



Epilepsy

Teenage Transition 2



Welcome

This is the second 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

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Memory and learning

Seizures and the medication used to control them can affect your memory, learning, and how quickly you can think about things like answers to questions.

Your memory can be improved by:

- following the same routine every day
- keeping things in the same place
- using memory aids like mobile phones, apps, 'post-it' notes and alarm clocks
- putting a note pad by your bed to remind you of the things you need to do.



How do you help your memory?

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Children with epilepsy often miss school because of hospital appointments or because they have had seizures. Your school should give you extra help, so you do not miss out on schoolwork because of your epilepsy.



If you are taking epilepsy medication your school can give you 25% more time in exams.

Frequent seizures can also affect your learning. It is important that you inform your doctor or epilepsy nurse how often you have seizures to make sure your medication is working properly.

A seizure diary or app can help you do this.



2 How stress and anxiety can be linked to epilepsy

Both epilepsy and epilepsy medication can affect your mental health. Low mood and stress is very common in the general population, and is even more common in people with epilepsy.

This might be a side effect of your epilepsy medication – talk to your nurse or doctor if you think that this could be the case.

Other times it might be because you're worrying about how epilepsy might affect your life.

Stress and anxiety can make you feel sad, anxious, worried, tired, frustrated, or angry.



I know I'm stressed when...

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What make you stressed?

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Improving mental health

Making small changes in life can help to improve your mood. Usually it lifts within a few days or a week. If it carries on for longer it might be worth discussing with your friends and family, epilepsy nurse, doctor or school to try and get some help.



**Apps like
Headspace and
Calm have useful
information and
advice to help.**

Tips to reduce stress and anxiety

- Sleep well
- Eat a well-balanced diet
- When you're in a good mood practice relaxation techniques like meditation, deep breathing techniques and grounding. You can then use these when you're stressed and it will help to relax you.
- Exercise – it releases natural happy hormones
- Do something little you enjoy everyday



What makes you happy?

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Planning for the future: college and beyond

Epilepsy can affect your daily life and it can affect what job you do in the future. Plan ahead and discuss with your school, parents and epilepsy nurse what you want to do after school so you can get the best support.

If your seizures are well controlled, you will have more choices.

If you have epilepsy, colleges and universities should provide extra support to make sure you're not at a disadvantage because of your epilepsy.



What job would you like to do in the future?

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On **The Epilepsy Space** website, you can hear about young people's experience of being a student with epilepsy.

Epilepsy is usually considered as a disability. The Equality Act 2010 protects your rights in work and education:

www.gov.uk/rights-disabled-person

Periods, contraception, and sexual health

Periods

Some girls and women find that their seizures can be worse when they have periods. This is because hormone levels rise and fall, and this can cause seizures. Keep a diary of seizures and periods to see if they're linked. Your epilepsy nurse or doctor can make a referral to the gynaecology team for help if you feel that your seizures are worse at certain times of the month.



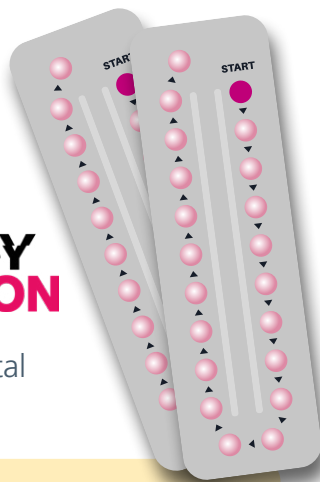
Do your periods affect your seizures?

Contraception

Your epilepsy medication could affect how well some types of contraception pills work. Let your epilepsy doctor or nurse know if you take a contraception pill.

The Epilepsy Action website has a list of epilepsy medications and how they affect each other. Your GP, local family planning clinic, epilepsy nurse/doctor, or hospital gynaecology team will be able to offer advice on this.

**EPILEPSY
ACTION**



Do you take a contraception pill?

If you're a girl, we don't often use sodium valproate (Epilem) once you get older because there is a risk to your unborn child if you get pregnant.

Sexual health



For most women who have epilepsy they can have a normal healthy sex life.

Problems with sex are more common in men who have epilepsy.

Some epilepsy medications can reduce the levels of testosterone in your body and affect your interest or ability to have sex.

In both men and women sex is unlikely to trigger a seizure.

Pregnancy

It can be difficult to know what to do if you have epilepsy and want to have a baby now or in the future. Most people with epilepsy can have normal, healthy pregnancies if they take the right precautions.

It is really important to talk about pregnancy with your epilepsy doctor or nurse before you become pregnant. This is called preconception counselling and it helps to keep you and your baby safe. Some epilepsy medicines can harm babies, and having lots of seizures during pregnancy can harm you and your baby as well. Your doctor or nurse can help you find the right medicines to take to keep pregnancy safe.

When you become pregnant you should speak to your epilepsy doctor or nurse again to make sure everything is in place for you to have a safe and healthy pregnancy. It is very important to keep taking your epilepsy medicines, as having more seizures can harm you and your baby. Only make changes to your medicines if your doctor tells you to. You should also start taking folic acid, which helps your baby to develop a normal healthy body.

www.epilepsy.org.uk/living/starting-a-family/pregnancy-birth-and-epilepsy

All medication comes with a drug leaflet that tells you more about things like side effects.





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)





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)



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