems

1. Write down ideas, suggestions, dates, appointments, information etc. in a small notebook which is carried at all times.
2. Have a “To Do” list which records daily tasks, people to contact, bills to pay etc.
3. Mark down appointments, birthdays, and important events down on a calendar.
4. Attach messages to your front door to remind you of something important.
5. Use your phone alarm to remind you when to take medication or appointments.
6. Use your phone for GPS readings of where you are travelling and where you live.
7. Organise your medication in a weekly pill box. (These are available at the chemist.)
8. Ask for phone call appointment reminders from your doctors, hair dressers etc.
9. Ask friends for reminder

How to make those neurons work!

1. Meet up with old and new friends for stimulating conversations and emotional support. Social interactions boost brain functions requiring memory and attention.
2. Learn a new skill, hobby, or language.
3. Join a social or sports or hobby group, or book club, or night class.
4. Speed up the time it takes for you to solve crosswords, Sudoku, Scrabble, word finds, etc.
5. Play online games such as Tetris.
6. Do a jigsaw puzzle to improve coordination and spatial thinking.
7. Harness your long-term memory by going through old photo albums and focusing on the positive. Scrapbooking is a way of preserving those precious memories.
8. See a problem as a challenge to be conquered by breaking it down into achievable steps so that you are not overwhelmed. Seek help. “A problem shared is a problem halved.”
9. Play memory games, like the one below. You can play it on your own or with others. Give yourself a time limit.

Choose a random letter of the alphabet	Country name	Capital city	Language	Animal	Plant	Boy’s name	Girl’s name
e.g. H	Hungary	Helsinki	Hindi	Hare	Hydrangeas	Harry	Harriet

10. Choose a long word out of a magazine or newspaper and see how many smaller words you can make from it. e.g. **Performance** (perform, man, or, form, for, romance, pane, ran, prance, reef, face, perm, ace, ram…)
11. Get plenty of sleep for your age.
12. Eat well
13. Have a positive outlook and enjoy life

Face and Name Game

Do you have difficulties remembering faces and names? Try this little activity and practice doing it in real-life. Be discrete! Have fun.

Here are some photos of people with their names.

Alice

Holly

Pete

1. Choose a face.

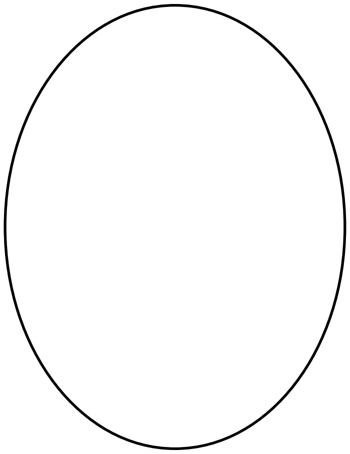
2. Describe that person to yourself. Mention hair colour/style, facial features, glasses, earrings etc.

3. Repeat the name of the person, as often as possible. Write his/her name down.

4. Hide the photo and see how much you can remember.

5. Draw it on the face shape below. How much can you remember about that person?

Name:



Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

Fact Sheet 16

Epilepsy and Mood Disorders

It is not uncommon for people with epilepsy to experience depression, anxiety or to sometimes feel suicidal. Some people may even develop personality disorders and psychosis. In fact, it is so common, that the overall rate of people with epilepsy experiencing a mood disorder stands at 25-50% higher than that of the general population. There is a relationship between epilepsy and mood disorders. The reasons for this relationship may be because:

1. The part of the brain which is affecting certain seizure types is also affecting mood. The more severe the seizure, the more severe the mood.
2. It is occurring as part of a person's seizure pattern. Some people may feel a sense of hopelessness hours, or even days, before a seizure (pre-ictal). This feeling usually resolves after the seizure. Others may experience sadness, fear, anxiety and a sense of hopelessness, or suicide, during a focal-aware seizure, and this is called ictal depression. A low mood following a seizure is called post-ictal depression. People can become tearful, experience a sense of hopelessness, become irritable, have sleep problems or even experience suicidal thoughts. These feelings can last for 12-24 hours after the seizure.
3. Some anti-convulsant medications can have a negative effect on mood.
4. Finding the right anti-epileptic medications to stop seizures from happening can take some time. This delay creates uncertainty in a person's mind and they may feel vulnerable, anxious or depressed.
5. Living with a condition that is episodic can be unsettling and people can live in a state of 'amber alert' – not knowing when a seizure is going to happen.
6. Living with a chronic condition can lead to negative feelings of sadness, anxiety, embarrassment and even anger.
7. Epilepsy is a challenging condition. People with epilepsy are often stigmatised in society despite laws aimed to protect the rights of people living with a disability. People with epilepsy can have issues around employment, education, transport, housing, finances and social isolation etc. (https://ewct.org.nz/living-challenges-epilepsy/) Facing ongoing difficulties in life can cause a sense of hopelessness which can lead to depression and sometimes suicide.
8. Other life's challenges such as divorce, the death of a loved one etc are also challenging events. Many people with epilepsy who are experiencing low mood often go undiagnosed, and are therefore untreated, and this leads to a poorer quality of life. Screening for depression and the risk to suicide should therefore be mandatory during all medical appointments. Depression can be mild, moderate or severe. It can be a single episode, a chronic recurrent issue, or a life-long illness but, regardless of this fact, there is hope in it being treatable.

The table below shows ‘feeling’ statements that could be asked over a two-week period. The higher the score denotes an urgent need to seek medical help.

Statement	Never (1 points)	Rarely (2 points	Sometimes (3 points)	Often (4 points)
Everything is a struggle				
Nothing I do is right				
I feel guilty				
I’d be better off dead				
I feel frustrated				

Most often anti-depressants and psychotherapy treatments, such as cognitive behavioural therapy, are used to successfully to treat depression and anxiety. Some medical professionals may resist prescribing anti-depressants to people with epilepsy, believing that these medications lower seizure thresholds but, according to the The International League Against Epilepsy (ILAE), this association is a myth. Anti-depressants are safe to use and are an established way of treating people with depression, even those with epilepsy. Anti-depressant medications should be started at a low dose, and slowly, to avoid interactions and side effects. Sometimes dose adjustments are made over several weeks before they become fully effective. Medications may even be switched to another brand before getting good results. Any problems should be immediately reported back to the health professional.

A good number of children living with epilepsy will also experience depression or anxiety, and some of these children will have suicidal thoughts. Mood disorder symptoms may look different in children. Many will have low self-esteem and negative thinking but some will show irritability and disruptive behaviours, poor school performance, changes in sleep patterns or appetite. Parents and teachers are to be aware of mood changes in children especially if seizures worsen, or after a

Statement	Never (0 points)	Rarely (1 point)	Sometimes (2 points)	Very often (3 points)
Everything is a struggle				
I have trouble finding anything that makes me happy				
I like crying				
I feel frustrated				
I think about dying or killing myself				
Nothing I do is ever right				
I feel sorry about things				
I feel sad				
I feel guilty				
I feel cranky or irritated				
I feel alone				

Suicide risk is a worsening world-wide phenomenon and, for those with epilepsy, the statistics look alarming. According to a recent report from Denmark, people with epilepsy have triple the risk of an attempted suicide and at least double the risk of death by suicide, compared with the general population. It is therefore vital to support people with epilepsy who may also be experiencing a mood disorder. Here are a few suggestions to gaining that support:

1. Continuity of care through a trusted GP/neurologists/epilepsy advisor or other health professional to discuss concerns around anxiety, depression and suicide. Concerns around low mood are to be taken seriously and treated accordingly.

2. Understanding what a mood disorder looks like.
   https://www.mentalhealth.org.nz/get-help/a-z/resource/13/depression

3. Using a helpline:
   a) Need to talk? Free call or text 1737 any time for support from a trained counsellor
   b) Depression helpline: Freephone 0800 111 757
   c) Healthline: 0800 611 116 (Available 24 hours, 7 days a week and free to callers throughout New Zealand, including from a mobile phone)
   d) Lifeline 0800 543 35
   e) Samaritans: 0800 726 666

Fact Sheet 17

St John Protocols

This information has been approved by Midland St John Ambulance, Hamilton

St John protocols for transporting someone who has had a seizure to the hospital

Quite often, when someone has had a seizure, a member of the public calls emergency services. However, the person having the seizure usually recovers within a few minutes, and an ambulance trip (for which there may be a fee) to the Accident and Emergency (A & E) Department at the hospital is often unnecessary and inconvenient for the person with epilepsy.

St John has put in place new protocols when determining if a trip to the A & E Department is required. Do not be alarmed if the person with epilepsy does not go in the ambulance to A & E, because it is recognised that normally the best thing for recovery is a good sleep at home.

What are the protocols?

St John ambulance staff **may not** transport a person with epilepsy to the A and E department if:

1) The person is known to have epilepsy
2) The person's epileptic seizure has not been complicated by injury
3) The person has recovered to the usual post-ictal state
4) The person is left in the care of a competent adult
5) The person has not received more than one dose of midazolam (a drug used for epilepsy)
6) The person has been instructed to see his/her family doctor to obtain treatment.

Having said all of that, if you are unsure and are really worried, then it is your right to ask for further help. St John staff are there to care for you and they are highly trained in dealing with people with epilepsy.

Witnessing someone having a seizure can be unsettling but remain calm, and understand that most convulsive seizures are temporary and do not necessitate a trip to the hospital. Trained ambulance officers will assess the situation and, if there is any doubt in their own minds, then further medical action will be taken.

For further information please refer to EWCT fact sheet 4 on “What to do if someone is having a convulsive seizure”.

Fact Sheet 18

Epilepsy Diagnosis and Treatment

Epilepsy is a common and complex neurological condition affecting at least 1 in 100 people. It can be regarded as a spectrum of disorders because there are many types of seizures and they vary in severity with each individual with epilepsy. Anyone can develop epilepsy regardless of age, ethnicity, socio-economic status, or gender and the condition will affect the quality of life of each person depending on the type and severity of the seizures. Not all seizures are epileptic ones. Some medical problems can mimic epileptic seizures and are called non-epileptic seizures, or pseudo seizures, and so a proper diagnosis is needed for effective treatment.

Epilepsy is typically diagnosed by visual observations since not all epileptic seizures are convulsive. A person on having a first seizure may be asked a series of questions by a neurologist to ascertain if he/she has focal epilepsy (seizures that occur in part of the brain) or generalised (seizures that occur in the whole brain) or both. The questions may include:

Did you:

- Experience deja vue?
- Experience any changes in smell or taste?
- Experience any abdominal/chest discomfort or altered heart and breathing rates?
- Lose consciousness or was your consciousness altered?
- Display unusual behaviours such as lip smacking, chewing, fumbling, picking?
- Wander off with no awareness of what you were doing?
- Turn your head to one side?
- Become incontinent?
- Convulse, drop onto the ground, or become stiff?

These types of questions build up a picture of a person's seizures but to be diagnosed with epilepsy a person would need to have the following conditions as defined by the ILAE (https://www.ilae.org/guidelines/definition-and-classification/the-2014-definition-of-epilepsy-a-perspective-for-patients-and-caregivers):

1. At least two unprovoked (or reflex) seizures occurring >24 hours apart;
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years;
3. Diagnosis of an epilepsy syndrome

Accurately diagnosing epilepsy can be challenging and so there are diagnostic tests that are used to help provide further information for the neurologists.

These include:

- An EEG (electroencephalograph) that measures brain activity
- Continuous video-EEG monitoring, which is useful in determining seizure types
- An MRI (magnetic resonance imaging) which uses magnetic fields to detect structural abnormalities in the brain such as tumours and scar tissue
- Initial blood tests that can detect diseases, infections, dietary deficiencies, etc. These show whether the body's organs or metabolism are working well.
- A neurological examination to show whether there are other problems with the brain

With technological advances it is also possible for family members to record seizures using mobile phones and digital cameras to help a neurologist with a diagnosis. If an epilepsy diagnosis is given then the use of anti-epileptic medication is discussed.

Seizure medications are used to control seizure recurrence, typically by decreasing brain excitation or increasing brain inhibition. For most people there is excellent seizure control with no, or few, side effects (See fact sheet 7 on medication).

Once a diagnosis and treatment of epilepsy has been made it is then necessary to self-manage the condition for optimum quality of life. Completing a seizure diary will enable a person to understand possible triggers. Triggers such as stress, tiredness, and high caffeine use can lower the seizure threshold thus making a person more vulnerable to seizures. Establishing a network of support from friends and family, and accessing community groups, can help with initial fears and anxieties that one may have regarding the epilepsy condition.

A trained epilepsy adviser can also help put in place support and advocacy to make adjusting to life with epilepsy as easy as possible.

Fact Sheet 19

Epilepsy and Motherhood

A mum with epilepsy has to work doubly hard in child-rearing, simply because of the effects of her condition and because of the medication she likely needs to take. She is often tired, fatigued, has memory issues or experiences confusion (if she is continuing to have seizures), and so being a new mum only compounds those feelings because looking after a baby is tiring in itself.

A mum with epilepsy has to make sure that both she and her baby/toddler are safe at all times. Careful thought and management strategies are needed so that a mum can enjoy the thrill of being a parent and at the same time have confidence in her ability in being a good one.

Here are a few suggestions that could help a new mother who has epilepsy care for her baby.

Take care of yourself

1. Continue to take your medication as directed by your epilepsy specialist. If you have any concerns about your medication always seek professional help.

2. Rest as much as possible. It is tiring having a baby, or running around after a toddler. You may also be working outside the home. Fatigue is a common seizure trigger.

3. Get enough sleep so that you can cope with the demands of being a mother. If you are breast feeding, that is tiring, and it may be necessary to express your milk so that your partner, or family/whanau, can feed your baby during the night. Sleep deprivation is a common seizure trigger.

4. Gladly accept help with chores, meal preparation, shopping etc. Prioritise what is important in your life.

5. Continue to record your seizures in your seizure diary. This information will help your epilepsy specialist in modifying or changing a care/medication plan for you. Always seek professional help with your concerns.

6. Keep yourself safe. Remember to say to yourself, “If I have a seizure now, what is going to happen?” Develop an epilepsy care plan so that others know how to help you in the event of a seizure.

7. Make your home safe. See: Fact Sheet 9 - Safety in the home (http://ewct.org.nz/safety-in-the-home/).

8. Talk to your community social services (such as a midwife) to receive the best support foryou and your family.

9. Have a copy of “Ben’s Buddies” (EWCT’s children’s epilepsy book) so that you can talk freely to your children about your epilepsy as they grow up.

10. Enjoy your baby!

Take care of your baby. Think safety!

A. Bathing your baby

- It would be wise to leave bathing your baby until someone is around to help you. Having a seizure whilst bathing your baby could possibly result in your baby drowning.

B. Changing and dressing your baby

- Change and dress your baby on the floor to avoid the baby falling off a changing table just in case you have a seizure

C. Feeding your baby

- Sit in a safe place to breast or bottle feed your baby, preferably on the floor, to avoid your baby from falling from any height and becoming hurt.

- Memory can be an issue if you are taking medications, or having seizures. Keep notes of your baby’s feeding times, what he/she has eaten, and any feeding issues.

- Contact your Plunket nurse for guidance regarding feeding tips, routines, and ages and stages denoting when to introduce solid foods to your baby.

D. Feeding your toddler

- Place your toddler in a high-chair that is attached to the kitchen-table rather than using a free-standing high-chair just in case you have a seizure and cause the high-chair to fall over.

- Strap your toddler into the high-chair.

- Have a supply of ready-made meals available for when you cannot cook meals. Making your own food for your toddler and freezing it into ice-cube trays is useful.

E. Keeping your baby / toddler safe- safety tips

- It is advisable to use a small pram, or car seat, to transport your baby around inside the home instead of carrying him/her. This will prevent your baby from injury should you have a seizure and drop him/her.

- If you need time to recover after a seizure, place your baby/toddler in the same room as you, in a playpen if necessary, and set an alarm to wake you, so that you can check on your baby/toddler.
  It would be preferable for someone to mind your baby/toddler whilst you recover.

- Make sure that your home is "child and seizure safe". See: Fact Sheet 9 - Safety in the home (http://ewct.org.nz/safety-in-the-home/)

- Do not cook whilst carrying your baby or toddler. See: Fact Sheet 14 - Safe cooking epilepsy (http://ewct.org.nz/safe-cooking-strategies-people-epilepsy/)

- Shut doors and gates (but do not lock them) to prevent your toddler from straying or running away should you have a seizure. If you lock your doors and gates, emergency services may not be able to help you quickly in the event of a crisis or emergency.

- Share an epilepsy action plan with a trusted neighbor, which could include the care of your baby/toddler in the event of you having a seizure. Your epilepsy advisor can help you design an epilepsy action plan suitable for you and your circumstances.

- Once you toddler is old enough to understand how to help you, then give him/her some simple instructions such as knowing how to seek help from your neighbour. As your child gets older involve him/her more in your care, such as learning how to phone for emergency services http://ewct.org.nz/wp-content/uploads/2013/05/17.How-to-dial-111-for-an-ambulance.pdf or learning how to put you in a recovery position
  http://ewct.org.nz/what-to-do-if-someone-is-having-a-convulsive-seizure/
  Get a copy of "Ben's Buddies", which is a child-friendly resource from your EWCT advisor.

- Make sure that your medications are out of reach of your toddler.

- Do not drive if you have been stood down by your neurologist or GP. See Fact sheet 11 - Driving and epilepsy (http://ewct.org.nz/driving-and-epilepsy/) for more information.

Fact Sheet 20

How to help a student with epilepsy

- 1 in 100 people has epilepsy.
- Anyone can develop epilepsy at any stage of their lives.
- Epilepsy is a sudden, unprovoked, recurrent burst of electrical activity within the brain, which produces a seizure.
- There are many types of seizures. Some seizures last only for a few seconds whilst others may last for minutes.
- Sometimes it is difficult to recognize the difference between a seizure and unusual behaviour

See fact sheet #1 "What is epilepsy" and fact sheet #2 "Epilepsy Types" for more information.

Seizures take many forms

Focal

- Purposeless actions such as lip smacking, chewing, fiddling at clothes
- Wandering off without apparent awareness
- Repeated unnatural movements, e.g. cycling action
- Sudden stomach pain or feeling unwell
- Smell/taste/visual/sound disturbances
- Sudden fear/anxiety /anger or panic attacks
- Loss of awareness
- Experiencing déjà vu, hallucinations

Generalised

- Blank stare lasting seconds. It looks like a daydream
- Rapid eye blinking
- Rhythmic head nodding
- A sudden fall without a reason
- Repeated jerking movements of the arm, legs and/or body
- Convulsing
- Incontinence

If you notice any unusual behaviour in a student, record your observations and report them to your school nurse or school principal. Follow the school procedures for reporting to parents.

To help a student with epilepsy, a teacher should know how to make them safe during a:

Non-convulsive seizure

- Act calmly
- Reassure the person
- Stay with him/her until he/she recovers

Convulsive seizure

- Keep calm
- Note time
- Make area safe
- Support head
- Do not put anything in the mouth
- Do not restrain the person
- Put person in recovery position after seizure finishes
- Stay with the person until she/

If a person recovers from the seizure:

- Stay with him/her until full consciousness returns
- Offer reassurance, comfort and support. He/she may be confused and tired
- He/she may need to go to the toilet or have a change of clothing should he/she have become incontinent
- Allow him/her to rest or have a sleep. He/she may wish to go home to recover
- Calmly explain to the class what has happened
- Resume class work. The person who had the seizure will need to be re-instructed

Phone 111 if the seizure:

- Lasts more than 5 minutes
- Follows one after another without full recovery
- Is in water
- Is the first one
- If the person is pregnant or has diabetes
- If a person has been injured
- If consciousness or breathing do not return to normal

View factsheet #4 on <u>what to do if someone is having a convulsive seizure</u> for more information.

A free EWCT seizure diary will help with recording seizures, understanding possible triggers, and provide important information regarding taking medications - contact maria@ewct.org.nz to obtain a diary

Students with epilepsy have a wide range of learning abilities. Epilepsy does not necessarily hinder learning and skill development but many with the condition do experience learning issues which may include motor skills or cognitive functions, as well as a difficulty acquiring new skills or knowledge.

Anti-epileptic drugs (AEDs) are commonly used for treating epilepsy and for most people they are generally well tolerated. However, all AEDs have a list of possible unwanted side effects. These include, for example, rashes, behavioural changes, swollen gums, acne, feeling drowsy/tired/fatigued, experiencing weight changes, feeling moody, nauseous or having problems with how the brain works. These side effects can be minor or severe, or long lasting and potentially irreversible. As a result of taking AEDs some people experience issues with memory and concentration and they can find it difficult to learn and store new information. This is because AEDs can interfere with the speed in which the brain can process information.

The seizures themselves may also have an effect on a person's ability to learn. People with the condition are often tired after a seizure, which in turn affects memory and concentration. A seizure also disrupts memory functioning processes. Memories before a seizure can be lost, because they are not fully incorporated into the memory system, and then the loss of consciousness further disrupts the encoding and storage of information. On recovery from a seizure, the confusion that follows further prevents memory from working properly. The type of memory impairment depends on where the seizures originate in the brain.

View fact sheet #15 on epilepsy and memory and fact sheet #3 "The brain" for more information.

To help a student with epilepsy the teacher should consider the social and emotional needs as follows:

1) Meeting with the student and parent to discuss, in detail, the student's epilepsy, i.e. seizure description, first aid instructions, medication, and triggers. Ensure that the student is in partnership in the management of their epilepsy and that he/she takes responsibility for it. (The EWCT epilepsy advisor could be involved in producing an easy-to-follow individualized epilepsy action plan for the family and school.)

See fact sheet #12 on risk management planning for teachers for more information.

In many cases, seizures are only a temporary interruption in a student's life, and so positive interactions are important. It is entirely up to the student and parents to decide whether or not to disclose the student's epilepsy condition to classmates.

2) Encouraging a 'buddy' system to operate within the classroom/school to prevent the student with epilepsy from feeling socially isolated. He/she should be encouraged to fully participate in all school activities, including most sports. A risk management plan is necessary to give confidence to the teacher and classmates in supporting the person with epilepsy.

Treat the student as the same as everyone else and avoid negative comments and actions that would discourage generally full participation at school. Overprotecting a student is unhelpful and it may lead to unnecessarily denying a person the opportunities that would normally be afforded to him/her.

See fact sheet 10 "Be empowered" for more information.

3) Educating the classmates about the epilepsy condition and explain how to help someone during a seizure. Epilepsy is still a misunderstood condition, and stigmas and prejudice are still present in schools and communities at large. This negative perception is detrimental to the psychological wellbeing of students with epilepsy and can have life-long psychological ramifications for them. Any emotional stress can lead to more seizures, which could mean absenteeism from school.

4) Identifying behavioural changes that could indicate a side effect from AEDs or a mood change leading to depression, poor self-esteem, and anxiety. Since epilepsy is an unpredictable episodic event, many students may feel embarrassed, angry, or anxious about having epilepsy and these emotions need to be addressed in order to avoid developing mental health issues

Teachers could help students with epilepsy by recognizing and understanding learning challenges by:

1) Understanding that stress is a well-known seizure trigger. Exams, tests, and deadlines may precipitate more seizures in a student with epilepsy. Please allow extra time for the student to finish an exam or test and, if necessary, provide a separate room for him/her to use. A reader/writer should be offered for those with processing difficulties.

2) Recognise that seizures and medications can cause memory and concentration issues. Put in place strategies to help aid in encoding, storing, and retrieving information.

- Eliminate distractions
- Give a short set of instructions that are clearly understood by the student
- Be prepared to re-instruct during a lesson
- Allow for processing time
- Give the student notes to use instead of having him/her copy from a whiteboard
- Revise new information daily
- Teach basic study skills such as highlighting, paraphrasing, outlining, and summarizing
- Encourage the use of organisational aids such as preparing lists, timetables, diaries
- Simplify tasks
- Use diagrams, graphs, and pictures
- Provide frequent feedback
- Provide additional time to complete work
- One-on-one instruction
- Provide extra tuition
- Create a supportive environment to enhance the student’s learning potential
- Positively help a child, absent with seizures, by providing notes for him/her

The rights of a student with epilepsy

The right to an education is a fundamental human right and students cannot be excluded or treated less favourably because of epilepsy. They have the right to feel safe, physically and emotionally, and reasonable care should be taken to ensure that they are not disadvantaged by their disability.

Laws protecting young people in New Zealand

- United Nations Convention on the Rights of the Child
- New Zealand Bill of Rights Act 1990
- Human Rights Act 1993
- Children, Young persons and their Families Act 1989
- Education Act 1989

Fact Sheet 21

Being a teenager and having epilepsy

Becoming a teenager is often a difficult time in a person's life and the path to adulthood can be a tricky one. Teenagers will experience intense physical and emotional changes as a result of puberty. They will face parental, societal and school expectations, peer and social pressures, discovering new relationships, independence issues and they will be developing self- identity and self-esteem. In other words, it is a period of dramatic growth and personal development.

For teenagers with epilepsy, there can also be added stress as they seek peer acceptance and autonomy around their condition. Stigma is associated with poor psychological health and it is keenly felt by teenagers with epilepsy who are already grappling with discovering who they are, and their position in the world. Teenagers with epilepsy may also face challenges such as medication compliance, driving, drinking, taking drugs, and unplanned pregnancies.

A teenager's guide to living well with epilepsy:

Seek support from your family and friends to live well with your condition. Practise PEACE: Participation, Encouragement, Acceptance, Comfort, Empowerment. A circle of caring and supportive friends can help you in your transition to adulthood as you live with epilepsy.

Participation: Epilepsy does not define who you are. Freely participate in safe activities that interest you whilst managing your epilepsy well. Take responsibility for keeping yourself safe by managing your seizure trigger(s) and regularly taking your medication.

Encouragement: To be who you want to be, within reason. Having epilepsy can potentially create employment and life challenges but it does not mean that you cannot be the person that you want to become. Take advantage of educational opportunities, learn a skill set and sell yourself. Keep focused on attaining goals for a positive future.

Acceptance: Telling your friends that you have epilepsy is entirely up to you but you may find them to be supportive and wanting to find out more about your condition so they can help you. If you experience any form of bullying, please seek help.
https://www.youthline.co.nz/infozone/bullying/

Everyone needs to feel safe in our society and it is important for your self-esteem that you feel accepted for having a condition that is actually not uncommon.

Comfort: You are not alone. Ask help from those around you regarding the various aspects of your epilepsy. Your epilepsy advisor can put you in touch with others your age. There is nothing like sharing your epilepsy stories to understand how to live positively.

Empowerment: Feel more confident and stronger in yourself by understanding your epilepsy condition. (http://ewct.org.nz/what-is-epilepsy/ and http://ewct.org.nz/epilepsy-types/) Take responsibility for self and freely ask questions of your GP, neurologists or epilepsy advisor about aspects of epilepsy that may concern you. Knowledge is power!

2. Understand your emotions

It is not unusual for teenagers to feel angry or anxious about who they are, or about their life, and a teenager with epilepsy is no different. A teenager with epilepsy, however, may be anxious about the unpredictability of the seizures and how his/her medications affect him/her, and have concerns about relationships, feelings of social isolation or coping with other's fears and prejudices. A chat with a trusted adult may help, however. Epilepsy is not a mental illness, it is a neurological condition and so feelings of anger and anxiety are perfectly normal reactions to stress. However, some medications can cause mood changes. Seek medical help if you are aware of this happening, especially if you believe that you are depressed as a result of your anti-epileptic medications.

There is also the commonground.org.nz website where you can access information that will support you to manage the hard times and enjoy positive well-being as a teenager.

3. Have regular epilepsy check-ups

Once you have been seen by a neurologist, your GP (doctor) will take responsibility for your epilepsy condition with regard to prescribing your medications, making sure that your seizures are under control and that you are feeling well. It is important to find a GP with whom you can openly talk to about your epilepsy. Show the GP your seizure diary, if you are recording your seizures, and freely discuss your concerns if you have any. You are entitled to take a support person with you to any medical consultations, and to take notes.

- You are covered by the "Health and Disability Code of Rights" http://www.hdc.org.nz/the-act--code/the-code-of-rights
- You may wish to phone Healthline 0800 611 116 for free and confidential health advice
- Get your free seizure diary from your EWCT epilepsy advisor.

Understand your medication

Get to know your pharmacist well. He/she will provide free, confidential and professional advice to you about your anti-epileptic medication. Discuss possible side effects, how to take your medication properly, and possible interactions with other medicines such as the contraceptive pill, alcohol, recreational drugs or natural therapies that you may be taking.

Do not adjust or stop taking your medications except on the advice of your epilepsy specialist.

Make sure that you never run out of your medications. Plan around public holidays and travel. If you intend travelling take enough medications for your trip and a copy of your prescription. Seek advice from your pharmacist should you be taking an overseas trip. See our fact sheet on epilepsy medication for more information.

5. **Understand your triggers**

Some events or situations can lower the seizure threshold and make a person more vulnerable to seizures. If you learn which things may trigger your seizures, then you and your GP can learn to manage your epilepsy more effectively. Get a free copy of a seizure diary from your EWCT epilepsy advisor to help you to record your seizures.

Here are some common seizure triggers:
- Missed medications or medication change
- Tiredness or sleep deprivation
- Stress
- Alcohol and recreational drug use
- Feeling unwell
- Menstrual periods in women.

6. **Driving**

Most teenagers want to learn to drive in New Zealand, and it is possible to do so in many cases, even if you have been diagnosed with epilepsy. In most situations, epilepsy treatment with medications should not prevent you from driving, but it is essential you seek the support of your GP or epilepsy specialist because there are strict regulations regarding driving with epilepsy in New Zealand.

See our driving and epilepsy fact sheet for more information.

7. **School**

Staff at schools are obliged to take into account the fact that you have epilepsy when understanding your social, emotional, academic and physical needs. Having epilepsy can be challenging and so encouragement and positive interactions at school are important for your general wellbeing.

If you’re a teacher please see ‘How to help a student‘ fact sheet for more information.

8. **Tertiary education**

Make yourself known to the disability co-ordinator who will be able to provide you with a support system in your classes, should you need it. Most students require strategies to handle the stress around assignments and so managing your stress levels are likely to be important to avoid having seizures.

Know your seizure trigger(s) and practise good seizure management, even if it means having plenty of rest and sleep, a good diet, cutting back on your caffeine intake and avoiding alcohol. This is easier said than done, when the work is piling up, but you may have to negotiate extra time for completion of work, or in exams, from time-to-time. Unless you make it known that you need help, then your disability co-ordinator will not know how to help you. At this stage in your life, you are considered an adult and so personal care and responsibility are expected.

9. Applying for a job

On many job application forms you are asked to disclose if you have a disability or health condition that could affect your ability to work. If there is no specific question on the application form, then there is no need to reveal it. Take a look at this website that clarifies when, and how, to disclose your health condition.

https://www.workwise.org.nz/uploads/files/resources/Sharing-personal-information.pdf

Some employers are reluctant to hire people with epilepsy because of their fear and prejudice, but there is no reason why your condition (if your seizures are well controlled) should be held against you when applying for jobs. You could ask your GP to write a letter of support for you. Most people do not understand what epilepsy is, and that it is a spectrum of disorders with at least 40 different types of seizures and with varying degrees of severity.

Most people with epilepsy (at least 70%) are well controlled with medications and they work in a wide variety of jobs where their epilepsy does not impact on their safety or the safety of others. Do your own research about a job that potentially suits your qualities, your qualifications, interests and skills, and at the same time consider your epilepsy condition. Complete the “careers quest quiz” if you need inspiration in choosing a career.
https://www.careers.govt.nz/tools/careerquest/

Some jobs have known occupational hazards that would pose even greater risks to people with epilepsy, and you would automatically be barred from applying for them. Use your common sense when applying for jobs. Be positive and seek help in finding employment. Most people find jobs through word of mouth and so sell yourself.

You could try organisations such as Workbridge that help people with disabilities find employment. Check out the Young Person’s Resource Centre http://www.ywrc.org.nz/ and know your employment rights.

10. If you have a job

If you have not disclosed that you have epilepsy, it may be useful to do so just in case you have a seizure at work. Let your colleagues know what sort of seizures you have and devise an action plan so that everyone knows how to help you should you have one.

You may need to have a conversation with your boss to discuss why you need some time off now and then for a neurology appointment or to recover from a seizure. It is about being reasonable and fair. Employers and employees are governed by the “Health and Safety in Employment” Act and reasonable care must be taken to ensure everyone’s safety, including yours.

If you have concerns about your employment, you may wish to contact the Young Person’s Resource Centre: http://www.ywrc.org.nz/

11. Partying

Most teenagers want to go out and have a good time with their friends but be aware that a lack of sleep and drinking alcohol may increase your seizure activity the following day. Both alcohol and recreational drugs will interfere with your medications, and so you will very likely experience an increase in seizure activity. Continue to take your medications anyway. If you are driving, you risk losing your licence should you have a seizure, and so you may wish to become your group’s ‘safety driver’ and enjoy the night out with a clear head!

On medical grounds, it is best to avoid drinking alcohol and taking (non-prescribed) drugs when you have epilepsy.

For general advice and information on drinking and taking drugs please see http://www.commonground.org.nz/common-issues/the-hard-stuff/

12. Forming relationships

It is often during this time that teenagers start to learn about, and experience romantic relationships with others. It can be a time of intense and emotional feelings and anyone involved in a relationship is likely to experience rejection at some time or another. Being rejected is not unique to people living with epilepsy.

As a teenager with epilepsy, there is no need to disclose that you have the condition in an early relationship until a feeling of trust has been established. Once you feel confident about the relationship developing into a positive one, then it is best to tell your ‘partner’ about your epilepsy. Good relationships are built on trust and so openness about your epilepsy is important.

People with epilepsy can generally enjoy the same sexual feelings and pleasure as everyone else. Having sex does not normally bring on a seizure but the anxiety about your sexual performance may. Some anti-epileptic drugs (AEDs) can possibly lower your sex drive.

Some AEDs can interfere with the contraceptive pill and some women with epilepsy may fall pregnant because of this interference. At other times the contraceptive pill may interact with the AEDs by reducing the amount of AED in the blood, therefore resulting in more seizures. Bleeding between periods is a sign that the contraceptive pill is not providing enough protection against an unplanned pregnancy. Professional advice on AEDs and contraceptive use is essential.

13. Becoming a mother

Pregnancies should be planned, at least a year in advance, as this enables the neurologists to review your anti-epileptic medication. Some AEDs can affect the development of the unborn baby and so specialist advice and support are essential at least 3-6 months before starting a family. Most babies are born healthy to mothers who are taking AEDs.

AEDs affect your body's ability to absorb folic acid and so it is advisable that you take higher-than-usual doses to prevent nervous system defects such as spina bifida in your developing baby. Iodine supplements are also recommended. Your specialist will prescribe an AED that gives you best seizure control whilst protecting your baby from its side effects. Any risks will be kept to a minimum. The effect of being pregnant is unpredictable in all women. Some may experience an increase in their seizures whilst others can have a decrease.

Read practical advice for new mothers in our 'epilepsy and motherhood' fact sheet.

14. Quality of life

There are certain factors that will improve your quality of life. How well you live with epilepsy is dependent on a number of things.

Accepting that you have epilepsy does not come easily for some but it is important that you come to terms with having this condition. Epilepsy is one of a number of medical disorders that can affect anyone in life. It is complex and requires the medical and professional support of your neurology specialists. Patience is often required when finding a suitable medication and epilepsy management plan. Do not get disheartened but think of your long-term goals in life and work towards them.

Taking responsibility for your epilepsy management which involves taking your medications regularly and knowing your seizure triggers. The idea behind doing this is to reduce having seizures and the risk of injury (and in some cases potentially death) as a result of them.

The impact of your seizures could also result in absenteeism at work, study or social activities, or even the loss of your driver's licence, if you have one. Be encouraged to learn that at least 70% of people with epilepsy have excellent control of their seizures through taking their medications.

Go easy on alcohol, recreational drugs and smoking. Preferably avoid them altogether. For general information on this topic see: http://www.commonground.org.nz/common-issues/the-hard-stuff/alcohol-and-cigarettes/

Understand the importance of sleep in seizure management. The lack of sleep and missed doses of medications are common causes of increased seizure frequency.

Take advantage of your mobile phone and what it has to offer. It can be used to help you with remembering tasks, when to take your medications, accessing help, keeping you in touch

Many phones can connect you with the internet for valuable information on epilepsy. Under your contacts list, have an ICE number (in case of an emergency), for quick access.

The downside of having a mobile phone is the dependency one can have with it. It is fun to have contact with your friends but make your last text message at night several hours before you go to sleep. Having a mobile phone can also create distractions and sometimes lead to cyber bullying which in turn creates stress. Stress is a known seizure trigger.

Don't let the computer replace human contact. It is important not to withdraw from family and friends and into the world of computer games when you have epilepsy. A lack of human contact is unhealthy psychologically. People with epilepsy can face social isolation and it is important for you that you do not allow that to happen. You need to place value on real events happening in your life and take responsibility for them.

Late night computer sessions will also hack into your much needed sleep time. This lack of sleep and missed medications will cause an increase in your seizures.

Stay fit and healthy. Consider engaging in physical activity such as jogging, gym work, or in a team sport. Get those natural endorphins whizzing around your body and feel good emotionally and physically. It is possible you may be able to participate in a range of sporting activities. Take a look at our Epilepsy and Sports fact sheet to see which activities best suit a person with epilepsy. Use your common sense when choosing a physical activity and protect yourself and those around you should you need their help in the event of a seizure happening. Let someone in your team/gym/swimming club etc. know that you have epilepsy. Put in place a simple seizure action plan.

Start to develop your own independence. Know that you can put things in place that will help you to build your confidence.

- Wear a medic alert bracelet or necklace for identity https://www.medicalert.co.nz/
- Join St John as a member. It is cheaper this way than having to pay for each ambulance ride, should one be called for you. http://www.stjohn.org.nz/
- Put in place some safety measures for yourself, especially if you are going flatting Say, "If I had a seizure now, what would happen to me?" Take a look at http://ewct.org.nz/safety-in-the-home/ and http://ewct.org.nz/safe-cooking-strategies-people-epilepsy/
- Set an alarm to remind you about taking your medication.
- Allow people around you to understand how you want to be treated should you have a seizure and tell them how you generally feel afterwards. Communication is the key to your autonomy and in developing a positive self-esteem.

Seek help at any time from you GP, neurologist, parent, counsellor, a trusted friend or adult. It is well recognised that the transition into adulthood can be a tricky one.

For more information on epilepsy, please go to http://ewct.org.nz

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Fact Sheet 22

Epilepsy and Sport

Participation in exercise and sport is important for general health and emotional well-being but, for people with epilepsy, their neurological condition must always be considered when choosing any activity.

People with epilepsy are advised to:

1. avoid an activity that involves the possibility of a head injury,
2. avoid an activity that results in a serious injury because of a loss of consciousness, and
3. avoid an activity where there is no bodily contact with the ground (e.g. surfing).

A person with epilepsy must consider their seizure type/control and triggers, apply normal safe-guards for participating in sport(s), and wear safety gear, if necessary. Extra supervision is required around water activities for people with epilepsy (See http://ewct.org.nz/what-to-do-if-someone-is-having-a-convulsive-seizure/ for more information). **Completing a risk assessment and seizure action plan would be ideal.**

These sports are relatively safe[1]. However, complete a risk assessment and seizure management plan. Wear safety gear

- Aerobics
- Archery
- Badminton
- Basketball
- Bowling
- Cricket
- Curling
- Dancing
- Golf
- Gymnastics
- Golf
- High jump
- Hockey
- Jogging
- Orienteering
- Running
- Shot put
- Soccer
- Softball

These sporting activities would require reasonable precautions[1]. Complete a risk assessment and seizure action plan and wear

- Canoeing
- Cycling
- Diving
- Football
- Horse-riding
- Hockey
- Ice skating
- Karate
- Kayaking
- Pole vaulting
- Roller skating
- Rugby
- Sailing
- Snorkelling
- Swimming
- Tennis
- Table tennis
- Volleyball
- Weight-lifting

These activities would be prohibited[1]. Talk to your GP or neurologist.

- Boxing
- Bungee jumping
- Hang gliding
- Jousting
- Rock climbing
- Scuba diving
- Sky diving
- Surfing
- Water skiing
- Table tennis
- Volleyball
- Weight-lifting
- Wrestling

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[1] These categories are derived from chapter 8 “Epilepsy and quality of life” (pp. 123-127) in Leppik, I.O. 2007. Epilepsy – a Guide to Balancing Your Life. AAN Press, American Academy of Neurology, Saint Paul; and Demos Medical Publishing, New York.

UNIREC

The below information has been provided courtesy of Kristina Jessup a High Performance and Rehabilitation Consultant, UNIREC Centre, University of Waikato

Exercise or physical activity is good for everyone and seizures during exercise are rare. However due to fear of a seizure those with epilepsy and their families, are often fearful or not sure where to start when it comes to commencing regular physical activity.

Benefits of exercise for epilepsy:

- Reduced seizure susceptibility compared with inactive people with epilepsy.
- Engaging in physical activity has been found to reduce sensitivity to stress, which may be a potential mechanism for decreasing susceptibility and frequency of seizures in people with epilepsy.
- Improvement in quality of life and social integration.
- Exercise has been found to help reduce anxiety and depression. Anxiety is one major trigger of seizures.
- People with epilepsy are able to reap the same benefits from exercise as healthy individuals, these include improved fitness, weight loss, increased aerobic and working capacity, improved lung capacity and reduced heart rate.
- Health benefits resulting from exercise also include reduced risk of heart disease, cancers, stroke, diabetes and arthritis.
- Anti-epileptic medications can have a side effect of weight gain, exercise helps maintain a healthy body weight and reduce the risk of obesity.

Checklist prior to exercise for people with epilepsy:

Some things to remember before engaging in exercise or a physical activity programme:

- Seek medical clearance from your doctor first.
- Avoid triggers of seizures – stress, fatigue, anxiety.
- Take medications and stay well hydrated.
- Ensure exercise is stopped if you feel faint, dizzy or nauseous.
- Wearing a medic alert bracelet if training alone so people will be able to know you have epilepsy.
- Carry a mobile phone with an emergency number listed (in case of an emergency- ICE), when out exercising alone, for example biking, running or walking. Let people know where you are going and how long you intend being away.

Unirec operates a unique group-based programme, MediFit, designed for people affected by pre-existing or current medical conditions. See www.unirec.co.nz/what-we-offer/medifit for more information.

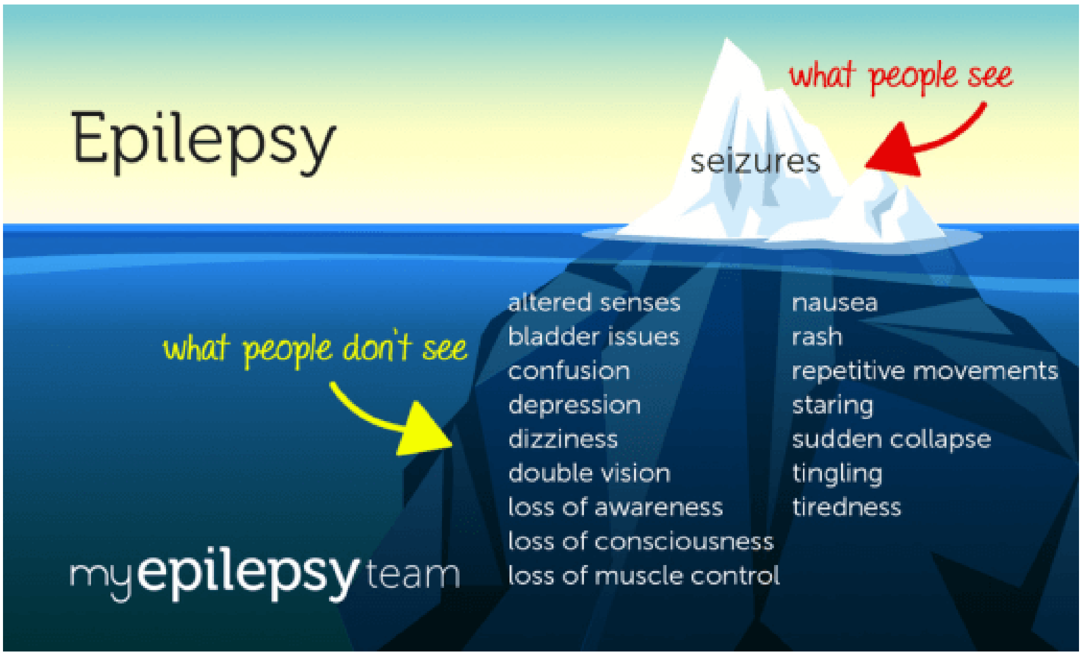
Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

Fact Sheet 23

Living with the Challenges of Epilepsy

Epilepsy (regardless of severity) creates life challenges and impacts on a person's quality of life

1. Epilepsy is the most complex and serious neurological condition and it affects at least 1–2 % of our population. This equates to over 40,000 New Zealanders and about 70 million people globally, with at least 80 % living in developing regions of the world. Epilepsy is the fourth-most common neurological condition after strokes, Alzheimer's, and migraines and yet it is the least understood. It is a spectrum of disorders affecting a wide range of people.
2. Throughout the ages, epilepsy has been a misunderstood condition and, according to a recent international report, the perceptions, fears and stigma still exist within parts of our community today. Although most people with epilepsy do live with near-normal lives, quite a few carry the burden of their condition daily in many different ways. For example, they may have difficulties in education, employment, financial constraints, finding safe and affordable housing, and social isolation.



3. There are about 40 different types of epilepsy involving either the whole brain (generalised), or part of the brain (focal). Many people mistakenly see the so-called 'convulsive seizure' as being epilepsy whereas it is only one form of the condition. Epilepsy is therefore still very much a 'hidden' condition.

There is a push by EWCT and similar organisations to bring epilepsy out from the shadows so that the needs of a person living with the condition are better understood by staff in government departments, in schools, places of higher learning, in employment, and in society more generally.

Fact: At least 60% of people with epilepsy have tonic clonic seizures, 20 % have focal impaired awareness seizures, 12 % have mixed tonic clonic and focal aware seizures and less than 5% have absence/myoclonic and other types. (Epilepsy Society UK)

4. Between 5870 % of people have good seizure control, mainly through using medications or by some other means (such as vagal nerve stimulation, diet, brain surgery, which all have potential side effects), but the remaining 42–30 % of people have absolutely none whatsoever. This means that a good section of people living with epilepsy have a diminished quality of life and can live in a condition of 'amber alert', which means, "When is my next seizure going to happen? Where will it happen? What will happen to me?"
5. Epilepsy is often difficult to diagnose since there is no specific diagnostic test, and this can cause anxiety, depression and stress for the person with seizures and for family/whanau members. There is a ripple effect when one person in the family has epilepsy, as it can impinge on every aspect of life and relationships.

Fact: In the UK, the misdiagnosis rate for epilepsy is between 21 and 30%. (Epilepsy Society UK)

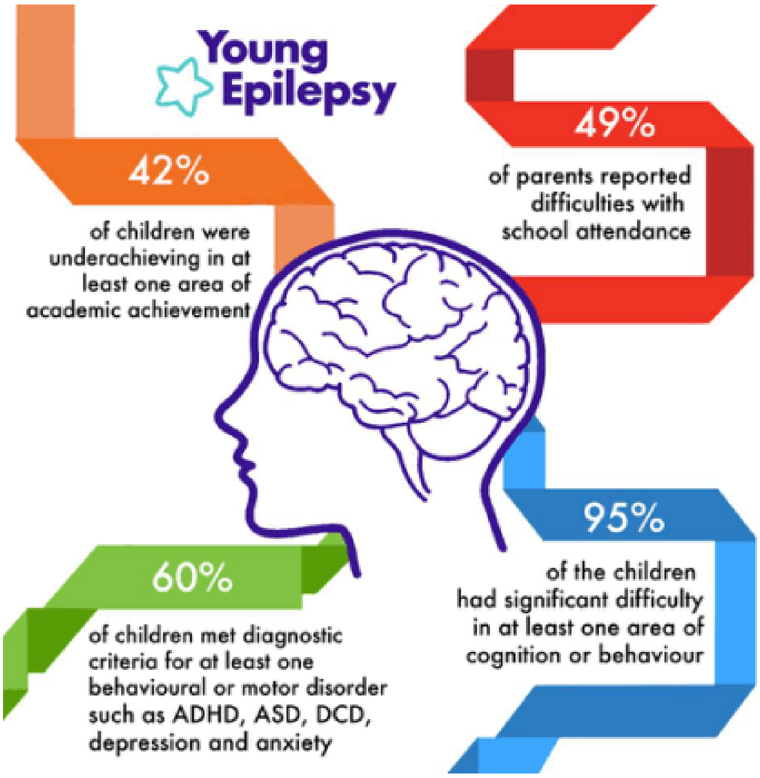
6. Medications are used to treat (not cure) epilepsy. They have potential side effects, e.g. behavioural/personality/physical changes, nausea, fatigue, drowsiness, double vision. It is preferable for a person with epilepsy to take just one drug (monotherapy) but quite often he/she may be on many different medications (polytherapy) to control his/her seizures. A mix of drugs potentially means more side effects and it can take years to find the most suitable medication control available. Some people are 'drug resistant' and this can cause increased anxiety and stress, along with other possibilities of having seizures that are non-epileptic.
7. Some medications, such as sodium valporate, have the potential to produce life-long, and debilitating side effects for children whose mothers take this particular drug whilst pregnant. Women who have epilepsy, and who are of child-bearing age, need to be carefully managed so that both the mother and child are protected from seizure risk and medication side effects. Children born with side effects caused by sodium valproate, in particular, have "foetal anti-convulsant syndrome".
8. Social isolation is a reality for some people living with epilepsy as they may be living under 'amber alert' conditions with little or no social support or transport. The person may also experience ostracisation by society, which further compounds that feeling of desperation and loneliness thus fuelling mental health issues.

9. Having epilepsy can be seen as a barrier to employment. However, many people living with the condition can participate in a variety of jobs because their epilepsy does not affect their ability to work. On the other hand, those with ongoing epilepsy issues face higher levels of unemployment or underemployment. In all cases, people with the epilepsy label face fewer career options because having a seizure is perceived as a higher health and safety risk to all. The Human Rights Act is designed to help protect people with epilepsy from discrimination **in** employment.

10. If people are affected by their epilepsy, or medications, whilst at school, or they have been bullied or teased, then they may end up leaving school with few or no qualifications. There are however, free courses available for young New Zealand citizens and so the possibility of participating in such courses offers hope for a positive future.

11. Epilepsy is seen as an episodic event and therefore no real recognition is given to children requiring extra funding for support at school unless they have an additional condition such as ADHD, or a co-morbidity. Epilepsy does not necessarily hinder learning and skill development, but many children do experience learning issues which may include ongoing motor skills or cognitive functions, as well as a difficulty acquiring new skills or knowledge. Children can experience medication side effects just like adults and they can have ongoing memory and self-esteem issues.

Fact: More than one in five people with epilepsy have learning or intellectual disabilities. (Epilepsy Society UK)



12. Receiving government or community-funded support can be problematic for adults if epilepsy continues to be considered as an episodic event by social service agencies. Some people are chronically affected by their epilepsy and therefore require a level of support that is given more readily to people with other medical conditions. Receiving any support can preclude a person with epilepsy simply because of the criteria for receiving help. Having epilepsy is a neurological condition and does not fit under the mental health, intellectual or physical health banners therefore reducing any quality of life for people chronically affected by their epilepsy.
13. Absenteeism from school or work as a result of seizures can be a problem. Children will start missing out on valuable learning time and adults may start compromising sick-leave entitlements if they have them.
14. Having epilepsy can be surprisingly costly with regular GP/pharmacy visits, the costs of personal and specialised alarms, ambulance costs, replacement costs of phones and wallets accidentally damaged or lost, repair costs for damage to homes (as the result of accidents resulting from a seizure), transport costs, and any additional support needed for a good quality of life.
15. There are no purpose-built residential/nursing care facilities in New Zealand to support those living with epilepsy. Some people are chronically affected by their condition. Epilepsy alone is not a mental health condition, and neither is it an intellectual or physical impairment. Rather, it is a neurological condition. Apart from a possible short-term stay in the hospital, there is nothing available to help those requiring careful and specialised epilepsy management for example, introduction of the ketogenic diet, monitoring medication changes, or stabilising a person who has no seizure control.
16. Many homes need modifications to keep a person with epilepsy safe from injury or death, which adds to the cost, or restricts where one may be able to live. Other costs come in the form of damages to property caused by seizure activity.
17. There can be transport issues for those who have lost their driver's licence as a result of a seizure. Loss of a licence can also mean a job loss which then has further ramifications on a person's quality of life. (Clients have to be seizure-free for one year before being considered to have their driver licence restored.) If a person does not drive then he or she is limited to using public transport, taxi vouchers (if he/she qualifies), walking, or relying on the goodwill of others.
18. Epilepsy can potentially shorten the life of a person living with the condition by way of SUDEP (sudden unexpected death by epilepsy), status epilepticus (non- stop seizures), injuries, and suicide.

    Fact: In the UK, approximately 42 % of the deaths per year relating to epilepsy are probably or potentially avoidable. (Epilepsy Society UK)

19. We must recognise those who care for others with epilepsy, be it a parent, spouse or friend as they need support too. Carers are our unsung heroes who battle away in providing the level of care needed to sustain a positive quality of life for those living with epilepsy. Carers may help with recording seizures, managing medication routines, tending to seizures and the aftermath, attending appointments and advocating for the rights of their charges. The carer's role can be stressful and fraught with problems as epilepsy is one of the most serious neurological conditions there is. Carers are an important part of the epilepsy care team.

20. To help people living with epilepsy and their family/whanau, the Epilepsy Waikato Charitable Trust (website address given below) has an advisor, who is specially trained in the epilepsy condition and the impacts of living with it. The role is diverse to cater for the complexity and age range of the people with epilepsy. The services provided include:

    - Free confidential advice and support around the medical condition. Support may be given at medical and specialist appointments. The advisor is an important part of the 'epilepsy team' of professionals which include paediatricians, neurologists, pharmacists, and medical technicians who use EEG (electroencephalogram), MRI (magnetic resonance imaging), and other scans to help diagnose epilepsy.
    - Advocacy in schools, employment and other services so that concerns are heard and met for the person living with epilepsy.
    - Free epilepsy seminars to help break down that fear, stigma, and prejudice that exists in some quarters of society.

21. The Epilepsy Waikato Charitable Trust aim is to help people living with epilepsy. We are the leading epilepsy provider in the Waikato region.

    The website provides information and contact details for the epilepsy adviser:
    https://ewct.org.nz

Fact Sheet 24

Taking your anti-epileptic medications

Anti-epileptic medications (AED) are given generally as the first treatment option for people diagnosed with epilepsy. They are preventative medications designed to calm the over-excited brain cells that cause seizures. Neurologists aim to stop seizures by choosing the best AED for a person based on age, seizure type, sex, side effects and optimum control. Their preference is always going to be monotherapy but, quite often, two or more AEDs are used to gain best seizure control.

Anti-convulsant medications generally have half-lives of less than 24 hours. Therefore, it is important that medications are routinely taken 12 hours apart, for example, 7 am and again at 7 pm every day. A half-life is the time it takes for half of the dose of your medication to be eliminated from your bloodstream. Regular dosing maintains therapeutic levels and hopefully maximises good seizure control.

Are you having problems taking your medications?

1. **You don't want to take them?**
   Please understand what epilepsy is (see https://ewct.org.nz/what-is-epilepsy/) and why medications are given. You may need to seek further advice from your neurologist, GP, pharmacist or epilepsy advisor for an explanation. No question is a silly question. Epilepsy is just another medical condition that can normally be treated, as occurs with asthma and diabetes for example.

2. **You don't like the side effects of medications?**
   If you are worried about the side effects of your medication, you are less likely to take them. It is important to take note of all side effects and to have a discussion with your neurologist, GP, pharmacist or epilepsy advisor. It may be that the dose of your medication is too high, or that the medication doesn't suit you. Many side effects disappear over a little while but always express your concerns so that you receive the best seizure treatment plan for you.

3. **You forget to take your medications?**
   You are not alone here. At least 30% of people with epilepsy can forget taking their medications because of poor memory caused by seizures, the medications themselves, because of another disability such as having had a stroke. Missing the odd dose of medications is normal but it is best to get into good habits, if you can.

If you forget to take your medication, take it as soon as you remember unless it is near to your next dose.

Do not double the dose to make up for the one that you forgot to take.

4. **You need some useful tips to help you remember when to take your medications?**
   • Get into a routine – such as taking medications at meal times.
   • Use an alarm, medication diary, smart phone application, chart, calendar, post-it notes etc to remind you when to take your medications.
   • Use a pill box to repackage your medications, or use a blister pack or sachet rolls. Your pharmacist will provide these for you. Better packaging may help you with what to take and when.

5. **You don't believe that you have epilepsy anymore?**
   Please do not stop taking medications to see if you still have epilepsy. All medication changes are to be made by the neurologist and this is to prevent any injury or death to you around seizures. Status epilepticus is a seizure that doesn't stop, and it is deemed to be a medical emergency, and SUDEP (Sudden Unexpected Death by Epilepsy) can be avoided in many cases, simply by taking medications correctly. It may be that you don't have epilepsy anymore but please allow the neurologist to make that assessment of you.

6. **You have difficulties swallowing your medications?**
   This is especially true for children who may have problems swallowing tablets, or for people who have had a stroke or head injury. Being unable to swallow is called dysphagia and it can occur at any age, but it is common in older adults. If taking tablets is difficult then some formulations of medications can be crushed or compounded into a suspension. Some medications may come in capsule form and be sprinkled onto food for easier administration. A chat with your local pharmacist could possibly help here.

7. **It costs too much?**
   Each prescription is currently charged at $5. You become eligible for a pharmacy subsidy once you have paid for 20 new prescription medicine items from the 1st of February of each year. Ask your pharmacy if you qualify for the subsidy. If you are receiving the Disability Allowance your medications are paid for through Work and Income.

8. **You find the list of your medications confusing?**
   You may find that you are taking more than just anti-epileptic medications as part of your daily medication routine. To better understand if these medications are working well for you, you can enlist the support of your local pharmacist or the **Medicine Management service**.

   They will discuss with you:
   • Medicines and why we take them
   • How medicines work in your body
   • How to take medicines correctly and at the best times
   • How to get the most out of your medicines

9. **You can’t travel to the pharmacy to get your medications?**
   Transport can be a major problem for some people with epilepsy and this can prevent them accessing essential services, such as going to a pharmacy to pick up medications. Help may be given through for the Community Pharmacy Long Term Conditions Service. Please ask your pharmacist if you are eligible for this service.

10. **You can’t follow the instructions on how to take your medications?**
    Ask your doctor to clearly explain how to take your medications, especially if there is to be a medication change. Write it down. Make sure that the pharmacist also clearly writes this information down on your medication package so that everyone knows the routine that you are to follow.

Please learn to take responsibility for your seizure control by correctly managing your medications.

Fact Sheet 25

Epilepsy and the older person

Many of us can hope to live well into old age but, unfortunately, it is in our later years when we can possibly develop epilepsy for the first time. In the UK, it is estimated that at least 25% of people with epilepsy are over the age of 60 years, with a proportion of that age group living in nursing homes. We can only assume, then, that similar proportions would apply here in New Zealand.

Epilepsy is the most common, serious neurological disorder in the older person after strokes and dementia, and yet it is often missed in diagnosis. Rapid investigation, a correct diagnosis, a comprehensive treatment plan, and a multidisciplinary team approach, recommended by a neurologist, would ensure a better quality of life for those affected by seizures associated with epilepsy.

Known causes of epilepsy in the older person

Epilepsy is a tendency to experience recurrent, unprovoked seizures and is often a symptom of other medical conditions.

The many causes of epilepsy in the older person can be because of:

1. Vascular disease: a disease that affects the veins and arteries and can cause life-threatening conditions such as strokes. Strokes are the leading cause of new-onset epilepsy.
2. Dementia: a disease caused by brain cell death that leads to significant memory loss and which may account for 20% of epilepsy in the older person.
3. Brain tumours: abnormal cell growth within the brain which can be cancerous or benign.
4. Head trauma: occurs when a bump, blow, jolt etc causes damage to the brain.
5. Metabolic disorders: abnormal chemical reactions in your body such as hyperglycaemia and hypoglycaemia.
6. Alcohol abuse and withdrawal: seizures usually occur between 6 to 72 hours after cessation of alcohol and are typically tonic clonic. Any traumatic brain injury, such as a result of alcohol withdrawal seizures, increases the likelihood of focal seizures.
7. Infections of the central nervous system such as meningitis, malaria, or Lyme disease.
8. Depression and anxiety: these are very common psychiatric conditions experienced by those with epilepsy.

In many cases, an underlying cause for having epilepsy is unknown but research has shown that a person with epilepsy is at greater risk of having a vascular or coronary artery disease than someone in the general population.

Seizures should therefore be regarded as warnings of that potential risk, and attention should be given to blood pressure and cholesterol checks, atrial fibillation tests and smoking cessation discussions.

Behaviours that imitate epilepsy

These are seizures that mimic epileptic ones such as fainting, sleep disorders, panic attacks, mechanical falls, confusion and memory problems. These 'imitators' can lead a doctor into making a wrong diagnosis of epilepsy or, worse, possibly misdiagnosing a life-threatening condition.

How epilepsy is diagnosed

There is no simple test for epilepsy but rather a series of seizure assessments that include visual accounts, physical examinations, blood tests, diagnostic tests (i.e . MRI, EEG) and a neurologic evaluation performed by a neurologist. See https://ewct.org.nz/epilepsy-diagnosis-treatment/ .

An accurate diagnosis of epilepsy in the older person is challenging, and is possibly undetected because of the presence of 'imitators', co-morbidities or lack of epilepsy awareness. Because of this, it has been suggested that older people comprise a large but somewhat neglected group when it comes to care, support and advice.

Medication as a treatment plan

Many older people with epilepsy often have other medical disorders (co-morbidities), which are treated with medications. These medications have the potential to interact with antiseizure medications (ASMs) and so the principal tenet of starting 'low and slow' to help to minimise side effects is given. As we age our metabolic rate slows down which makes us more likely to have dose-related side effects, such as pronounced tremors resembling Parkinson's disease. In other cases, some medications may induce more seizure activity. ASMs, therefore, are chosen according to what is known about a person's seizure type (e.g focal, tonic clonic or myoclonic), knowing his/her known co-morbidities and the possible medication side-effect profiles. The aim of giving ASMs is to improve the quality of life of a person living with epilepsy and not to compound his/her overall health issues.

Adhering to a medication regime is paramount to reducing seizures and the potential risk of serious injury or death. Any medication concerns must be discussed with a neurologist or GP.

The epilepsy burden in old age

Despite the growing numbers of older people being affected by epilepsy today, there is little research to show how best to support them. Epilepsy is usually intermittent and unpredictable. It is not easy to diagnose and it poses many challenges to the person concerned, such as:

1. Having epilepsy which has not being diagnosed and therefore no treatment, care and support plans have been put in place
2. Having seizures which have the potential to be longer lasting, resulting in status epilepticus, and are therefore more life-threatening
3. Being at increased risk of fractures due to osteoporosis or falls or both
4. Fearing seizures because of the associated risk of injury and/or death
5. Feeling vulnerable because of the unpredictable nature of epilepsy and therefore becoming socially isolated
6. Becoming inactive as a result of the fears listed above
7. Experiencing social isolation because of society's fear and prejudice
8. Experiencing increased memory issues as a result of seizures or medications or both
9. Feeling unsupported by a lack of epilepsy awareness
10. Possibly losing a driver's licence and, with it, independence
11. Living alone and with no support during, and after, a seizure

For more information on the epilepsy burden please go to:

https://ewct.org.nz/living-challenges-epilepsy/

There is epilepsy support at hand

Contact your EWCT epilepsy advisor, Maria Lowe (021 888 293 or maria@ewct.org.nz), for epilepsy information advice and support. Maria will also liaise with the appropriate social services to help improve the quality of life for those living with epilepsy.

Fact Sheet 26

Epilepsy and employment

Epilepsy is a spectrum of disorders, with at least 40 different seizure types and a large number of ways in which it is displayed. It is a condition that can provoke a negative response from some, but it need not be something to be feared.

Most people with epilepsy seeking employment have a good level of seizure control and, hopefully, they would be aware of their own limitations and understand their rights and responsibilities to themselves and to others. A person with epilepsy also has rights and obligations as set out under the Employment Relations Act 2000 and the Health and Safety Act 2015.

A political movement called the Access Alliance (https://ewct.org.nz/access-alliance-seek-support/) is campaigning for the introduction of an "Accessibility for New Zealanders Act", which aims to cover all people with disabilities including visible, invisible, permanent or episodic events. Epilepsy is regarded as an episodic event, which can be relatively well managed largely through medications, and so many people with epilepsy have the potential to be gainfully employed. In some circumstances, however, an epilepsy diagnosis does preclude a person from entering some career pathways such as becoming an airline pilot.

Information for the employee

1. Choose your job according to your set of skills and qualifications while bearing in mind your possible limitations as well. It is not possible to be the airline pilot, deep-sea fisherman, or roofer, for example, but there are plenty of other jobs suitable for you. Sell yourself if you want to find work that suits you well. Many people are employed by simply networking actively with family and friends.
2. Take responsibility for yourself in managing your epilepsy with regard to regular medication regimes, understanding and mitigating seizure triggers, and by ensuring you attend medical appointments.
3. Have a conversation with your colleagues and employer regarding your seizure type(s) and how you would like to be helped in the event of a possible seizure. Your EWCT epilepsy advisor is able to design a personalised epilepsy action plan for you, and is prepared to provide epilepsy awareness training to reduce that fear or misunderstanding that may surround your condition at work.

The Health and Safety at Work Act is New Zealand's workplace health and safety law which came into effect on 4th April 2016. Apart from understanding what your work-related health and safety risks are, it is also important to minimise your own potential risk should you have a seizure at work.

Look closely at your working environment and say to yourself, "If I had a seizure now, what would happen to me?" A personalised epilepsy action plan and epilepsy awareness seminar will hopefully provide an appropriate level of care and reassurance for all concerned.

4. Ongoing, or break-through seizures could potentially jeopardise employment if absenteeism from work, driving restrictions, or changes in circumstances become an issue. Enlist the support of your epilepsy advisor to help advocate for you. Under the Human Rights' Act 1993, the employer is obliged to take reasonable measures to accommodate a person with a disability which could be as simple as changing attitudes or opening up means of improved communication. (https://www.hrc.co.nz/news/reasonable-accommodation-guide-focussing-persons-disabilities-released/)

   Effectively communicate your request for reasonable accommodation. The failure to provide reasonable accommodation to a person with disabilities can amount to discrimination depending on circumstances.

5. Losing a driver's licence is an inconvenience and a possible reason for a job loss. Through Workbridge, you should normally be able to access the Job Support Fund (https://workbridge.co.nz/employers/funding/) to help with possible transport to, and from, your place of work.

   The Land Transport Agency is responsible for ensuring the safety of all people who use our roads, and so there are rules governing the rights of the person with epilepsy to drive. For more information please go to: http://www.nzta.govt.nz/driver-licences/getting-a-licence/medical-requirements/epilepsyseizures-and-driving/

6. An accident at work, as a result of an epileptic seizure, is covered by ACC and this organisation/fund will usually cover treatment costs, loss of earnings, social rehabilitation and provide lump sums for permanent impairment.

   (http://communitylaw.org.nz/community-law-manual/chapter-18-accident-compensation-acc/costs-covered-by-acc-treatment-compensation-and-other-support-chapter-18/)

Information for the employer

1. At least ~70% of people with epilepsy have seizures that are either well established or managed, and, therefore, they do not affect their ability to work. People with epilepsy can participate in a whole variety of jobs and they are normally only limited by their skill base and qualifications.

   If you need support around employing a person with epilepsy you may find help with Workbridge. Workbridge provides funding to cover any additional costs an employee has as a direct consequence of their disability when undertaking the same job as a person without a disability. Such costs could include modifications to a workplace, productivity allowances, or additional transport costs for example. For more detailed information, please go to: https://workbridge.co.nz/employers/funding/

2. Occasionally a person with epilepsy may have a break-through seizure, which may necessitate a day (or two) off work to recover. Seizures are really tiring and a person may feel ashamed or upset at having them. People may even have to endure medication changes over time to bring the seizures back under control. Please enlist the support of the EWCT advisor to help both yourself and your employee. Some epilepsy awareness training will be really helpful, too. Workbridge support funding may help in this situation as well.

3. From a business perspective it makes good sense to employ a person with a disability such as epilepsy. Society's views on a business are influenced by the people who work there, and if businesses are shown to celebrate diversity and support people with disabilities then there would be strategic, commercial, legal, social, ethical and personal benefits. (https://www.employment.govt.nz/workplace-policies/employment-for-disabled-people/the-benefits-of-being-a-disability-confident-organisation/)

4. To meet the needs of a person with a disability an employer must take reasonable measures to provide services and facilities for them. (https://www.employment.govt.nz/workplace-policies/employment-for-disabled-people/reasonable-accommodation-measures/)

   For a person with epilepsy this would perhaps mean understanding seizure triggers in a workplace environment so that measures (mitigation) can be taken to reduce the likelihood of a seizure from happening. Possible seizure triggers may include aberrant temperature (a person being too hot or cold), undue stress, light sensitivity, noise, night duties, etc. It could be possible, for example, to mitigate against these seizure triggers by adopting and modifying environmental stressors or changing the hours of work to some degree, perhaps even by a slight amount. Please have a conversation with your employee or epilepsy advisor, or both, to discuss seizure triggers and how to prevent seizures from potentially occurring in the workplace.

   Please check the support funding section of Workbridge to see if you are eligible for additional financial support. (https://workbridge.co.nz/employers/funding/)

5. Please seek the support of your EWCT epilepsy advisor who will provide additional information, advice and support for your organisation or business.

References/URLs

1. Employment Relations Act (http://communitylaw.org.nz/community-law-manual/chapter-15-being-employed/key-legislation-the-employment-relations-act-2000-chapter-15/)
2. Health and Safety Act (https://worksafe.govt.nz/laws-and-regulations/acts/hswa/)
3. Human Rights Act (http://communitylaw.org.nz/community-law-manual/chapter-5-discrimination/overview-of-the-anti-discrimination-laws-chapter-5/)
4. New Zealand Transport Agency (http://www.nzta.govt.nz/driver-licences/getting-a-licence/medical-requirements/epilepsyseizures-and-driving/)
5. Workbridge (https://workbridge.co.nz/employers/funding/)

Fact Sheet 27

SUDEP (Sudden Unexpected Death by Epilepsy)

SUDEP (Sudden Unexpected Death by Epilepsy) is a very sensitive topic because it highlights the fact that epilepsy, as a condition, carries a small risk of premature death. To die from SUDEP is uncommon but it is the single-most important cause of death in people with epilepsy, and it happens suddenly and without warning. American studies suggests that SUDEP occurs in approximately 1 in 1,000 adults and 1 in 4,500 children, accounting for 8-17% of deaths of people living with epilepsy and therefore it is a very real burden to those living with the condition. SUDEP is usually targetted to those under the age of 40 years and whose seizures are largely difficult to control, but the mortality rates in older adults may be underestimated.

SUDEP is defined as 'the sudden and unexpected, non-traumatic and non-drowning death of a person with epilepsy and with no other known medical conditions.' It can be witnessed, or unwitnessed, and generally happens during or after a seizure. In most cases, SUDEP occurs during sleep and may involve a nocturnal generalised convulsive seizure and a disruption of the autonomic system contributing to respiratory disturbance and heart failure. Lying in a prone position is also a contributing factor. The mechanisms of SUDEP remain uncertain but there is ongoing world-wide research to try to find answers, and a cure, for this devastating event.

A neurologist should explain if you are at risk of SUDEP but it is often a difficult subject to broach with some people. Because there are many potential burdens associated to living with epilepsy, the idea that the condition may also reduce life expectancy could be overwhelming for some. It is often necessary to have a frank discussion to help allay any unnecessary fear and anxiety, remembering that the risk of dying from SUDEP is very small.

At present the only strategy available to help prevent SUDEP is to minimise risks.

The following steps are advisable:

- Take medications as prescribed by a neurologist. Medications are designed to control seizures and should be taken routinely each day. If there are unpalatable side effects then it may be possible to change one medication for another. Always get immediate advice in the event of worsening seizures during a medication change. This is always a potentially hazardous period from the point of view of SUDEP.

  More information: See fact sheet 7 on epilepsy medication.

- Do not stop taking your medications for any reason. Adherence to taking medications is important in controlling seizures. It is likely that any drug therapy which reduces the frequency of convulsive seizures will reduce the incidence of SUDEP.

  More information: See fact sheet 24 on taking anti-epileptic medication.

- Keep a record of your seizures and discuss any changes with your neurologist.

  Contact us if you wish to receive a free copy of our seizure diary.\

- Supervision at night should be considered when there is a risk of uncontrolled seizures occurring.

  Use a mattress alarm, a baby monitor or surveillance camera to alert loved ones of a seizure taking place at night.

  https://www.samialert.com/
  http://www.reidtechnology.co.nz/site/reidtech/files/Emfit_Epileptic_A4_web.pdf

  There is even the Embrace watch that alerts people of a generalised seizure happening.

  An epilepsy assistance dog may also help give comfort and support.

- Manage seizure triggers such as alcohol/drug abuse and sleep deprivation.

A particular feature of sudden death is the need to understand why it happened. Some of that pain is perhaps associated with the fact that there is a general lack of SUDEP awareness in our community which can leave bereaved families feeling socially isolated and uncared for.

There are various online support groups for SUDEP to help raise awareness and to support research in this area.

For further support and advice please contact your EWCT epilepsy advisor.

Fact Sheet 28

Epilepsy and Women

Some women living with epilepsy face many challenging issues simply because of their hormones, oestrogen and progesterone. Oestrogen makes the neurons in the brain produce more electrical discharge, and is seen as an excitatory hormone, whilst progesterone calms them down and is the inhibitory hormone. If a woman's body is producing more oestrogen than progesterone then the central nervous system is more excitable and a woman is at greater risk of seizures. The hormones are not causing the seizures themselves; rather they influence when the seizures occur.

About 12% of women discover that their seizures are affected by their menstrual cycle and this is called **catamenial epilepsy.** Tracking seizures to know when they are happening helps with a treatment plan and so a discussion with the neurologist becomes important. It may be decided that seizures can be simply controlled by anti-epileptic medications whilst in other situations hormone treatment may be deemed necessary. Since no two people are the same, there will be different solutions to the same problem.

Research has shown that for most women with catamenial epilepsy, their seizures occur towards the end of the menstrual cycle (i.e., just before, or at the start of menstruation when progesterone levels have dropped), whereas for a small number of women their seizures are taking place at, or just before, ovulation in the middle of the cycle when there is a lot of oestrogen.

A normal menstrual cycle is about 28 days when the lining of the womb is shed, but for many women with epilepsy they live with menstrual cycle disorders when periods become irregular and the egg is not released from the ovary. This situation is called an anovulatory cycle and it means that pregnancy cannot occur. One of the major causes of menstrual abnormalities is **polycystic ovary syndrome (PCOS)** and it poses a great burden for about 5-10% of women with epilepsy in the reproductive age group.

The epilepsy connection and PCOS may be related to the left temporal lobe, which may have certain hormonal abnormalities that prevent the follicles in the ovary from maturing. Research has also shown that in some cases there is a relationship between young women taking sodium valporate (Epilim) and PCOS. PCOS can worsen seizure activity and anxiety levels, because a woman is producing more oestrogen than progesterone. Always consult with your neurologist to discuss treatment options, which may include medication and life-style changes such as exercise and weight loss, which can help mitigate PCOS.

The definition of having a polycystic ovary is when the thickened ovary contains 10 or more cysts measuring about 2-8 mm across. Not all women with polycystic ovaries will have PCOS.

Contraceptive use for women with epilepsy can be problematic simply because of the effects of contraceptives, anti-epileptic medications (AEDs), and seizures. Some AEDs can interfere with the contraceptive pill and some women will fall pregnant because of this interference. At other times the contraceptive pill may interact with the AED by reducing the amount of the AED in the blood, therefore resulting in more seizures. Bleeding between periods is a sign that the contraceptive pill is not providing enough protection against pregnancy. A conversation with a neurologist is important in finding the best anti-epileptic and contraceptive combination for a woman with epilepsy and for a woman to have informed consent when using them. It is preferential that women should be offered two effective forms of contraceptives, such as the Depo Prevera injection or IUD and condoms, which are two contraceptive methods not affected by anti-epileptic medications.

Having epilepsy does not affect a woman's ability to have children or to have a healthy pregnancy. However, it is advisable to see the neurologist at least 6–12 months before becoming pregnant. Continuing to use the two forms of contraceptives and taking anti-epileptic medications is important whilst in this planning stage since it may be necessary to have a medication change. Some anti-epileptic medications such as sodium valproate (Epilim) can be harmful to the unborn baby and so the neurologist may suggest a change in medication whilst maintaining seizure control. The neurologist will also likely suggest taking folic acid, also known as folate, which is a vitamin that is important in the development of the neural tube in the foetus. As the foetus grows, the neural tube develops into the brain and the spinal cord. Folic acid helps reduce the risk of a baby developing tube defects such as spina bifida. If a woman falls pregnant unexpectedly, it is important not to stop, or even change the dosage of anti-epileptic medications, as it could be dangerous to do so. Making lifestyle choices such as eating a healthy diet, exercising regularly, getting enough sleep, and avoiding smoking, alcohol and illegal drugs are also optimum ways to manage a healthy pregnancy.

Babies born with birth defects as a result of a mother taking anti-epileptic medications during pregnancy are said to have **foetal anti-convulsant syndrome (FACS)**. Babies can display a range of congenital and neurodevelopmental problems. For more information on anti-epileptic medications and the effect of them on some unborn babies, please follow this link: www.facsnz.com

Most women with epilepsy do not experience seizures during **pregnancy** but many will experience morning sickness (i.e., nausea and vomiting) usually within the first 12 weeks, but it can also last for much longer. Morning sickness can happen at any time of the day and so gauging when to take AEDs can be tricky. Get support from your neurologist and healthcare team as to when it is best to take your medications. A solution is to maybe alter the time of day when you take medications but remember to try to keep the length of time between the doses the same to maintain the dose effectiveness. If you should vomit within one hour of taking medications, and you can still see the tablets in the vomit, then it will normally be possible to retake them.

If seizures do break-through during pregnancy, or they become severe or change, then a conversation with the neurologist becomes essential since a medication change may be suggested. Staying safe for both the mother-to-be and the unborn baby is paramount, but it may help to know that many women who have seizures during pregnancy do deliver healthy babies.

During the pregnancy, women with epilepsy will be offered the same ultrasound scans to detect any developmental problems in the baby, and they may be offered more clinical support along with more blood tests to check medication levels, depending on the AED taken. A healthy pregnancy typically lasts 40 weeks and a woman with epilepsy can look forward to the milestones found in all three trimesters. There will be teams of midwives and specialists working together in managing both the mother's health and that of the unborn baby.

Getting ready for the birth of a baby is a period of mixed emotions for all women but there are many ways to mentally and physically prepare for labour. Attending ante natal classes will provide a lot of support, and friendships are often made during this time. Knowing when to go to the hospital, and who will be assisting in the birth, will contribute to a greater peace of mind in those final weeks of pregnancy. Seizures usually do not happen during labour and so most pregnant women will deliver their babies without complications. If there should be a seizure during labour then the healthcare team may deliver your baby by caesarean section. Remembering to take your AED medications during labour is still important and you may have to be reminded to take them.

The baby is born and a new life adventure begins for you all. Please view fact sheet #19 on epilepsy and motherhood for suggestions on how to manage a new baby whilst having epilepsy. By following a few simple safety precautions it may significantly reduce the risk of accidents and minimise your anxiety.

It is normally appropriate to breast feed your baby whilst taking AEDs and you should be encouraged to do so, but it is up to you in your choice of feeding method. Do whatever is best for you and what suits your family/whanau. You should feel supported in whatever choice you make. The decision to breastfeed and the AED that you use is made between you and your neurologist and is based on weighing the benefits of breastfeeding against the potential risks of the medication affecting your baby and your seizure control.

Anywhere from the age of 45 (and sometimes younger for women with epilepsy) a woman's menstrual cycle can stop and **menopause** can begin, bringing along its unpleasant symptoms that may include hot flushes, night sweats, poor sleep, and possibly depression. Some women will choose to use hormone replacement therapy (HRT) to alleviate these symptoms but the HRT may affect AED medication and increase seizure frequency. A good conversation with a neurologist will help navigate this tricky problem.

In menopause there is a hormonal shift as both oestrogen and progesterone levels in the body decrease. This shift could cause a woman to experience epilepsy for the first time in her life (if there is no other known cause for it). For those already living with epilepsy, some women will experience worsening seizures, whilst most, especially those with **catamenial epilepsy,** will experience fewer or no change whatsoever. The epilepsy treatment plan need not necessarily be changed or adjusted as women age, but depends entirely on the number and severity of seizures happening at the time.

The biggest burden affecting menopausal women is the increased risk of bone fractures, osteoporosis and osteomalacia (softening of the bones due to a lack of vitamin D) as a result of taking AED medication. Moderate weight-bearing physical exercise and vitamin D and calcium supplements can help counter the effects of such bone loss or softening.

Fact Sheet 29

Understanding Seizure Disorders

People can have seizures for many reasons. There are some medical problems that can cause seizures to occur, such as hypoglycaemia (low blood sugar), a sudden drop in blood pressure, sleep problems, the effects of drug and alcohol withdrawal, or febrile convulsions in young children, to name some of them. These seizures are said to be 'organically derived' because they have a physical cause and normally can be easily diagnosed and treated.

Others seizures though may occur at a deep subconscious level and sometimes can be called psychosomatic, non-epileptic, pseudo-seizures, conversion disorders, functional seizures, stress seizures, non-epileptic attack disorders, or psychogenic non-epileptic seizures (PNES). But a more correct term to use would be 'dissociative seizures' (DS).

These seizures involve the mind, rather than the brain, and can be difficult to diagnose, and treatment would involve some form of psychiatric or psychological support. An early diagnosis of DS and a treatment plan, often involving cognitive behavioural therapy, would hopefully improve the quality of life for those who often struggle daily with their dissociative seizures. These seizures are very real and a person with DS would face the same challenges as those with epilepsy including issues with employment, education, driving, independence and relationships. It is a very isolating condition because of the complex nature of it, and a wrong diagnosis and treatment plan would only add to a person's distress.

Most people identified as having DS would likely have been initially diagnosed with epilepsy and prescribed anti-convulsant medications whilst presenting with epileptic-type seizures. Sometimes these prescribed medications appear to work but, for most, they are proven to be ineffective.

Consequently, around 25% of people with DS in this situation would have been considered to have epilepsy with 'drug resistance'. People with DS are often subjected to multiple medication trials with associated medication side effects, possible hospitalisation for 'status epilepticus', and given various tests to understand a condition that they do not have.

It can often take between 7 and 10 years to properly diagnose a person with DS. Such diagnosis is usually made by a psychiatrist who, during an assessment, would understand the source of distress for the client. Many people with DS have experienced some form of lifetime physical or sexual abuse, or possibly an event or trauma that causes considerable pain that is subsequently buried at a deeper subconscious level. These events are then triggered by some stressful event that reminds them, consciously or subconsciously, of a past trauma and a person will consequently have a seizure. A smaller number of people with DS may simply find it difficult handling stress. Whatever the cause, a compassionate and caring approach to helping someone with DS is needed.

Fact Sheet 30

We are...

removing stigma, fear and prejudice around epilepsy

Epilepsy is a complex neurological condition that impacts on the quality of life for those living directly, and indirectly, with it. Epilepsy can be difficult to diagnose and to treat but, also importantly, it is a disease that can engender unnecessary stigma, prejudice, and fear within families and communities

1. Throughout the ages, epilepsy has been a misunderstood condition and, according to a recent international report, the perceptions, fears and stigma still exist within parts of our community today. Although most people with epilepsy do live with near-normal lives, quite a few carry the burden of their condition daily in many different ways. For example, they may have difficulties in education, employment, financial constraints, finding safe and affordable housing, and social isolation.

   Epilepsy is still the least understood and most maligned of all medical conditions and it continues to conjure up negative stereotypes of what epilepsy is. It is therefore important to improve public awareness of the condition at all levels of society if we are to eliminate that stigma. Removing terms such as ‘epileptic’ in preference to ‘a person with epilepsy’, is also important since, epilepsy is the medical condition and does not identify who a person is.

   Stigma can cause people living with epilepsy to feel shame, fear, rejection and discrimination.

2. We need the support of others in our community to provide the level of care necessary to improve the quality of life for those living directly, and indirectly with epilepsy. EWCT will continue to educate providers such as “Work and Income”, government ministries etc, on the many challenges affecting people living with epilepsy. Without their awareness of the epilepsy condition, people with epilepsy will continue to encounter stigma, fear and prejudice in New Zealand at that level.

   Collaborative endeavours are also important between organisations which represent related conditions such as with mental health, stroke and autism. EWCT regularly identifies common goals and carries our joint activities so that a person living with epilepsy is better supported.

   Despite the impacts and social cost of epilepsy, it generally has a low priority in many systems. The most likely reason for this will be the lack of understanding of what it is like to have epilepsy.

3. Epilepsy is a complex neurological disorder that is characterised by unpredictable seizures. It is considered a spectrum disorder since it affects people in many different ways. Some people live well with little, or no, impact from having epilepsy. Others feel that their lives are greatly affected by it. The challenge facing approximately 48,000 New Zealanders living with epilepsy is having access to a high-quality and coordinated health care system whilst dealing with stigma and common public misunderstandings. Epilepsy can impose immense burdens on individuals, families and society. To improve the quality of life for all we must learn to speak out about these challenges, and the most persuasive advocate to do this is the person living with the condition. See our "Postcard Project" (https://ewct.org.nz/postcard-project/) on what 32 New Zealanders shared about living with epilepsy.

   Barrier of fear, ignorance and stigma are broken down when people take the risk to break the silence and speak out.

4. Becoming a young adult is often a difficult time in a person's life and the path to adulthood can be a tricky one. Young adults will experience intense physical and emotional changes as a result of puberty. They will face parental, societal and school expectations, peer and social pressures, discovering new relationships, independence issues and they will be developing self- identity and self-esteem. In other words, it is a period of dramatic growth and personal development.

   Adults, especially parents, play an important role in helping to alleviate any negative impacts on the wellbeing of young adults living with epilepsy, by taking care of the physical and emotional health of them. Hopefully this help, guidance and support will help young adults feel empowered to face any challenges confidently.

   Stigma is associated with poor psychological health and it is keenly felt by teenagers with epilepsy

5. Many children develop epilepsy. Some types of childhood seizures are benign (the child grows out of them and his/her development and intellect are usually normal). Some types are more serious and are associated with other problems. These problems are often greatest for children whose epilepsy starts in the first two years of life.

   Children with epilepsy have a wide range of learning abilities. Epilepsy does not necessarily hinder learning and skill development, but many children do experience behavioural and learning issues which may include ongoing motor skills or cognitive functions, as well as a difficulty acquiring new skills or knowledge.

   Many children have problems with global delay, adaptive behaviours, such as learning to walk, talk or getting dressed etc, and they will have significant problems in sleep. The majority of children will also have significant difficulties with social and emotional development as featured in ADHD and autism.

   Unfortunately, many children with epilepsy do not fit the New Zealand Ministry of Education's criteria for funding help, with only 2.5% of children receiving support compared to children with other medical conditions, such as diabetes (38% of children). Having epilepsy can have a profound effect on a child but, the Ministry of Education's funding model sees epilepsy as an episodic event unworthy of support.

   The EWCT works with SENCOs in schools, writing up applications for HHN and ORS funding so that a child's voice is heard.

There are five laws protecting the rights of young people in New Zealand
- United Nations Convention on the Rights of the Child
- New Zealand Bill of Rights Act 1990
- Human Rights Act 1993
- Children, Young persons and their Families Act 1989
- Education Act 1989

Epilepsy affects 1 in 100 people, and most have their first seizure in childhood

6. About 15,000 New Zealanders have uncontrolled epilepsy and cannot achieve seizure control with conventional anti-epileptic medications and will have multiple hospital admissions. These people are considered to be drug-resistant and are more likely to have cognitive, psychological and social problems, and will require more help within health and education systems.

Despite the addition of new anti-epileptic drugs, overall seizure control in newly diagnosed epilepsy patients has not fundamentally changed over the years. Surgery may help some of these people but, for most of them, the medications do not work, and surgery is not an option. Ketogenic diets, however, are proven, effective treatments in children and adults with intractable, medication-resistant epilepsy.

We know that the ketogenic diet successfully treats children with epilepsy, with approximately 60% of children who start on the diet having a 50% seizure reduction, and with 30% of children having greater than 90% seizure reduction. Adults living with epilepsy also experience a dramatic decrease in seizures whilst using the diet.

See https://ewct.org.nz/ketogenic-diet-therapies-for-epilepsy/ for more information about the ketogenic diet and epilepsy.

At least 30% of people living with epilepsy have uncontrolled seizures

7. There is a ripple effect from having a person living with epilepsy in the family. Families will often struggle to find information about epilepsy, how it is treated, how to manage it and what services can be available to them for support. Families will discover that eligibility criteria come to play when trying to access some social service supports, which are governed by funding agencies. Generally, in funding models, there is an apparent lack of epilepsy awareness of what it is like to live with this condition. Epilepsy may be seen as an episodic event but the impacts can be ongoing. It is best to see beyond the seizure to the needs of a person living with the condition as there will be physical, social and emotional challenges.

Family members can often live in ‘amber alert’ around when the next seizure may happen and this can cause severe anxiety and depression. There will be stress in all aspects of the family’s life.

Education for people with epilepsy and their families therefore plays an important role in adapting to life with epilepsy, developing self-confidence, and becoming competent in self-management. By obtaining knowledge and skills related to epilepsy and its management can promote an enhanced quality of life for all and help prevent misconceptions about the condition and reduce concerns about stigma.

Epilepsy has a significant impact on family functioning

8. Having epilepsy can be seen as a barrier to employment. However, many people living with the condition can participate in a variety of jobs because their epilepsy does not affect their ability to work. On the other hand, those with ongoing epilepsy issues face higher levels of unemployment or underemployment and were either on a Job Seeker's benefit or Supported Living.

   In all cases, people with the epilepsy label can face discrimination as employers often cite 'health and safety' laws as an excuse not to employ someone with epilepsy. See the "Epilepsy and employment" (https://ewct.org.nz/epilepsy-and-employment/) fact sheet for more information.

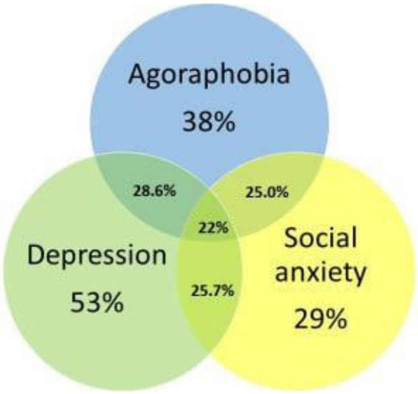
   Having epilepsy can be seen to be a barrier to employment

9. It is not uncommon for people with epilepsy to experience depression, anxiety or to sometimes feel suicidal. Some people may even develop personality disorders and psychosis. In fact, it is so common, that the overall rate of people with epilepsy experiencing a mood disorder stands at 25-50% higher than that of the general population.

   Many people with epilepsy experience social anxiety and agoraphobia (feeling scared of situations or places) which affects their quality of life. This can lead to social isolation and to lowering a person's self-esteem.

   Research suggests that people who have ongoing seizures are more likely to have agoraphobia compared to those who are seizure-free. Social anxiety disorder is more common in people taking multiple antiepileptic medications, which indicates poor seizure control. This condition is different from other anxiety disorders as it has a lot to do with seizure control, the outside environment and the way society sees epilepsy. People with epilepsy often feel ashamed and embarrassed about having seizures in public. The fear of being judged in a society that has a degree of ignorance about what to do when someone is having a seizure can be overwhelming. More epilepsy awareness is necessary to break down the fear, stigma and prejudice around the condition so that people living with epilepsy feel comfortable about being out in public.

   It is possible to be treated with social anxiety and agoraphobia but many people living with the conditions won't talk about it. It is therefore important that medical professionals are aware of the subject.



   Social isolation, stigma, anxiety or depression are frequently experienced by people with epilepsy.

10. Some people in New Zealand continue to experience poorer health outcomes because of where they live, who they are and their poorer socioeconomic status. Maori predominantly live in our deprived and rural communities, and they experience epilepsy at a higher rate than non-Maori. Maori with epilepsy have higher rates of hospital admissions, with many having four or more admissions in a year.

    Easily understood epilepsy education and support would help people with epilepsy, and their families, to develop skills and behaviours that would enable them to actively participate in patient-centred care. Having access to information on topics such as: what is epilepsy, how it is diagnosed, treatment options, strategies for injury prevention and healthy living, employment rights and protections, and self-management would increase the individual's (and family's) sense of empowerment and enhance their quality of life. Health literacy and attention to cultural considerations are particularly important if we are to reach all those living with epilepsy.

    People living directly, and indirectly, with epilepsy need to have the tools to understand how to deal with it.

Fact Sheet 31

Seizure Alarms and Monitors

There are many alarms and monitors available in New Zealand. These devices are designed to detect seizures and alert someone when you are having one.

It is possible to choose which seizure alarm or monitor suits your purpose by looking at the various options below.

You would need to do some homework and read the information and reviews available to be able to make an informed choice whilst understanding that there is no proven evidence to indicate that using a monitor or alert device can guarantee the safety of a person experiencing seizures. No alert device or monitor has been designed to prevent seizures or the possible impact of them.

Some alarms have a one-off cost whilst others have a monitoring cost.

Some alarms are from accredited medical alarm suppliers, such as St John, which means that the cost of their alarms is normally covered by Work and Income. You may be eligible to apply for Work and Income funding under the Disability Allowance even though you may not currently receive it:

www.workandincome.govt.nz/documents/forms/disability-allowance-application-for-existing-clients.pdf

To receive funding specifically for a medical alarm your GP or other health practitioner also needs to complete a Medical Alarm form here:

www.workandincome.govt.nz/documents/forms/disability-allowance-medical-alarm-assessment-form.pdf

ACC may also cover the cost of a seizure detector or monitor if you are recovering from an accident. See your case manager to discuss this possibility.

Other funding sources are:

a) Community Matters - www.communitymatters.govt.nz/lottery-individuals-with-disabilities/
b) Free Masons - freemasonsnz.org/charity/grants-to-individuals/
c) Mazda Foundation - www.mazdafoundation.org.nz
d) Variety - www.variety.org.nz
e) NZ Government website - www.govt.nz/browse/health/financial-help/lottery-grants-for-disabled-people/

Here is a list of seizure alert alarms and monitors and where you can buy them online or in New Zealand

Watches

Embrace (for tonic clonic seizures)

It detects possible convulsive seizures and instantly alerts caregivers, whether they're sleeping next door or are living miles away. Created to offer round-the-clock safety and comfort to help people with epilepsy get help when they need it most.

www.empatica.com/embrace2/

The Apple Watch series 6

The Apple watch series 6 not only measures blood oxygen levels but the app Epi Watch, which is available to go with the watch, can track seizure data before, during, and after the event. By learning more about a person's seizures it is believed that it could help to detect an episode before it occurs, making it easier for a person living with epilepsy to get somewhere safe and to get help.

www.spark.co.nz/shop/apple-shop/

Galaxy 3 4G

This watch automatically detects hard falls and sends out an SOS to your emergency contact with your location.

www.spark.co.nz/shop/samsung-shop/z-series/z-fold-3/

Apps

The My Medic Watch Fall Alert

"The My Medic Watch Fall Alert app" needs to be downloaded on a smartphone first and then paired with a compatible smartwatch such as an Apple, Samsung or Android. You must set up an account and profile to use the app. My Medic Watch apps allow people who are vulnerable to falls, have epilepsy, or people with a chronic illness to get immediate care and assistance when they fall or have a seizure so they can keep their autonomy.

www.mymedicwatch.com

Sleep Monitors

Nightwatch

For tonic clonic, hyper motor and myoclonic seizures; also changes in heart rate.

Warns caregivers remotely in the event of epileptic seizures during sleep. The NightWatch consists of a comfortable wireless armband that closely monitors heart rate and motion while the wearer is lying in bed. When the NightWatch detects a potentially severe seizure, a warning is transmitted to a caregiver via a wireless signal to the armband's corresponding base station.

www.seizurealertaustralia.co.nz

The Pulse Companion

Monitors heart rate changes that could indicate a seizure

The Pulse Companion uses a discreet wearable armband sensor to alert caregivers of a potential seizures. When the Pulse Companion identifies heart rate change that could indicate a seizure, an urgent alarm sounds on the caregiver's pager, giving them peace of mind and reassurance during the night.

www.tewanaltd.co.nz
(03 242 0267) or (021 431 8067)

SAMi Alert camera

This alarm only works with on iOS devices, such as iPhones

During sleep, audio-video information from a remote infrared video camera is sent to an app that runs on an iOS device such as an iPhone or iPod Touch. The SAMi app records and analyzes the video for unusual activity. When an unusual event is detected, it sounds an alarm and records live audio and video from the SAMi network camera. Within seconds, the individual or caregiver can take any necessary action. You can adjust the sensitivity of this alarm by downloading the SAMI alert App.

www.seizurealertaustralia.co.nz

Under-mattress sensors

Companion Mini Pro and Companion Mini

Designed to detect tonic clonic seizures

The monitor is placed under the mattress where it constantly monitors your movements. The

Companion Mini is designed to be placed and secured in the centre of the bed between the base and the mattress. When in place the Companion Mini monitors activity until movements associated with seizures are recognised. Verified and ongoing seizures then result in the transmission of alerts to a hand-held pager.

www.tewanaltd.co.nz
(03 242 0267) or (021 431 8067)

Emfit

Emfit's tonic-clonic seizure monitor is used for detecting and notifying a caregiver if the person with epilepsy experiences a tonic-clonic seizure.

It also monitors an individual's presence in bed and will give notification if the person leaves the bed or does not return to the bed within a certain amount of time.

Suitable for both adults and children.

healthcare.reidtechnology.co.nz
(0508 20 20 10)

Or

www.smartcaller.co.nz/high-care/epilepsy-safe-bed/
(0800 762 782)

EEG headset

Epihunter

This uses brainwaves from the EEG headset to automatically detect, signal and log absence seizures in real time. Seizure duration is shown too and additional notes can be logged. Available for Android only.

www.seizurealertaustralia.co.nz

Personal alarms

Tracecare GPS medical alarm

The wristband is waterproof and designed to be worn at all times. It senses motion and detects falls as it has an accelerometer. The wristband communicates wirelessly with the clip. By pressing the button, you can send an alert to your friends and family by text or email. They will receive your GPS location as well if you are out and about.

nzmedicalalarms.co.nz
(0800 559 720)

GPSOS independence alarm

Monitored alarm with 24/7 specialist support

GPSOS has a panic button and fall detector. Also has a GPS tracker. Works wherever there is cell phone coverage or wifi.

gpsos.co.nz
(0800 115 906)

Safe-Life pendant

Professional monitoring option

This device allows a person to contact help in the event of a fall or other emergency. Has a location finder and falls detector.

www.smartcaller.co.nz
(0800 762 782)

Personal emergency response system (PERS)

Consists of a pendant and a base unit that has 24/7 monitoring and emergency response. Can be added with a fall detector

securely.nz/in-home-medical-alarm/
(0800 865 865)

St John alarm

This alarm is connected directly to the St John ambulance service

This is a waterproof pendant, wristband or mobile alarm which is activated when you push the 'help' button.

www.stjohn.org.nz

Other safety aids

Breathe-zy Anti-Suffocation Pillow

This pillow is a Class 1 Medical Device which is designed to be breathable, practical and comfortable whilst assisting in the prevention of SUDEP.

www.seizurealertaustralia.co.nz

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

Fact Sheet 32

Epilepsy and oral health

Having epilepsy can affect our oral health in a number of ways.

Medication use

The medications we use can cause *Gingival hyperplasia* which is a common and mild form of gum disease which causes irritation, redness and swelling of our gingiva (the part of our gum around the base of our teeth). Gingival overgrowth can prevent proper care of our teeth and gums and it can cause pain when chewing and eating. It can also look unsightly when the growth of the gums completely covers a tooth or teeth.

It may be possible to change the medications that are causing Gingival hyperplasia with the support of your neurologist or GP, but a visit to the dentist to discuss treatment options such as gingivectomy (the removal of gum tissue) will help to treat the problem. Removing plaque that has hardened into tartar may also be recommended.

If *Gingival hyperplasia* is left untreated then it can lead to more serious gum disease known as periodontitis, which is when the gum infection damages the soft tissue and destroys the bone that supports the teeth. By practicing good oral hygiene (i.e. flossing between your teeth, brushing your teeth at least twice a day with a soft toothbrush, using fluoride toothpaste, and using a mouthwash) will help to maintain good gum health.

Other recommendations for good oral health are eating a good balanced healthy diet that is low in sugary or acidic foods, (b) avoiding smoking and tobacco products, and (c) visiting your dentist or dental hygienist at least every six months.

Seizures

People who experience tonic clonic seizures are at risk of damaging their teeth, cheek, lip, jaw or tongue during a seizure. It is not possible to prevent these injuries.

Please follow the guidelines in our EWCT first aid poster to know how to help someone having a tonic clonic seizure.

The tongue is a moveable set of eight muscles that allows us to speak, eat, drink, taste, chew, swallow and defend our mouths against germs. It is anchored to the floor of our mouth and so we cannot swallow it during a seizure. However, if we were to have a seizure on our back, the tongue would flop back and block the airwave and we would not be able to breathe until we are rolled into the recovery position. At that point, the tongue would flop forward allowing us to breathe.

Nothing should ever go into the mouth during a seizure with the mistaken belief that a person is swallowing their tongue. Any foreign object going into the mouth at that time could badly injure a person’s teeth or jaw.

We cannot stop tongues being badly bitten either during a seizure. Tongues that are badly bitten will require stitching.

To prevent bitten tongues some people may consider wearing properly fitted mouth guards which are used by those who teeth grind but not for epilepsy. However, these mouth guards present two potentially serious hazards for those with tonic clonic seizures. They are

(a) A mouth guard becoming loose during a seizure which may then block the airway; and

(b) mouth guards, which are made of silicone or plastic, disintegrating or breaking down during forceful biting and being accidentally swallowed or breathed down into the lungs. These particles would not show up on imaging and be hard to remove.

It is recommended that mouth guards are not used for tonic clonic seizures, especially for those people who have seizures during sleep.

A visit to your dentist

On a first visit to see your dentist, or dental hygienist, it is important that you tell them about your epilepsy and what it may look like. Your EWCT advisor can help minimize any anxiety you may have by writing up an epilepsy action plan which can then be shared.

All dental health professionals are taught about the many types of seizures and how to respond in the event of a seizure or emergency. They understand your anti-seizure medications and triggers such as anxiety, stress and bright lights. They will do their best to make sure that your experience sitting in the dentist chair is a positive one.

Fact Sheet 33

Epilepsy and diets

Celiac disease, epilepsy, and the gluten-free diet

Celiac disease, or gluten-sensitive enteropathy, is an immune response in the small intestine to eating gluten, a protein found in wheat, barley, and rye. When gluten is eaten the body overreacts and is unable to properly absorb nutrients in the food which leads to an immune response leading to malnourishment, loss of bone density, miscarriage, infertility, certain cancers, and even to neurological diseases including epilepsy. In fact, celiac disease appears at a significantly higher rate in people living with epilepsy than those of the general population and could therefore be considered as an underlying cause of cryptogenic epilepsy (i.e., where there is no known, or obvious, reason why seizures are occurring). Investigating links between celiac disease and epilepsy becomes especially important if there is a family history of autoimmune disease, gastrointestinal problems, or vitamin deficiency.

Research is being undertaken to understand the relationship between celiac disease and epilepsy and it has been shown that a gluten-free diet may effectively manage epilepsy by reducing seizure frequency, enabling the doses of anti-seizure medications to be reduced, or even stop seizures altogether, especially if the diet is adopted in early childhood.

Before embarking on a gluten-free diet it is essential to be diagnosed with celiac disease and to seek advice from a neurologist and a dietitian.

For more information on the celiac disease:
www.webmd.com/digestive-disorders/celiac-disease/celiac-disease
www.coeliac.org.uk/information-and-support/living-gluten-free/the-gluten-free-diet/

The ketogenic diet and epilepsy

This diet can be trialled on those people living with epilepsy who have tried a number of different anti-seizure medications but have failed to gain seizure control. It is a relatively safe and tolerable dietary treatment for both adults and children.

There are many forms of the ketogenic diet but it is essentially any diet with high fat, adequate protein, and low carbohydrate that forces the body to burn fats for energy instead of glucose, which is found in carbohydrates, such as in sugar, bread, and pasta. When the body uses fat for energy, the liver produces a chemical called ketones and these are able to have an anti-electrical effect on the brain.

Some of the many variants of the ketogenic diet are listed below.

Classical diet: This diet is very strictly measured with a fat to protein and carbohydrate ratio of 4: 1. Ninety percent of calories come from fat with very little protein (6%) and only 4% from carbohydrates. Most of the fats in this diet come from naturally fatty foods including butter, cream, and oils (such as olive and coconut oil).

Medium chain triglyceride (MCT) diet: The MCT diet allows for more carbohydrates and protein to be added in comparison with the classical ketogenic diet.

Modified Atkins diet (MAD) or modified ketogenic diet: This diet is more flexible and would suit older children and adults. The diet uses a high proportion of fats and a strict control of carbohydrates but more protein can be added.

Low glycaemic index treatment (LGIT): The LGIT diet focuses on glucose levels in the blood as well as the amount of carbohydrates eaten. Food is not weighed but approximate portion sizes are used.

To check if the ketogenic diet is producing enough ketones, ketone levels are regularly measured using a blood test or urine stick. Ask your neurologist if the ketogenic diet is suitable for you.

For more information visit:
intechopen.com/online-first/ketogenic-diet-therapies-in-children-and-adults-with-epilepsy
ewct.org.nz/ketogenic-diet-therapies-for-epilepsy/

Balanced diet and epilepsy

A good balanced diet from different food groups helps the body, and brain, to remain healthy. Most of our nutrition and daily calories should come from fresh fruits, fresh vegetables, whole grains, legumes, nuts and lean proteins and with ample sources of B6, B12, and folate.

There are no specific foods that generally trigger seizures but individuals may say that they cannot eat certain foods containing monosodium glutamate (MSG) or artificial sweeteners and colourings. Others will avoid certain foods if they believe them to trigger seizures. Grapefruit juice does not trigger seizures but it can interfere with medication levels associated with the Tegretol brand, and increase the side effects of certain ASMs. Ask your medical professional for advice if these concerns apply to you.

Drinks containing caffeine, such as coffee, tea, and energy drinks, have a stimulating effect on the central nervous system. How this stimulation affects people living with epilepsy and their anti-seizure medications is unclear. Some reports suggest that caffeine can increase the possibility of seizures occurring in some people.

Alcohol can make epilepsy medication less effective or make the side effects of medication worse. You could ask your GP or pharmacist if you are unsure.

Drink plenty of fresh water to avoid dehydration.

The kitchen, with its ovens, burners, and sharp knives is a potentially hazardous area. Adjustments in methods of food preparation, cooking, and clean-up will make the kitchen safer for people with seizures.

Please follow these links to see what food and drinks our bodies require during each of the main stages of life:

a) Infants and toddlers: nutritionfoundation.org.nz/healthy-eating/Infants-and-Toddlers

b) Children: nutritionfoundation.org.nz/healthy-eating/children

c) Teenagers: nutritionfoundation.org.nz/healthy-eating/Teenagers

d) Adults: nutritionfoundation.org.nz/healthy-eating/adults

e) Pregnancy and breastfeeding: nutritionfoundation.org.nz/healthy-eating/pregnancy-and-breastfeeding

f) Older adults: nutritionfoundation.org.nz/healthy-eating/older-adults

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

Fact Sheet 34

Epilepsy and Wellness

Epilepsy is a complex neurological condition that can affect the quality of life for each individual living with it. However, with education and support it may be possible to improve the way in which those with the condition are able to live well.

Once an epilepsy diagnosis has been made, and a treatment plan has been developed, then the next phase is about living well and improving quality of life. You can do this with managing the things that you can control for yourself, for example by taking your medications correctly, sleeping well, controlling your stress levels, and eating healthily. In a nutshell, managing your epilepsy and living well is about taking control and being empowered to live a good life despite coping with a condition that is complex and sometimes challenging to manage medically. Here are some strategies to help you to live well (extracted mainly from EWCT's book "Understanding and Managing Epilepsy – an Introductory Guide" by M. Lowe and D.J. Lowe. See https://ewct.org.nz/product/understanding-and-managing-epilepsy-an-introductory-guide/).

A. Find yourself a good GP

Once your neurologist has your epilepsy under control you will discharged from their care and you will be looked after by your GP. It is really important, therefore, that you find a GP who you can relate to since managing epilepsy can sometimes require a lot of patience, and trust, in order for things to go well. It is preferable to see the same GP for each visit because that person will know your history and be aware of specific personal circumstances relating to your condition. Appointments to see your GP are often limited to 15 minutes and so make the most of that time (or ask for a double appointment).

Take along your seizure diary. It provides a record of your seizures and possible comments, or concerns, about medication side effects, seizure triggers, sleep, anxiety, mood, etc. Be prepared with your list of questions and ask someone to go with you if you are in need of support. Sometimes that extra pair of ears is needed to understand and remember what is being said. If you need to see a neurologist again to review your medications, or to discuss major issues associated with your epilepsy, ask your GP to refer you to the neurology department at the hospital. Remember to attend all GP and hospital appointments. If you cannot go to your appointments, please let the receptionists know in advance so that another person can take your place.

B. Find yourself a good pharmacist

Pharmacists can support you by providing sound information about your medications, how to take them correctly, and by offering a range of other advice to help you manage your condition in an

C.Regularly take your medications

Taking medications correctly will become an important part of your daily routine. Having a 'steady state' of ASM in your blood at all times helps to prevent seizures from happening. It is recommended that ASMs are taken routinely, twelve hours apart, for example at 7 am and again at 7 pm. Sometimes you may forget to take your medications (and that is very normal). Use the guide in the box below to help you decide what to do if you forget your medications.

- If you take medications once a day: take the forgotten dose as soon as you remember it.
- If you take medications twice a day: take the forgotten dose if you remember within six hours after it was due. If you forget altogether, just take the next dose at the due time.
- If you miss a dose, do not take twice as much at the next dose time as this larger dose may cause side effects.

When you collect your ASM medications from the pharmacist, please make sure that they are the ones that you have been prescribed. Receiving the wrong medications can lead to side effects or break-through seizures. A single break-through seizure can have an impact on your ability to drive, your employment, your wellbeing and, in some cases, it increases your risk of injury or harm. ASMs have the potential to increase, or decrease the blood levels of other medications that you may be taking (such as antidepressants, birth control pills, blood thinners, etc). Make sure that your GP and pharmacist have a complete list of the prescription, and also any over-the counter medications that you are taking, so that they can check for potential medication interactions. Have your medicines organised in blister packs or sachets by your pharmacist if you need support to enable you to regularly take your medications. Alternatively, you can manage the ASMs yourself by putting them in a weekly pill container. These options take away the guess work of remembering whether or not you have taken your medications on any given day.

If you are having problems with your medications, do not give up. It can take a long time to find the right medications, or combinations of medications, that can work for you. Voice any concerns about your side effects with your GP, pharmacist, or neurologist, and ask them to explain how to take your medication correctly. Medications can be changed, if they are not working, or the dose can be 'tweaked' − but remember that all changes are to be made by your medical professional and not by yourself.

D.Use your seizure diary

A seizure diary, whether in book form or as an app on your phone, is a really useful way of keeping a record of your seizures and their manifestation.

The aim of your seizure diary is to record:

- What your seizure looks like
- How often your seizures occur (frequency)
- The medications that you are taking

- The side effects that you are experiencing from your medications
- Events or situations that may be triggering your seizures (e.g. exam cramming, partying).

These details are known as the history around the seizure. You need to ask others who have seen your seizures to help you describe them fully and accurately. Please take time to carefully record your seizure types so that others may help you with managing your epilepsy successfully. Remember to note anything that you did that was unusual (e.g. forgetting to take your medication, poor sleep, excess alcohol, recreational drug taking). You may have to think back 24 hours before the seizure took place to get a clear picture. By using a seizure diary, it helps you to understand your epilepsy better. In some cases, if you understand your seizure trigger, then you may be able to change or modify situations or behaviour to prevent seizures from happening again. (You can obtain a free epilepsy seizure diary from your EWCT epilepsy advisor.)

E.Sleep well

Having good, regular sleep is helpful for your general wellbeing. It helps your body to heal itself, for the brain to forge new connections, and memory retention. Poor sleep, on the other hand, can affect your overall health and make you prone to medical conditions such as obesity, heart problems, heart disease, high blood pressure, and diabetes. People living with epilepsy can experience poor sleep. This poor sleep can make seizures more likely to occur during the day. For others, sleep seizures can occur at night. They are linked to the different stages of sleep.

- **Stage 1 non-REM**: This lasts for only a few minutes. Breathing, heart rate, and brain waves begin to slow. (REM = rapid eye movement.)
- **Stage 2 non-REM**: This stage occurs before the body enters deep sleep. The muscles relax even more, and body temperature drops.
- **Stage 3 non-REM**: A person needs to reach this stage of deep sleep to feel rested, and it lasts longer in the first half of the night. Breathing and heart rate slow to their lowest levels.
- **REM sleep**: Within 90 minutes of falling asleep, a person enters REM sleep. The brain becomes more active, maximum dreaming occurs, and the arms and legs become temporarily paralysed.

If the body does not go through these stages several times a night, a person may wake feeling fatigued and unfocussed. Keep a sleep-seizure diary to record what is happening in your life and discuss any concerns that you have with your GP or neurologist. Be aware that sleep may be affected by the ASMs that you are taking and this is also worth mentioning.

Achieving healthy sleep routines becomes an important strategy in living well with epilepsy. How can this be achieved? Know that sleep routines may start several hours before you actually go to bed. Once you are in bed, on average, it should take you between 10 to 20 minutes to fall asleep.

- Avoid the temptation of having a late afternoon/early evening cup of coffee/tea or other caffeinated drink. It is believed that caffeine should be avoided for at least six hours before you go to bed.
- Avoid eating too late into the evening.
- Avoid exercise too late in the day. Try more relaxing activities instead.
- Go to bed at the same time each night, even on weekends and holidays.
- Likewise, wake up at the same time each morning, even on weekends and holidays. These nighttime and daytime routines help us to remember to take our medications on time. We will even function better during the day.
- Make sure that your sleep environment is quiet, dark, and safe especially if you are prone to having seizures during sleep.
- Turn off all your electronics such as phones, tablets, computers etc an hour or so before going to bed. The ‘blue light’ from these devises interferes with the production of our melatonin, the hormone which controls our sleep/wake cycles, and makes it harder for us to fall, and stay, asleep.

The National Sleep Foundation (NSF) in the United States of America recommends that people of different ages get the following amounts of sleep every 24 hours:

- **newborns (0–3 months)**: 14–17 hours
- **infants (4–11 months)**: 12–15 hours
- **toddlers (1–2 years)**: 11–14 hours
- **preschoolers (3–5 years)**: 10–13 hours
- **school-age children (6–13 years)**: 9–11 hours
- **teenagers (14–17 years)**: 8–10 hours
- **younger adults (18–25 years)**: 7–9 hours
- **adults (26–64 years)**: 7–9 hours
- **older adults (65 years and above)**: 7–8 hours

F. Manage your stress

When you are living with stress it can affect your entire well-being. You may find yourself struggling emotionally and physically or experiencing problems managing normal every day events. Little things can suddenly loom into feelings of helplessness and, when you have epilepsy, these can suddenly mean more seizures. Stress is a well-known seizure trigger and so managing your stress becomes an important life-skill to master if you are to avoid having them. No, or few, seizures definitely improves your overall quality of life.

We all have our own ways of managing stress but here are a few coping strategies that have been proven to be effective for most people.

- Assess your life stressors. What are they and when do they happen? Keep a record of how you are feeling because this may help you to process what is actually going on in your life. By identifying the problem, you may find better ways of coping.

- Try to avoid people or situations that are causing you to feel stressed. If that is impossible, could you think about changing your approach and your reactions? You may have to seek help from a counsellor to help you. If your stress is work-related then please seek professional employment advice. Your epilepsy advisor can also help if the problem is associated with epilepsy.
- Set aside sometime in your day to completely relax. You may wish to read a book, meditate, listen to music, or do some art. It is your choice.
- Practice a breathing technique. Many of these ideas are found on the internet when you google the words 'breathing techniques for stress relief'. Even simply counting to 10 slowly can help when you are feeling overwhelmed.
- Use positive thinking techniques that help you to see a situation in a different light. Quite often 'silver linings' can be found in stressful situations.
- Have a daily routine to help you to manage the demands on your time. Set priorities in your life, pace yourself, and avoid procrastination.
- Build exercise into your daily routine. Exercise has proven health benefits for stress levels, mood, sleep, and overall health. Choose an activity that you enjoy doing. Go outside and connect with nature!
- Connect with family/whānau and friends. Join a support group or club.
- Seek help from a member of your epilepsy team, GP, or counsellor if you are finding your stress too difficult to manage. They understand how epilepsy can affect your life and are available to help you.

G. Take care of your mental health

It is not uncommon for people with epilepsy to experience depression, anxiety, or to sometimes feel suicidal. Some people may even develop personality disorders and psychosis. In fact, it is so common, that the overall rate of people with epilepsy experiencing a mood disorder is 25-50% higher than that of the general population. Depression can be mild, moderate, or severe. It can be a single episode, a chronic recurrent issue, or a life-long illness but, regardless of this fact, there is hope in it being treatable.

There is a relationship between epilepsy and mood disorders. The reasons for this relationship may be because of one or more of the following situations.

1. The part of the brain which is affecting certain seizure types is also affecting mood. The more severe the seizure, the more severe the mood.
2. It is occurring as part of a person's seizure pattern. Some people may feel a sense of hopelessness hours, or even days, before a seizure (pre-ictal). This feeling usually resolves after the seizure. Others may experience sadness, fear, anxiety and a sense of hopelessness, or suicide, during a focal-aware seizure, and this feeling is called ictal depression. A low mood following a seizure is called post-ictal depression. People can become tearful, experience a sense of hopelessness, become irritable, have sleep problems, or even experience suicidal thoughts. These feelings can last for 12 to 24 hours after the seizure.
3. Some anti-seizure medications can have a negative effect on mood.

4. Finding the right anti-seizure medications to stop seizures from occurring can take some time. This delay creates uncertainty in a person's mind and he or she may feel vulnerable, anxious, or depressed.
5. Living with a condition that is episodic can be unsettling, and people can live in a state of amber alert – not knowing when a seizure is going to happen.
6. Living with a chronic condition can lead to negative feelings of sadness, anxiety, embarrassment, and even anger.
7. Epilepsy is a challenging condition. People with epilepsy are often stigmatised in society despite laws aimed to protect the rights of people living with a disability. People with epilepsy can have issues around employment, education, transport, housing, finances, and social isolation etc (see https://ewct.org.nz/living-challenges-epilepsy/). Facing ongoing difficulties in life can cause a sense of hopelessness which can lead to depression and sometimes suicide.
8. Other events that effect mood such as divorce, the death of a loved one, etc. If you are unsure of how depressed, or anxious you are, ask yourself how often the following statements feel true (or use a questionnaire for anxiety and depression):
    - Everything is a struggle
    - Nothing I do is right
    - I feel guilty
    - I would be better off dead
    - I feel frustrated
    - I have difficulty finding pleasure

If you can tick the box for one, or more, unhappy thoughts then it is best to seek help. Numerous organisations and websites provide questionnaires and offer avenues of support, including:

- www.depression.org.nz
- www.sparx.org.nz
- www.beyondblue.org.au
- www.lifeline.org.nz
- www.youthline.co.nz
- www.health.govt.nz

Most often anti-depressants and psychotherapy treatments, such as cognitive behavioural therapy, are used to successfully treat depression and anxiety when you have epilepsy.

H.Eat well

A good balanced diet from different food groups helps the body, and brain, to remain healthy. Most of our nutrition and daily calories should come from fresh fruits, fresh vegetables, whole grains, legumes, nuts and lean proteins and with ample sources of B6, B12, and folate.

There are no specific foods that generally trigger seizures but individuals may say that they cannot eat certain foods containing monosodium glutamate (MSG) or artificial sweeteners and colourings. Others will avoid certain foods if they believe them to trigger seizures. Grapefruit juice does not trigger seizures but it can interfere with medication levels associated with the Tegretol brand, and increase the side effects of certain ASMs. Ask your medical professional for advice if these concerns apply to you.

Drinks containing caffeine, such as coffee, tea, and energy drinks, have a stimulating effect on the central nervous system. How this stimulation affects people living with epilepsy and their anti-seizure medications is unclear. Some reports suggest that caffeine can increase the possibility of seizures occurring in some people.

Alcohol can make epilepsy medication less effective or make the side effects of medication worse. You could ask your GP or pharmacist if you are unsure.

Drink plenty of fresh water to avoid dehydration.

You may opt to use a specialized diet such as the ketogenic diet or gluten-free diet (if you have celiac disease and epilepsy) to control seizures. Please consult your neurologist and dietitian to help with this choice.

For more information see our fact sheet on epilepsy and diets.
https://ewct.org.nz/epilepsy-and-diets/

I. Exercise

Participation in exercise and sport is important for general health and emotional well-being. It can improve fitness levels, help with weight loss, increase aerobic and working capacity, and reduce stress. Choose an activity that you enjoy doing, but bear in mind that some sports and activities require a sensible level of health and safety precautions. Avoid activities that involves the possibility of head injuries, or serious injury because of a loss of consciousness. Activities where there is no bodily contact with the ground, or in water, are best to be avoided.

Here are some tips on how to exercise safely when you live with epilepsy:

- Seek medical clearance from your doctor first
- Avoid triggers of seizures such as stress, fatigue, and anxiety
- Take medications and stay well hydrated
- Ensure exercise is stopped if you feel faint, dizzy, or nauseous
- Wear a medic alert bracelet (see below) if training alone so that people will be able to know you have epilepsy
- Carry a mobile phone with an emergency number listed (in case of an emergency – ICE), when out exercising alone – for example, biking, running, or walking. Let people know where you are going.

J.Manage your seizure triggers:

A seizure trigger is an event or situation that can lower your seizure threshold and make a person more vulnerable to seizures. If you learn which things or situations may trigger your seizures then you can learn to manage your epilepsy. Common seizure triggers are:

- Missed medication
- Medication change
- Tiredness or sleep deprivation

- Caffeine/alcohol/drugs
- Stress (physical/mental/emotional)
- Illness and high temperature
- Missed meals/diet change
- Sensory stimulation, e.g. taste, smell, vision
- Menstrual periods in women (especially flashing lights)
- Atmospheric conditions
- Hormonal changes
- Feeling too hot/cold
- Being bored/thinking too hard
- Sleep apnoea
- Having a headache/migraine
- Hyperventilation
- Individual triggers

Fact Sheet 35

Epilepsy and Behaviour in Children

Some children find living with epilepsy challenging and may show their unhappiness in a number of ways such as becoming irritable or angry, or by becoming disruptive. All behaviour is a form of communication and as adults our first step in understanding any challenging behaviour is to fully understand what epilepsy is and how children can be impacted by seizures and medications. Also, some children may have another comorbidity or syndrome that needs consideration. Our role is to support children in their journey with epilepsy and its impacts.

What is epilepsy?

Epilepsy is a complex neurological condition characterised by seizures. Seizures happen when the neurons misfire, causing periods of unusual behaviour, sensations, and sometimes loss of awareness. Seizures can happen either in part of the brain (focal seizures) or in the whole brain (generalised seizures). There are at least 40 different seizure types and people can have more than one type of seizure. A seizure is often seen as an episodic event but in fact seizures affect people in a number of additional ways that can endure for life. See ewct.org.nz/living-challenges-epilepsy/ for more information.

Some seizures are well identified because of what they physically look like, such as with tonic clonic, tonic, atonic, or myoclonic seizures (ewct.org.nz/epilepsy-types/). Other seizures are subtle in appearance and are not as easily identified.

All seizures can cause changes in behaviour, personality, or mood before (pre-ictal), during (ictal), and after a seizure (post-ictal). These changes may include inattentiveness, hyperactivity, irritability, or verbal or physical aggression. During this period, certain triggers may further irritate a child and thus increase their frustration or aggression. Understanding a child's seizure type (or types) and how it (or they) presents helps adults to recognise uncharacteristic behaviour in a child and how to offer support around a seizure and its aftermath.

Sometimes it is possible to witness a mood and behaviour change in a child hours or days before a seizure happens. This is called a prodrome period.

Many children have seizures in the temporal lobes and they may experience strange sensations which are often hard to describe. The sensations may include deja vue, hallucinations, vertigo, smell and taste changes, sweating, ringing sounds, and out-of-body sensations. Such seizure events and associated sensations can be quite frightening and a child may become upset, especially if they recognise that another seizure event is imminent.

Temporal lobe epilepsy can also present with automatic behaviour (automatisms) and with decreased awareness. Children may look to be swallowing, picking at their clothes, screaming, laughing, or crying for no known reason, undressing, or losing bladder and/or bowel control. They will slowly become aware of their surroundings and be unaware of their seizure.

Many children are diagnosed with a syndrome which affects behaviour. A syndrome is a group of signs or symptoms that share common features (ewct.org.nz/children-and-epilepsy/). Understanding a child's syndrome helps provide support for the child.

Epilepsy and other disorders

There is a link between epilepsy and other disorders such as in autism, attention deficit hyperactivity disorder (ADHD), cerebral palsy (CP), and Down Syndrome. These comorbidities can affect behaviour in a child with epilepsy.

a) **Epilepsy and autism:** Epilepsy is found to be more common in children with autism, and autism is more prevalent in children who have epilepsy. The link between the brain abnormalities that are associated with autism spectrum disorder (ASD) may also contribute to seizures occurring and affect mood. Some medications used to stop seizures may bring about severe behavioural deterioration and cause a child to feel hyperactive and irritable.

b) **Epilepsy and ADHD:** Research has shown that the symptoms of ADHD sometimes start before the first seizure and, despite good seizure control, children still struggle with ADHD.

ADHD negatively affects children's behaviour even more than the seizures.

c) **Cerebral palsy:** Epilepsy occurs in up to 50% of children with CP. Behavioural problems are common in children with CP, and even more so when epilepsy is present. Difficulty with communication seems to be a significant factor in understanding and mitigating challenging behaviors.

d) **Down Syndrome:** Seizures occur in about 5-10% of children with Down Syndrome. Challenging behaviour is a common occurrence.

Epilepsy, anxiety and depression

A good number of children living with epilepsy will experience depression or anxiety, and some of these children may have suicidal thoughts. Mood disorder symptoms may look different in children. Many will have low self-esteem and negative thinking but some will show irritability and disruptive behaviour, poor school performance, and changes in sleep patterns or appetite. Parents and teachers need to be aware of mood changes in children, especially if seizures worsen, or after a medication change.

Some behavioural issues may mask anxiety and depression (ewct.org.nz/epilepsy-and-mood-disorders/).

Anti-seizure medications

Epilepsy is largely controlled (but not cured) by the use of anti-seizure medications. Around 70% of people become seizure-free, or will have reduced numbers of seizures. For most people there are few or no side effects. Parents and carers, however, are able to notice sudden and negative changes in their child's behaviour or mood when an anti-seizure medication is introduced or increased. Some medications are known to be associated with behavioural changes for some people.

The side effects of medications may be minor or severe, short-lasting and reversible, or long lasting and potentially irreversible.

Medication side effects could cause dizziness, clumsiness, nausea, headaches, becoming fatigued or tired, and low mood. Other side effects affect the different systems of the body and are checked by regular blood tests.

Social and emotional challenges

There are many challenges affecting children living with epilepsy apart from those mentioned above. Seizures are unpredictable and can cause anxiety for a child who may already fear losing control of the body during a seizure. This embarrassment may lead to social isolation and to poor self-esteem, anxiety, depression, or suicide.

Some children experience unpleasant symptoms, including strange sensations (noted above), around their epilepsy and consequently become fearful or distressed especially if they are unable to talk about those 'strange' feelings.

Medical appointments and procedures such as blood tests, EEGs, etc interrupt normal life and can be tiring and potentially frightening.

Children will communicate their distress by becoming angry, irritable, or having tantrums etc, but many children will adjust to having epilepsy over time with the right support.

Any concerns about a child's behaviour need to be discussed with a paediatrician. In some cases, further help from a mental health professional specialising in children or adolescents may be needed.

Behaviour and cognition

Children with epilepsy (CWE) have a wide range of learning abilities but many will experience problems with cognition, memory, learning processes, concentration, or behaviour. It is suggested that at least 25% of CWE will function in the learning-disabled range as a result of the underlying cause of epilepsy and their seizures and/or medications. Consequently, many CWE, especially boys, are at risk generally of underachievement and make less progress than would be expected for their age and intelligence level. CWE have very high rates of behavioural and learning difficulties which often go unrecognised.

It is suggested that up to 70% of children with epilepsy have subclinical discharges which do not show up as seizures. These discharges impact behaviour.

Epileptic seizures affect cognitive processes in many ways and can cause long-term learning difficulties for children in the school system.

a) Children may find it difficult to concentrate on the task at hand. They will be unable to block out distractions and finish work on time.

b) Children will be unable to store and retrieve new information. Following instructions is difficult.

c) They will find it difficult to process information quickly.

d) Children often fail to develop friendships because of their inability to modify their behaviour and behave appropriately.

The many frustrations and failures faced by CWE in the classroom can lead to behavioural issues which are associated with epilepsy. It is important therefore that there is awareness around behavioural challenges and epilepsy so that effective and appropriate management techniques and support can be given to children.

Further information

Further information about epilepsy and its management is summarised in EWCT's book entitled "Understanding and managing epilepsy: an introductory guide". It is available from your EWCT epilepsy advisor or it can be purchased via the EWCT website: ewct.org.nz/product/understanding-and-managing-epilepsy-an-introductory-guide/

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Fact Sheet 36

Travelling overseas by air travel when you have epilepsy

Having epilepsy does not necessarily mean that you cannot enjoy the adventures of air travel. With planning and thought it is possible to meet your epilepsy needs and enjoy what travel has to offer. If you can travel with a friend who understands your epilepsy it makes that adventure even better.

Here are some tips to help you along the way.

1. Wear **personal identification** to alert people that you have epilepsy.

   Not all seizures are epileptic. First aid responders will look for the reason for your seizure and treat you accordingly.

2. Carry **additional information** about your epilepsy in your wallet or purse. You could print the information on a small card and laminate it for safe keeping.

   Your card could look like this, for example:

EPILEPSY

My name is……………

My emergency contact person is……

I am staying at…….

I am from Aotearoa New Zealand

My seizure (s) looks like this: (Briefly name and describe them)

My medications are: (Name them and state how often you take them)

3. Do your own research and **contact the New Zealand embassy** in the country you are about to travel. Ask:

   a) Can I take in my current medications into the country?
   b) How much can I take in?
   c) What paperwork is required by customs?
   d) Can I carry them on as hand luggage?
   e) Do I need any special vaccinations to enter the country (or evidence of vaccinations including for covid)?

Other reliable sources of information are:
- Safe Travel: www.safetravel.govt.nz
- Ministry of Foreign Affairs: www.mfat.govt.nz/en/countries-and-regions/europe/united-kingdom/new-zealand-high-commission/safetravel/
- International society of travel medicine: www.istm.org
- Medsafe: www.medsafe.govt.nz
- Fit for Travel UK: www.fitfortravel.nhs.uk
- World Wide Health clinics: worldwise.co.nz

4. **Have a check-up with you GP to see if you are fit to travel**. You may have to provide a letter from your GP to the airline and insurance companies stating that you are okay to fly.

   a) Ask your GP to write a letter stating the list of all your medications and your medical condition (s). Carry this letter, and your medications in the original packaging, in your carry-on bag. You may have to present this to customs when you arrive at your new destination. Once you are settled you may then use your pill container for your medications to help you to remember when to take them.

   b) Ask your GP for a prescription for all your medications just in case you lose them or need a repeat. You would need to present this prescription to a local GP for the replacement.

   Google the names of your medications as they will be called something different where you are travelling.

   Keep your medications safe and cool.

   c) Check that your vaccinations are up-to-date and discuss which vaccinations you may need to have before travelling overseas. It is advisable to have them several months before you go so that your body can develop immunity.
   https://www.healthnavigator.org.nz/medicines/v/vaccines-international-travel/
   https://worldwise.co.nz/travel-vaccinations-nz-vaccination-planner/

   Check if your need anti-malaria medications where you are travelling. Some anti-malaria medications cause seizures in people with epilepsy. Get proper advice from your GP or pharmacist.

5. **Travelling through different time zones** can affect when you take your medications. Take your medications regularly in normal New Zealand time (if you live here) and gradually adjust to any time differences when you are travelling overseas. The World Clock on your smartphone can help you to keep track of any time difference. Set an alarm to remind you when to take your medications.

   Your GP or pharmacist could possibly advise you on how to manage time zone adjustments.

Forgetting to take medications when you are travelling could lead you to having seizures. Be aware that travelling through different time zones can also make you suffer from jet lag. Jet lag is a temporary sleep disorder. It occurs when the body's internal clock is out of sync with cues from a new time zone.

6. Contact your pharmacist and discuss what to do if you should have a bout of **diarrhoea and/or vomiting** after you have taken your anti-seizure medications whilst travelling.

   The UK guidelines are as follows but do double-check with your pharmacist if these apply to you.

   a) if you are sick within one hour of taking medication, take another dose; or
   b) if you are sick more than one hour after taking medication wait until your next dose is due before taking it.

7. **Carry a basic first aid kit:**

   For more information on first aid kits for travellers visit:
   https://www.familydoctor.co.nz/categories/travel-health/first-aid-kit-for-travellers/

   Your GP can also order any kits from Worldwise Travel and prescribe them to you.
   https://worldwise.co.nz/travel-health/medical-kits/

8. Manage your seizure triggers when travelling.

   a) **Missed medications.** Set an alarm to remind you when to take them.

   b) **Tiredness and sleep deprivation.** Time your air travel so you arrive at your destination in the afternoon or evening, when it's closer to bedtime, to make the transition easier. You might even want to consider a stop-over if the flight to your final destination is a lengthy one. If you like travelling with Air New Zealand you may wish to book their Skycouch: www.airnewzealand.com/skycouch

   Discuss with your GP ways to manage sleep disruption and jet lag. You may wish to organize more sleep and rest breaks whilst you recover. Block out light when you are catching up on sleep with an eye mask.

   c) **Stress:**
   - Identify if there is a problem. You may wish to have a travel checklist to work through so that you don't become overwhelmed.
     www.scti.co.nz/travel-advice/ultimate-travel-packing-checklist
   - Seek help from others. You may wish to use a travel agent to arrange your flight, transport and accommodation. Flying with a travel companion is helpful especially if

you have frequent seizures.

- Try a **breathing technique** if you start to feel stressed.
- Don't over-do things. Set aside time to **relax**.

d) **Alcohol:** Drinking alcohol when flying can make you more dehydrated because of the diuretic effects of alcohol and the very dry air in the aircraft. Being dehydrated can cause seizures. Drinking alcohol can also disrupt sleep patterns which can then make you forget to take your medications. Alcohol is known to make your anti-seizure medications less effective when you take them both together.

Keep hydrated by drinking water.

9. **Carry travel insurance;** it is the peace of mind that you need whilst travelling. If you have epilepsy some insurance companies will charge you more because epilepsy is classed as a 'pre-existing medical condition'. To make sure that an insurance policy meets your needs, insurance companies will usually pass you on to their medical department. Be honest and accurate because a non-disclosure of your epilepsy may invalidate your insurance policy.

10. **Notify the airline that you have epilepsy** so that the cabin crew are aware that you may need help if you have a seizure. If you are travelling alone, you may even wish to tell the person sitting next to you that you have epilepsy

11. Let security know, when you go through customs, if you have a **vagal nerve stimulator** (VNS). Show security evidence that you have a VNS with a letter from your specialist. Airport security should not affect the VNS.

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

Fact Sheet 37

Epilepsy and men

Population studies have revealed that slightly more men than women have epilepsy. This may be because of a higher rate of cerebrovascular disease (such as strokes), head trauma incidents, or alcohol and drug related issues, for example. Men with epilepsy also have a higher rate of anxiety and depression than men who do not have the condition. However, there is hope in men finding the right level of support within their communities. It involves asking for help, understanding what epilepsy is, and how medications work. It is important to appreciate that epilepsy is a medical condition that for many people can largely be controlled.

Those with epilepsy experience it in different ways. For men living with epilepsy, there are certain common experiences and concerns that become apparent. Having honest conversations with others can help to change the perspective of what it is like living with epilepsy and help to provide solutions for what may appear to be an insoluble, and sometimes, an embarrassing problem. It is time to open up!

Let's talk frankly.

1. What is epilepsy? Why do I have it?

Epilepsy is a common neurological condition that affects at least 1% of the population. It can be developed at any age regardless of who you are. Many times we understand the reason why a person develops epilepsy such as having had a stroke, brain injury, bleeding in the brain, substance abuse etc but many times we do not know why it happens.

To have epilepsy, a person must experience seizures that happen suddenly and without warning at any time and with no known reason.

Some seizures are called focal and affect part of the brain. You can either be aware of them happening such as with deja vue, or you can experience something like a smell or taste change for example. Sometimes your awareness can become impaired. At other times seizures affect the whole brain and are called generalised seizures. The most common seizure that most people recognise as being epilepsy is the tonic clonic seizure.

For more information on epilepsy types see: https://ewct.org.nz/epilepsy-types/

2. Talk to me about medications. Why should I take them?

Most people respond well to anti-seizure medications and that is always going to be the first treatment option given to a person diagnosed with epilepsy. Medications are prescribed by a neurologist once there is an epilepsy diagnosis, and there will be a discussion around how to take them safely and effectively. A pharmacist can then discuss medications further, especially if you have concerns around being able to drink alcohol or take recreational drugs.

It is strongly recommended that you take your medications routinely to avoid having prolonged seizures or being seriously harmed. The consequence of being non-compliant and having seizure difficulties usually involves emergency hospital treatment.

For more information on epilepsy medication please see our fact sheet: https://ewct.org.nz/epilepsy-medication/

3. **Can I drink alcohol?**

You need to have that discussion with your neurologist and/or pharmacist as they understand the anti-seizure medications that you have been prescribed and they will make recommendations for you. But, generally speaking, alcohol can make epilepsy medication less effective or make the side effects of the medications worse. Excessive binge drinking is likely to increase the risks of seizures and lead to other health problems.

What about taking recreational drugs?

The effects of recreational drugs may directly affect the brain or seizures themselves, or they may interact with anti-seizure medications. The effects will vary for different drugs and from one person to the next. If drug taking is combined with alcohol use, it greatly increases the chances of seizures happening.

Drinking and taking drugs is a lifestyle choice. If you need support about this issue then do have a chat with your GP or counsellor.

4. **Will epilepsy affect my sex life?**

Not necessarily. Many men with epilepsy have normal sex lives but there can be problems which are worth discussing.

Men with epilepsy can experience a lower sex drive (libido), decreased sexual function, and higher rates of erectile failure compared to men without epilepsy. These differences may be because of testosterone levels being below the normal control range. Testosterone is a male hormone.

Libido can also be affected if there is general anxiety or depression present. The way you see yourself, especially if you have a low self-esteem or low confidence, may also impact on your sex drive.

Some men's sex drive may be affected by the fear of having a seizure during sex, or knowing that a seizure is triggered by hyperventilation or physical exertion. Having sex is unlikely to trigger seizures and most men with epilepsy do not have seizures during sex. However, the physical and emotional impact of seizures may affect interest in engaging in it.

Some areas of the brain such as the temporal lobes may also interrupt sexual function. A man may find it difficult to get and keep an erection.

Apart from having a conversation with a neurologist or GP to discuss sexual concerns, it is also important to have that conversation with your partner. Men are often a bit reluctant to discuss sexual matters but, if you are in a sexual relationship, your partner may be frustrated by your lack of interest. It really is best to be honest and open here about how you are feeling.

5. Will anti-seizure medications affect my sex life?

Many men's sex lives are not affected by taking their medications but, if you feel that yours is, then it is time for a chat with your neurologist or GP. Simply switching medications may improve your sex life. In some cases, you may wish to seek the specialised help from an endocrinologist whose job it is to sort out the complex interactions between hormones, seizures and anti-seizure medications.

Some medications list sexual problems as a possible side effect whilst other medications list a reduction in testosterone.

6. Will epilepsy affect my fertility?

Having epilepsy may not make you as fertile as men who live without the condition The sperm produced often has abnormalities in structure and function, thereby making it more difficult to father a child.

Some medications can reduce the amount of sperm produced or affect the quality of it. In some cases, medications may have lowered testosterone levels (noted above in (4)), which makes you less fertile.

If you believe that you have fertility issues, please talk to your neurologist or GP.

7. Will my children develop epilepsy?

There is a slightly higher risk of your children developing epilepsy than the general population. If both you and your partner have epilepsy then that risk increases more.

8. Epilepsy is affecting my mental health. Why?

There are a number of reasons why your mood may be affected.

a) There is a relationship between epilepsy and mood disorders and it is not uncommon for person to have both. In fact, the likelihood of having a mood disorder is between around 25 and 50% higher than that of the general population when you have epilepsy.

   With regard to having anxiety, there is a bidirectional relationship between anxiety and epilepsy. People with anxiety are at a greater risk of developing epilepsy and people with epilepsy are more likely to develop anxiety. It is really important, therefore, that you discuss your anxiety and/or depression with your GP or neurologist so that a treatment option can be discussed. Your treatment options may include medications and/or psychotherapy and relaxation therapies. If you continue to struggle without professional support then your mental health will impact on your seizures; they may increase despite you taking anti-seizure medications especially if you are newly diagnosed with epilepsy.

   Keep talking to your GP or neurologist about how you are feeling, particularly if you are having thoughts about suicide or about death generally.

   Keep a simple seizure diary to keep track of your seizures and mood.

b) Your anti-seizure medications could be affecting your mood. Most people are able to

9. I have really low self-esteem

Having epilepsy should not affect the way you see yourself since the condition does not define you as a person. Your character does that. Seeking support from a social group where you can meet others to discuss issues can be helpful. Through friendly chats you will discover the many common themes that affect men living with epilepsy. Such engagement may offer possible solutions to your problem. You can then work on the things that can be changed in life and accept those that can’t.

How you feel about yourself could potentially damage family and friend relationships, cause you to become socially isolated, and contribute to problems with your general wellbeing and overall quality of life. There is help at hand, however. Seek support if there are issues around your medical condition. Improvements can usually be made around seizure control, medications, and issues associated with having epilepsy. A clinical psychologist or a counsellor, who use cognitive behavioural therapy (CBT), will challenge the way you see yourself and provide you with life skills.

Your EWCT epilepsy advisor is connected to your community and will help with other aspects of your life such as with transport and employment.

10. Having epilepsy is causing me stress

Living with a condition that is episodic can be unsettling and some people find this stressful.

The fear of living in ‘amber alert’ waiting on edge for a seizure to happen only increases the chances of seizures happening. Stress is a well-known seizure trigger.

We all have ways for managing stress. Please see the “Wellness” Fact Sheet on our website.

11. I don’t sleep well

Having good, regular sleep is helpful for your general wellbeing. It helps your body to heal itself, for the brain to forge new connections, and sleep helps with memory retention. Poor sleep, on the other hand, can affect your overall health and make you prone to medical conditions such as obesity, heart problems, heart disease, high blood pressure and diabetes

People living with epilepsy can experience poor sleep. This poor sleep can make seizures more likely to happen during the day. For others, they may experience sleep seizures which are linked to the different stages of sleep. Keep a sleep-seizure diary to record what is happening in your life and discuss any concerns that you have with your GP, or neurologist. Be aware that sleep may be affected by the anti-seizure medications that you are taking and this is also worth mentioning. Please see the “Wellness” Fact Sheet on EWCT’s website.

12. I have lost my driver’s licence

Anyone having had a seizure regardless of the cause will lose their driver’s licence for a period of time. This is an NZTA ruling.

Driving requires a complex array of neurological functions and skills that involve vision, thinking, attention and judgement, co-ordination, reaction time, and motor control. Any of these can be impaired by epilepsy and seizures. People who drive vehicles may present safety concerns for themselves, their passengers and the public.

For more information see our fact sheet: https://ewct.org.nz/driving-and-epilepsy/

13. My job is at risk

Having epilepsy can be seen as a barrier to employment. However, many people living with the condition can participate in a variety of jobs because their epilepsy does not affect their ability to work. A person with epilepsy has rights and obligations as set out under the Employment Relations Act 2000 and the Health and Safety Act 2015. Employers also have an obligation to accommodate the needs of disabled employees and provide a safe environment in the workplace under the Commonwealth Disability Discrimination Act 1995 (Disability Act).

Seek the support of your EWCT epilepsy advisor who will advocate on your behalf.

Further information

Further information about epilepsy and its management is summarised in EWCT's book entitled "Understanding and managing epilepsy: an introductory guide". It is available from your EWCT epilepsy advisor or it can be purchased via the EWCT website.