

# Epilepsy, your life and your safety

There are some issues around your epilepsy and choices that you need to be aware of so you can safely manage your epilepsy and make the best decisions.



Information for young people



## Words of support to you from other teenagers with epilepsy

When things seem hard, there's always someone who's got your back so smile because I believe that you can get through it.

*Charlotte, 15*

Be Happy.

*Shaida, 15*

Trust and listen to your doctors and keep doing what you did before you had epilepsy.

*Cara, 17*

If people put you down, ignore it! They are not your friends. Stay with people you can trust as these are your true friends.

*Alex, 14*

Stay Positive, don't panic you will get through it.

*Saphron, 12*

Believe in yourself.

*Victoria, 14*

Bad times won't last forever.

*Surina, 19*

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## Enjoying yourself and keeping safe when you are out and about

It's important that you go out, see your friends and enjoy your life. The following safety tips are issues you need to consider, although this is good advice for anyone, whether or not they have epilepsy.

When you are outside the home:

- Plan ahead so that, if you did have a seizure, you and the people around you would know what to do. Keep in touch with your family during the evening by text. Your family will worry and this way they may feel more relaxed about you going out.
- We advise that you wear medical identification jewellery such as a bracelet or a necklace in case you have a seizure outside your home. There are various brands available including Medicalert® – details are on their website at [www.medicalert.org.uk](http://www.medicalert.org.uk)
- You can also carry an identification card, which we will give you in clinic – please ask if we have not given you one already. The identification card includes details of medication you take, how long your seizures normally last and who to contact in an emergency.
- Make sure you and your friends look after each other, ensure all your close friends know about your epilepsy.
- If you are alone, make sure you stay on roads that are well lit and that are relatively busy. This will keep you safe and also make people



aware if you do suddenly have a seizure. Walk with someone else or a group of friends, particularly if you are going to parties.

- Try not to travel with people that you don't know well or trust as they may not know that you have epilepsy. Only travel in licensed minicabs – never accept a lift from someone you don't know. When you ring to order a cab, ask what make and colour of car is coming to pick you up and the driver's name. When the taxi arrives, before you get into it, make sure you confirm the driver's name.
- Avoid taking shortcuts through alleyways and parks for personal safety and for the public to help and call emergency service if you did have a seizure.
- When taking the bus on your own, sit near the driver so you are not isolated at the back of the bus in case you have a seizure.
- Avoid situations that are stressful for you if you can – being stressed can trigger seizures and you may rely more on alcohol to get over your nerves, which also increases the risk of seizures.
- When in pubs/clubs/house parties:
  - Don't leave your drink unattended (alcohol or non-alcoholic) – ask a trusted friend to guard your glass if necessary. If your drink has been left unattended, do not drink it. Sometimes, people can put drugs in drinks (spike them).
  - Be cautious about mixing alcohol

and your AEDs as previously mentioned.

- Nightclub strobe lights have a flash rate restricted to a maximum of four flashes a second. Most people with epilepsy are not affected but some people may still find this flash rate triggers a seizure. If these lights trigger a seizure, it may be best to avoid night clubs. If you feel funny look down and cover one eye, tell a friend and leave the area.
- Never leave with someone that you don't know. Most people seem nice when you first meet them, but you don't know if they can be trusted until you know them better. Always leave the party with the same friends.

- Never feel ashamed about setting sexual (or other) limits for yourself. Do not perform or let anyone perform any sexual act towards you that makes you feel uncomfortable or exceeds your personal limit.
- If you use internet chat rooms (such as Facebook®, Snapchat®, and Twitter® or Instagram®) use a nickname, and never give your real name or address.
  - If you receive an indecent image or naked selfie from anyone, do not respond or reply with one of you – we recommend you report it.
  - Remember anything you post online is outside your control and can be spread without your permission. Information posted online stays available for ever – you may be embarrassed about it later on in life.



# Sports and hobbies

We want you to live a happy and healthy life – staying active will always be the best medicine for health and wellbeing. Staying active may involve taking part in sports or hobbies or other activities you enjoy. Teenagers with epilepsy can take part in most sports – seizures during exercise are very rare. There are, however, a small number of people who find strenuous exercise triggers a seizure – if this is the case with you, talk to us about other things you can do instead. If your seizures are well controlled, there is little reason to avoid taking part in low or moderate risk activities.

We tend to group sports and activities according to how risky they may be if you have epilepsy. Remember, this is not a definitive list and to an extent, the level of risk will vary from person to person and also where the activity takes place. Some schools or leisure centres may be stricter than others. Governing bodies for these sports may also have safety requirements that have to be followed.

Please talk to us about what sports and activities you want to do so we can work out if there's a way you can take part safely – be aware though that the high risk activities may best be avoided altogether.

## Activities during which if you had a seizure you are unlikely to injure yourself

- Aerobics
- Bowling
- Dancing
- Golf
- Gymnastics \*\*
- Hiking
- Jogging
- Rounders
- Tennis
- Track and field athletics
- Walking
- Yoga\*

\*Although if over-breathing triggers a seizure, take extra caution

\*\* Gymnastics such as floor routines are low risk and relatively safe

## Activities during which if you have a seizure, injury might occur

- Basketball
- Canoeing\* \*\*
- Cycling\*
- Football
- Gymnastics using equipment \*\*\*\*
- Hockey
- Horse riding\*
- Ice hockey
- Ice hockey\*
- Ice or roller skating\*

- Skateboarding\*
- Skiing\*
- Snowboarding\*
- Swimming\*\*\*

\* Usual protective headgear should be worn for these activities

\*\* With a partner or supervision

\*\*\* In a pool with a lifeguard

\*\*\*\* Climbing robes, high bar, vaults, rings and uneven parallel bars are a much higher risk and will require appropriate measures and direct supervision. A safety harness maybe used to allow you to participate.

### **Activities during which if a seizure occurs, may result in serious injury which in some cases may be life threatening**

- Bungee jumping
- Free climbing without ropes
- Hang gliding
- Martial arts and boxing
- Parachuting
- Scuba diving
- Swimming in open seas, rivers and lakes

**Remember: All sports have a governing body that sets safety regulations – you will need to follow these too.**

## **How you can take part and reduce risk**

Whichever sports or activities you want to do, think beforehand about your safety and how any risks can be minimised through supervision or protective clothing.

- Assess your individual risk and avoid your seizure triggers wherever possible: talk to your parents, consultant and CNS about this
- Wear appropriate safety gear and follow all safety precautions
- If you tend to have seizures at a particular time of day, schedule your sport or activity session outside these times
- Have a ‘buddy’ with you whatever the sport or activity
- Tell your friends, teachers, supervisors or coaches that you have epilepsy and what to do if you have a seizure
- If you have an aura (pre-seizure warning), leave the game or activity immediately, call your buddy and do not get back up until the seizure is over
- Wear protective headgear and padded clothing if there is a risk of injury if you have a seizure
- If you are not feeling well or just ‘not right’ sit it out – it’s not worth taking the risk

- Make sure you drink plenty of fluids
- Get a good night's sleep before the sport or activity
- Do not overdo things – know your limits and take a break when you need

## Safety in and around water

We advise avoiding swimming and other water-based activities if your seizures are not well controlled so you are having frequent seizures. If your seizures are under control, you should still follow a few common sense rules:

- Tell the supervisor or life guard that you have epilepsy. They are trained to keep people safe in the water and will know what to do to help you
- Confirm that they know what to do if you have a seizure – see next section for details
- Only take part in supervised activities – do not swim in the sea, rivers or lakes
- If you do not feel well, do not take part
- Stay within your depth: waist to shoulder deep water

## Dealing with a seizure in or around water

Even if a person recovers fully from a seizure in or around water, they should still have medical attention in case they have taken in any water.

### Tonic-clonic seizures

- From behind, tilt the person's head so it is out of the water
- Move the person to shallow water, keeping their head out of the water
- Do not restrain the person or put anything in their mouth
- Once the jerky movements have stopped, get them out of the water as soon as possible
- Lay the person on their side on the floor or pontoon and put something under their head

Anyone who has a seizure in water will require medical attention as they may have inhaled water

### Absence seizures

- From behind, tilt the person's head so it out of the water
- Support them in this position until they come round
- Get them out of the water as soon as possible
- Stay with them until they recover – they may be confused and need to rest
- Call an ambulance



# Contraception

Some antiepileptic drugs (AEDs) can make the contraceptive pill and morning-after pills work less effectively, which could lead to an unplanned pregnancy. When you become sexually active, arrange an appointment with your family doctor (GP) or local family planning clinic to choose the appropriate contraceptive method.

The following types of contraception are not affected by epilepsy, or epilepsy medicines:

- Barrier methods, such as diaphragms, caps and condoms.
- Depot® injections of progesterone
- Intrauterine devices (IUD) (coil)

As well as reducing the risk of an unplanned pregnancy, barrier methods also protect you against developing a sexually transmitted infection (STI), so we always advise using a barrier method as well as other methods of contraception.

Most women with epilepsy have healthy pregnancies and healthy babies. However, there is a small risk that having epilepsy, or taking certain epilepsy medicines, could affect the health of your unborn baby. This is why we encourage you to seek advice before pregnancy. If you do become pregnant, seek advice from your doctor as soon as possible. Folic acid 5mg daily is recommended for all girls who could become pregnant to help protect against a problem in the unborn child.

# Cigarettes, alcohol and drugs

We do not advise anyone to smoke – cigarettes contain many toxins, which are harmful to you and people around you. If you are smoking during a seizure you may burn yourself. It can be also very dangerous if you have a seizure while smoking on a sofa or bed. A cigarette discarded during a seizure can start a fire.

Drinking more alcohol than you should (getting drunk) may stop your AEDs from working effectively and can seriously increase the risk of a seizure.

We recommend that you should not drink any more than two units of alcohol per day. As a rough guide, a standard 175ml glass of wine contains 2.1 units and a pint of lager, beer or cider is 2.5 units. For more information on units of alcohol, visit [www.nhs.uk/Livewell/alcohol/Pages/alcohol-units.aspx](http://www.nhs.uk/Livewell/alcohol/Pages/alcohol-units.aspx). Skipping medication in order to binge drink is very dangerous and increases the risk of having seizures.



## SUDEP

Street drugs such as cocaine, ecstasy, heroin, cannabis and legal highs are all thought to increase the likelihood of having a seizure, as well as increasing the risk of mental and physical health problems. This information is the same for people without epilepsy; however the risks are higher with epilepsy. For more information about drug use, visit the Talk to Frank website at [www.talktofrank.com](http://www.talktofrank.com)

Excess alcohol and street drugs are also dangerous as you may lose consciousness and if you then have a seizure too this could be life threatening.

We all face risks in life from crossing the road to driving on the motorway. For example, you are two and half times more likely to die in a car accident than from having epilepsy. However, young people with epilepsy have a higher rate of accidents and injuries than other people. The risk of accidents in general and death are slightly increased due to accidents like drowning or prolonged seizure activity. There is a known risk to people with epilepsy called SUDEP, which stands for Sudden Unexpected Death in Epilepsy. SUDEP is the risk of dying unexpectedly. This is very rare. Taking epilepsy medication regularly may help to reduce the risk. If you are concerned about this please discuss it with your neurologist or find information on the Epilepsy Action website at [www.epilepsy.org.uk](http://www.epilepsy.org.uk)



# Confidentiality

We strongly encourage you to discuss anything that worries you with a healthcare professional. We will keep these discussions private on a 'need to know' basis and these will not be discussed with other people without your consent unless we think that you, or someone else, could be at risk. If you are under 16 years old and we are concerned about the situation, we will talk with you to encourage sharing this information with a responsible adult.

You can book an appointment with a clinical nurse specialist via the telephone, after school or college if you want to discuss any of these issues again or you can bring them up when you are next in clinic. At any age, please be aware that should there be any illegal or risky behaviour that could put you or other people in danger, we are obliged to inform other departments and services.



# Managing your epilepsy in school or college

Managing your epilepsy at school or college can be challenging. It can be difficult due to poor seizure control, medication side effects or unwanted attention from other people. Many teenagers feel that their seizures have affected their education but there are things you can do to make life more manageable. Teenagers like you have told us that the following things can help:

- Be open about your epilepsy – tell teachers and close friends that you have epilepsy and explain what it means to you
- Make sure they understand what to do if you have a seizure
- If you feel tired following a seizure, ask the teacher to be excused from class until you feel better
- School work and exams can be adjusted to take account of your epilepsy – perhaps by having more time to complete the exam or longer for handing in course work

Anything that makes one person stand out or be different in some way can lead to bullying – not just epilepsy, but wearing glasses or having spots for instance. In many cases, unwanted attention or bullying comes from lack of understanding.

Explaining your epilepsy and the impact it has on your life will help people understand.

The majority of people will be very worried and concerned about you – if they do not show any concern they are probably not worth bothering with in the first place!

**It is not right for you to feel or experience any of the following:**

- Hitting
- kicking
- teasing
- name calling
- telling nasty stories about you
- sending nasty notes or text messages to you
- stealing or hiding your belongings
- being ignored

**Other people should not make you feel:**

- lonely
- isolated
- worthless
- helpless
- anxious about seeing certain people
- depressed
- suicidal
- angry
- uncomfortable

If you are feeling bullied or left out, talk to an adult you trust – this could be your parents, an older brother or sister or your teacher. They will be able to help you understand why it is happening and come up with strategies for dealing with it. There are lots of organisations who can help if you are feeling bullied – a few are listed below so why not get in touch with them to see what support they offer.

- [www.childline.org.uk](http://www.childline.org.uk)
- [www.kidscape.org.uk](http://www.kidscape.org.uk)
- [www.bullying.co.uk](http://www.bullying.co.uk)

# How can my friends help?

It can help to involve your friends so they can tell you about what they see happening to you when you have a seizure and for them to keep you safe.

- Tell your friends you have epilepsy and that you may have seizures
- Tell your friends and people around you what to do if you have a seizure and who to contact if you need help
- Inform your friends if there is anything about your seizures that might put you at risk of accident or injury
- Suggest that your friends have training in first aid, see [www.redcrossfirstaidtraining.co.uk/What-we-do/First-aid-for-the-public.aspx](http://www.redcrossfirstaidtraining.co.uk/What-we-do/First-aid-for-the-public.aspx) for details

When you need emergency medication, it would be good for your friends to know how to give the emergency medication to help you if they are comfortable with this. You could give your friends a copy of our information sheet on buccal midazolam so they know what to do. It is available online at [www.gosh.nhs.uk/medical-information/medicines-information/buccal-ormucosal-midazolam](http://www.gosh.nhs.uk/medical-information/medicines-information/buccal-ormucosal-midazolam)

We advise that a paramedic is always called if a friend has to manage a seizure.





## Feeling positive

Many teenagers with epilepsy have times when they feel very down especially if epilepsy has affected day to day life. Having epilepsy can affect how confident you feel about yourself and can be associated with worries and anxiety. Getting support from your friends and family can help. If you still feel low, ask for referral for support from a psychologist. There are also support groups in the UK.

Try to focus on the positive things in your life. There are lots of teenagers and adults with epilepsy who take part fully in everything that they want to do.

# Goals to help you take responsibility for your medical treatment

## Below are some goals to help you with independence

- 1** Remembering to always take your medicines as prescribed (never stop or make changes without talking to your doctor).
- 2** Wear identity jewellery and carry some form of epilepsy awareness card.
- 3** Always carry Buccal Midazolam around with you. (Emergency treatment is important for your safety).
- 4** Take control over your own hygiene needs. This involves taking showers and avoiding baths (this is case you have a seizure).
- 5** Make sure that are you able to tell people how they can help you when you have a seizure.
- 6** Organise your medications in a drug wallet that has different containers for each day of the week.
- 7** Keep your seizure diary up to date. (Paper Diary & App).
- 8** Write down any questions for health care professionals before your clinic visits.
- 9** Learn what medications you are on and the doses you are prescribed. (Keep a copy of your prescription if this helps you remember or keep a photo of the box/bottle label on your phone).
- 10** Ensure you have a good supply of your epilepsy medicines and start ordering your own repeat prescriptions form the GP and Pharmacy.
- 11** Avoid situations which may trigger your seizures. Common triggers include forgetting to take epilepsy medicines, lack of sleep stress and too much alcohol.
- 12** Make your own medical appointments including GP and Neurologist.

# Transition support worker in London

These goals will help you get on with living an independent adult life. To enable this you need to start thinking about some of the above points in advance, otherwise it maybe too much to do all at the last minute. We will discuss the information given in this leaflet with you in clinic appointments. We will choose two goals every six months for you to aim to achieve to prepare you best for the transition

As your epilepsy can change over time, you may need to reassess your situation at a later date. By the end of transition, with the help of these goals, we would aim that you are able to manage your healthcare needs regarding epilepsy independently.

Young Epilepsy has a transition support worker called Janine Palm. She provides support and guidance in achieving life goals to young people with epilepsy aged between 14 and 25 years old across London.

She helps provide support in the following:

- CV writing
- Jobs/employment
- Housing
- Benefits
- Volunteering
- Education
- Meeting new people
- Health

For more information, call Janine on 07825 188 829 or email [jpalm@youngepilepsy.org.uk](mailto:jpalm@youngepilepsy.org.uk) or ask us about this in clinic.





# Notes

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## Looking for information online

Be aware that not everything you read on the internet is medically correct and it is not a supplement for seeking medical advice. However, some support sites may be able to give you ideas of what to discuss with your healthcare professional. For further information on searching the internet safely, please ask for a copy of our Finding reliable medical information on the internet information sheet. This information sheet is also available on our website at [www.gosh.nhs.uk/medical-information/general-health-advice](http://www.gosh.nhs.uk/medical-information/general-health-advice)



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