Epilepsy

Teenage Transition 3

Welcome

This is the third of 3 booklets designed to help you be ready for adult epilepsy (neurology) clinics. You will also be invited to special teenage (transition) clinics. This will help you understand more about epilepsy, how epilepsy might affect you, and how to manage your epilepsy.

Contents

1 Moving to adult clinics

The move to the adult epilepsy clinic usually takes place around your 16th birthday. This is when the hospital usually considers you an adult. Your parents can't make treatment choices for you anymore but they can help you make decisions.

Your consultant will refer you by letter to the adult team.

The children's epilepsy nurse will invite you to a 'transition clinic' where you will meet one of the adult epilepsy nurses. You, your parent(s)/carer and the children's epilepsy nurse will tell the adult nurse all about you and your epilepsy.

What type of seizures do you have?

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From now on clinic and appointment letters will be addressed to you.

When you are 16, you can order your own medication from the GP or pharmacy. You will need to do this at least 7 days before you run out of it.

How do you order your epilepsy medication?

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If your epilepsy is well controlled, your epilepsy care may be moved to the GP. If you have a phone appointment, the nurse, consultant or GP should ring you instead of your parent(s)/carer.

2

College and work

Information about your epilepsy should be passed on from school to college so that they are aware and can plan how best to support you. Your parent(s)/carer or children's epilepsy nurse can help to write a plan that tells people what your seizures look like and how to support you in a seizure. College/work have to make sure you get extra support so that your epilepsy doesn't put you at a disadvantage, but having epilepsy may mean that its more difficult for you to do some jobs.

Speak to your teachers, career adviser or epilepsy nurse about what course or job you'd like to do.

What are you going doing when you leave school?

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The **Equality Act 2010** is there to ensure fairness in the workplace and education so they can make reasonable adjustments to support you.

If you have ever had a diagnosis of epilepsy, you might still be able to join the armed forces or the police.

3 Reducing your risk of SUDEP

SUDEP stands for Sudden Unexpected Death in Epilepsy (**www.sudep.org**)

SUDEP Action SUDEP.ORG

The risk is rare in children – approximately 1 in every 4,500 – but the risk increases when you get older. This is partly because of lifestyle choices and because you are more independent, so won’t have as many people around you.

You can reduce your risk of SUDEP by taking control of your epilepsy and staying healthy.

Keep a seizure diary

Keep a diary of your seizures so you can tell your nurse or GP if your seizures are getting worse. You can download an app to help keep track of seizures.

For more information about how your risk score was created, tap each green segment above.

How do you keep a record of your seizures?

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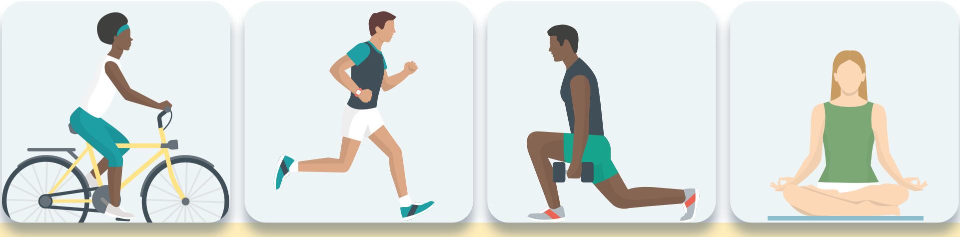
Look after yourself

Like other health conditions, it helps to look after yourself. If you keep yourself fit, healthy and sleep well, your risk of seizures decreases.



How do you stay healthy?

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Read your drug leaflet

All medication comes with a drug leaflet. This will tell you things like what to do if you forget a dose or take too much, what other drugs might affect your epilepsy medication and side effects.

Medication is worked out in milligrams (mg). So, if you need to take 100mg and you're given 25mg tablets, you'd need 4 x 25mg tablets to make up 100mg. The label stuck on your medication will have the instruction on how much you should be taking.

What's your medication called and how much do you take?

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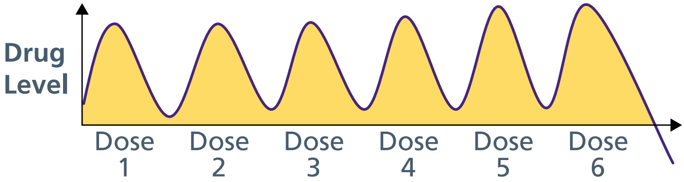
Take your daily medication at the right time

Medication levels in your body rise when you take your meds and lower in between doses. If you miss a dose, the medication level in your body can get too low and cause you to have a seizure.



When do you take your medication and how to do you remember to take it?

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What to do if you run out of your medication

Order your medication 1-2 weeks before you run out of it. Sometimes the pharmacy can have difficulty getting hold of epilepsy medication, so you need to give them plenty of notice that you need some more.

It's important that you don't miss a dose as this can make your seizures worse.

If you do run out, call your GP or your epilepsy team to ask for an emergency supply. If you can't do this, go to your usual pharmacy and ask if they can give you an emergency supply.

If you can't go to the pharmacy, ring 111 to see if they can get you an emergency supply.

How do you order your medication?

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Alcohol and recreational drugs

Alcohol in small amounts may not trigger seizures, but most people are at risk of seizures if they drink a lot. The risk is still there for up to 48 hours after you stop drinking alcohol.

Drinking alcohol can cause poor sleep. Lack of sleep can trigger seizures.

Vomiting can lower the level of epilepsy medication in your body and cause seizures.

If you’re having a night out remember to take your medication before you go, and set an alarm to wake you in the morning so you can take it at the right time – even if you go back to sleep again.

Taking drugs like cannabis, ecstasy and cocaine can make seizures worse.

Do you drink alcohol or take recreational drugs?

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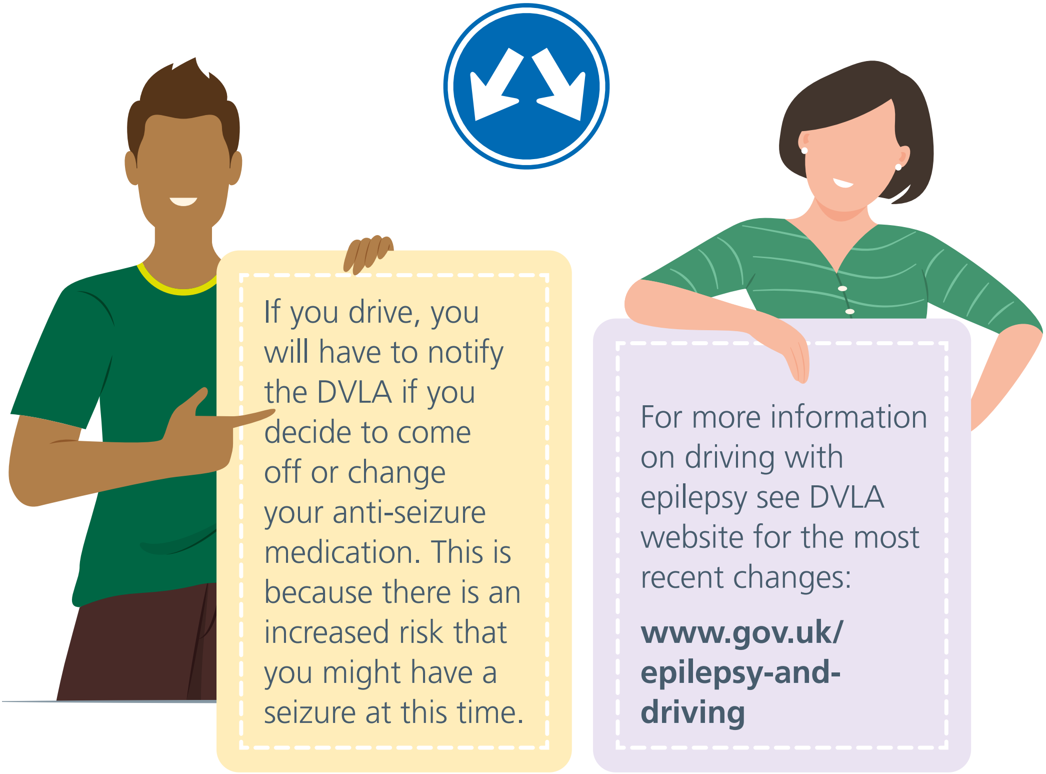
5 Driving

You might be able to learn to drive if you have epilepsy, though there are strict rules

You need to inform the DVLA when you apply for a provisional licence that you have a diagnosis of epilepsy. The DVLA will contact your epilepsy doctor to confirm this and to get more information.

There are stricter restrictions if your seizures are during the day: you will need to be seizure free for a year on medication if you have seizures during the day which alter your awareness.

You may have to re-apply for your licence every 1,2,3 or 5 years.



If you drive, you will have to notify the DVLA if you decide to come off or change your anti-seizure medication. This is because there is an increased risk that you might have a seizure at this time.

For more information on driving with epilepsy see DVLA website for the most recent changes:

www.gov.uk/epilepsy-and-driving

We are Young Epilepsy

Epilepsy can be frightening, and it can feel lonely. Sometimes people just don't understand what you are dealing with.

Young people living with epilepsy have told us how important it is for them to understand their condition, and how making connections with other young people, and hearing their experiences, really helps.

From trusted information and real stories about living life with epilepsy, to support services and opportunities to have your say and influence the world around you, we're here for you.

youngepilepsy.org.uk

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy Charitable Trust. Registered Charity number 311877 (England and Wales)

GO PURPLE

GET TALKING ABOUT EPILEPSY

For more information about epilepsy, what it is, and how it is managed can be found on these websites:

www.epilepsy.org.uk

www.youngepilepsy.org.uk

www.youngminds.org.uk

www.howareyoufeeling.org.uk (Hull)

www.TheEpilepsySpace.org.uk (16-25 year olds)

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