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Fact Sheet 1

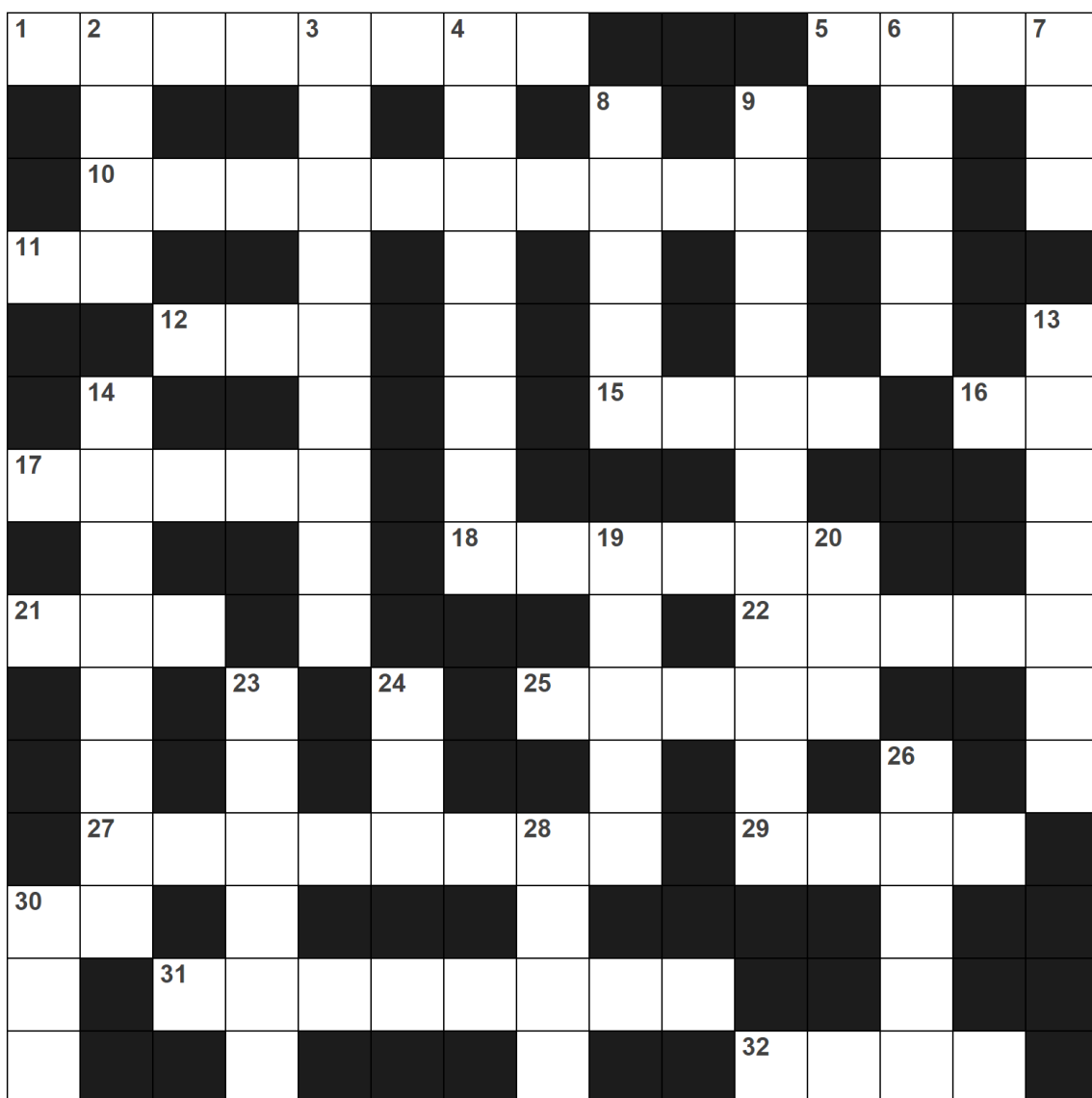
What is epilepsy?

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.

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

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 recurring 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 déjà 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



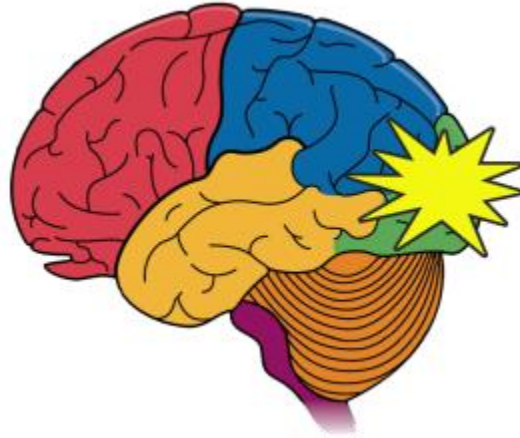
Occipital Lobes

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

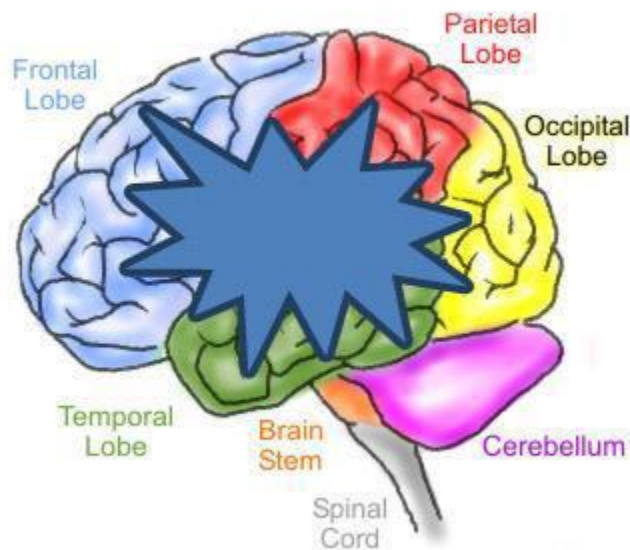
Be prepared for a generalised seizure



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

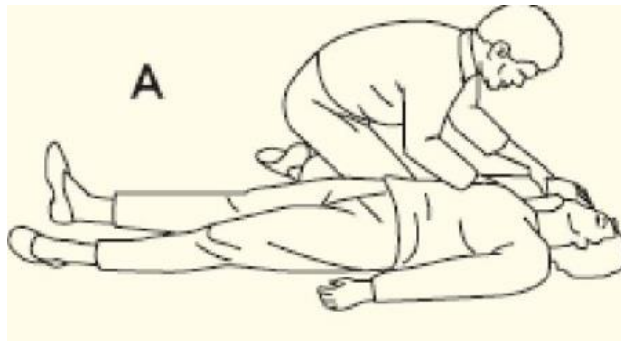
The person is pregnant or has diabetes

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 .

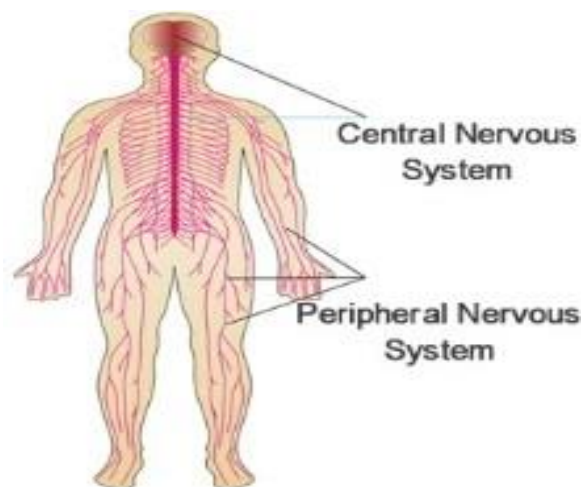
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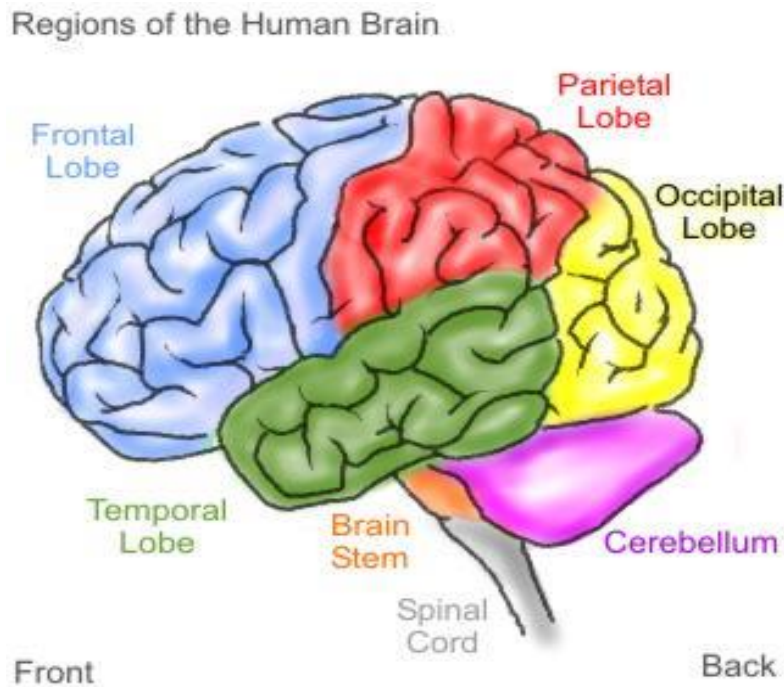
Fact Sheet 3

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

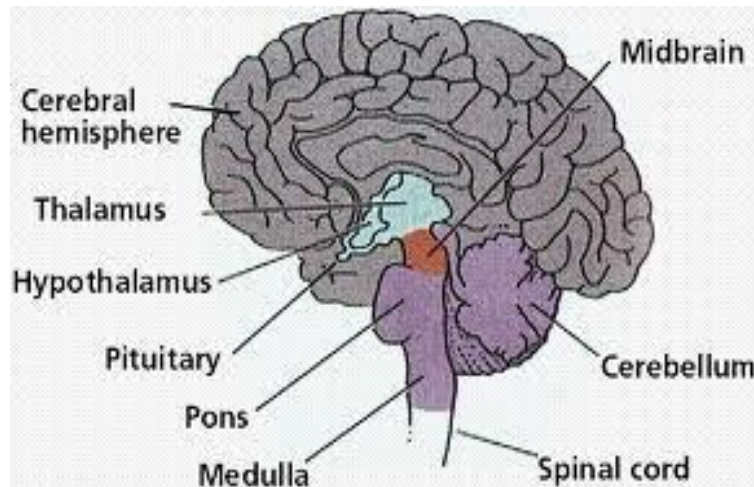
Temporal lobe: regulates memory, hearing, language/ learning and speech comprehension.

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

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

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.

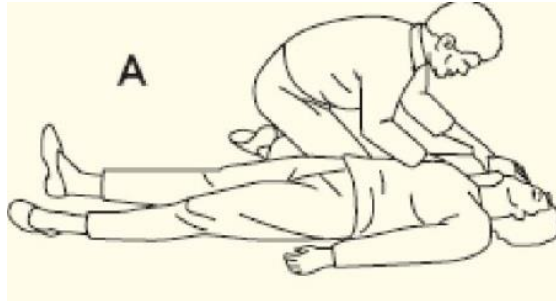
What to do if a seizure occurs whilst a person is in a wheelchair

- 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 airway 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 his/her development and intellect are usually normal). Some types are more serious and are associated with other problems. If your child has a syndrome you can receive more information from this website.
<http://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.
- Anti-epilepsy drugs (AEDs) are commonly used for the treatment of epilepsy and most children’s seizures are controlled with their use. All medication needs to be taken regularly every day, and compliance in taking them is essential in maintaining seizure control. Status epilepticus (or non-stop seizures) is a serious medical emergency. Phone 111 for help.
- All AEDs can cause unwanted side effects and an epilepsy specialist will work to alleviate them where possible (see “Epilepsy Medication” fact sheet). Report all side effects to your specialist. It is important that your child remains on his/her medication at all times unless directed otherwise by your epilepsy specialist.
- Establish with the epilepsy specialist a comprehensive care plan for your child.



- For those children with refractory epilepsy, the ketogenic diet (which is high fat, adequate protein, low carbohydrate) has been used to treat seizures, and is often seen as a last resort. 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.
- 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 to help establish seizure control for your child.
- 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).
- Ask for information, help and support from your EWCT epilepsy advisor
- Help your child to enjoy his/her life.





My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



My name is.....

I have epilepsy. Please contact.....

Phone.....



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!

Only call an ambulance (111) if, after my seizure
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PLEASE STAY CALM!

My name is.....

I have epilepsy. Please contact.....

Phone.....

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.....

.....

.....

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 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.

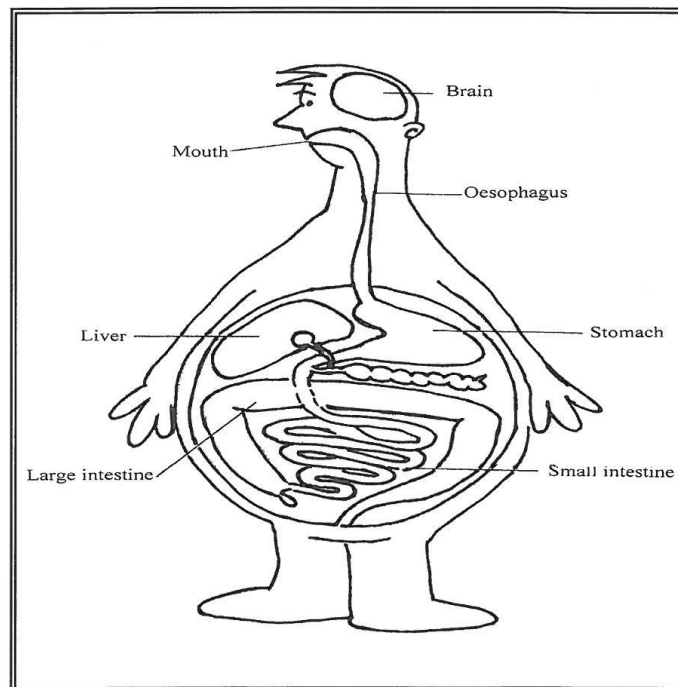
- Consult your neurologist before taking herbal medicines, homeopathic substances or supplements (e.g. ginko biloba, St John's wort, and evening primrose oil) as these may interfere with your AED and affect seizure control.
- Vomiting, diarrhea, and dehydration may increase seizure activity because of 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, Moline, Logem)
 - Levetiracetam (Keppra)
 - Phenobarbitone, Primidone
 - 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

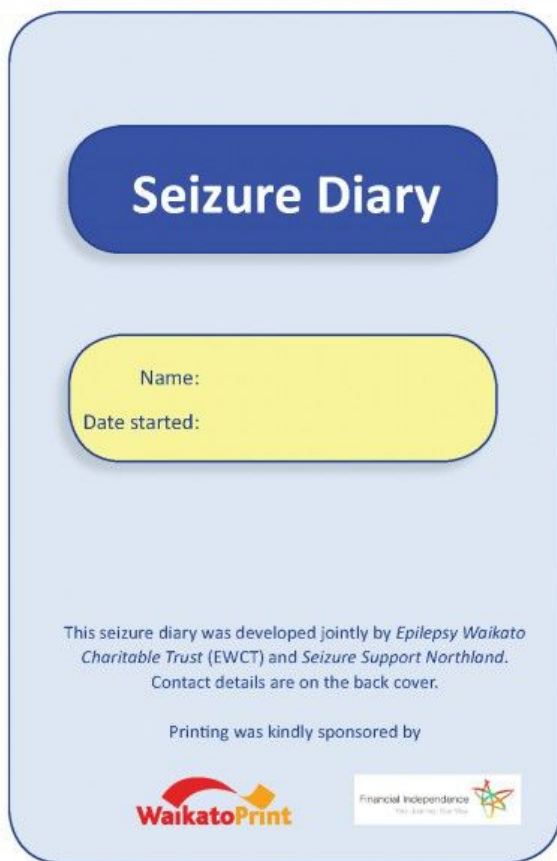
Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

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.



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

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:

<http://www.nzta.govt.nz/resources/factsheets/17/epilepsy-and-driving.html>

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

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.

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

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 put in 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?

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

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

from the Epilepsy Waikato Charitable Trust

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 instead of 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 a 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.

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

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



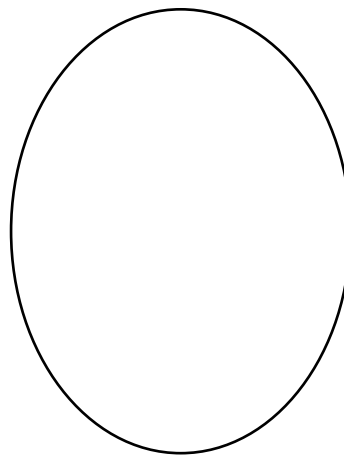
Holly



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:



Fact Sheet 16

Epilepsy and Depression

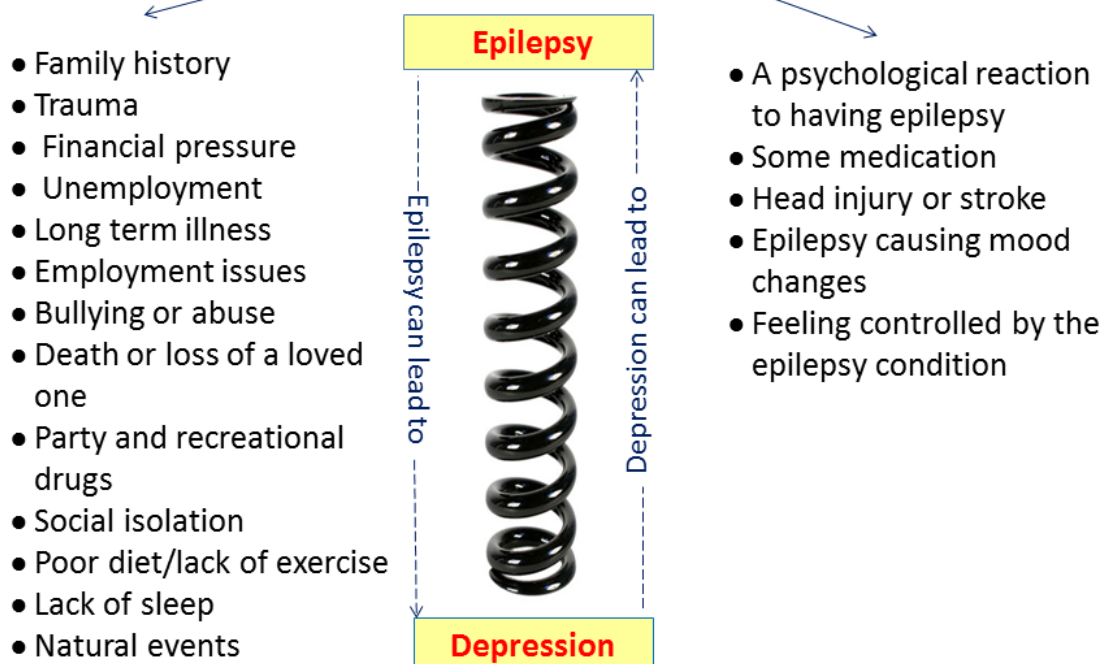
Depression can occur as part of a person's epilepsy. Some people may feel a sense of hopelessness hours, or even days, *before* a seizure (pre-ictal). This feeling usually resolves after the seizure.

Others may experience sadness, fear, anxiety, and a sense of hopelessness or suicidal thoughts, *during* a simple partial seizure. This is called ictal depression.

Low mood/depressive symptoms *following* an epileptic seizure are described as post-ictal depression. People can become tearful, experience a sense of hopelessness, become irritable and have sleep problems or even suicidal thoughts. These feelings commonly last 12 to 24 hours after a seizure.

People with epilepsy can also feel depressed because of stress factors affecting the quality of their life.

Some stress factors that can affect people with epilepsy



If a symptom of low mood or sadness persists for several weeks, then a visit to a qualified health professional (such as a GP or neurologist) is important. It may be that the depressive mood is the result of an anti-epileptic medication that a person is taking, or it may be the result of one or more of the factors listed above. Self-diagnosis is never recommended. For more information on depression, it is important for a person with epilepsy to seek medical advice for effective treatment for both the depression and epilepsy, because untreated depression can potentially worsen epileptic seizures.

Mood barometer



- It is okay to feel unhappy and sad some of the time

Seek help if you:

- Feel unhappy most of the time
- Lose interest in life
- Can't cope with things
- Feel restless, agitated or irritable
- Have problems with weight
- Have lost self confidence
- Can't get to sleep easily
- Avoid people
- Have difficulties with concentration
- Have decreased energy
- Have changes in appetite
- Have negative thoughts about self
- Have thoughts of suicide

**If in doubt, seek medical advice.
Depression can be treated.**

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

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”.

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

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 déjà vu?
- 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.

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

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 for you 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 your 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.

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

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

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.

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

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 what to do if someone is having a convulsive seizure 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

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

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>

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 safe¹. 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 precautions¹. 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 prohibited¹. 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

¹These 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.



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.

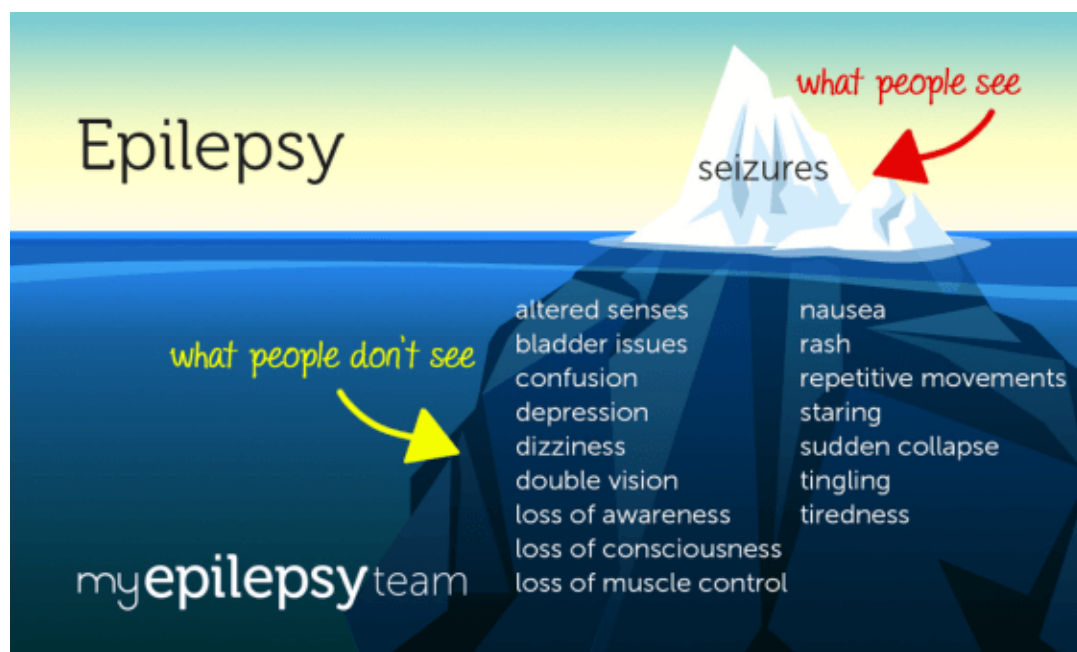
Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.

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)

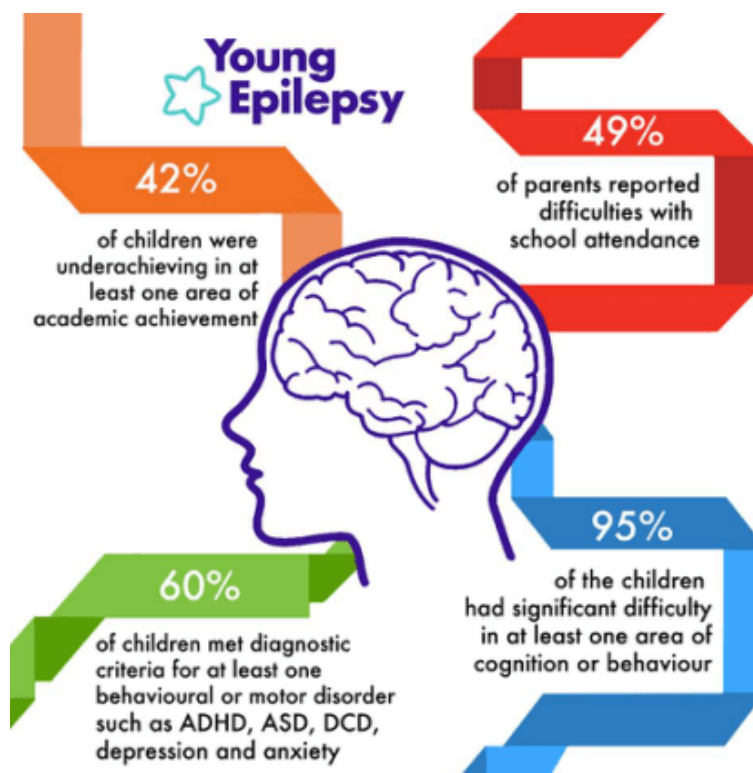
4. Between 58-70 % of people have good seizure control, mainly through using medications or by some other means (such as vagal nerve stimulation, diet, brain surgery, which all have potential side effects), but the remaining 42–30 % of people have absolutely none whatsoever. This means that a good section 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 valproate, 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>

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

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 repack 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.

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

Fact Sheet 25

Epilepsy and the elderly

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 elderly 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 elderly

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 elderly 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 elderly.
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 fibrillation 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 elderly 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 elderly people comprise a large but somewhat neglected group when it comes to care, support and advice.

Medication as a treatment plan

Many elderly people with epilepsy often have other medical disorders (co-morbidities), which are treated with medications. These medications have the potential to interact with anti-epileptileptic (AEDs) 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. AEDs, 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 AEDs 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 elderly 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 been 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.

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

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

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.

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

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.

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

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 body, 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.