Ashford and St. Peter's Hospitals
NHS Foundation Trust

Epilepsy Transition

Paediatric to Adult Services

Patient Information

Transition

Transition is the process of preparing young people to move from the children to the adult service. This normally starts around the age of 12-14 years. It will continue from this point until you move to adult services when you are about 18 years old. The epilepsy nurse will help support you after you move to adult services for a few years more.

This service helps prepare you at your own pace. You will spend time alone with your epilepsy team to get used to becoming independent. Your parents will have a lot of helpful advice on how they have been helping, for example by making appointments / getting your medicine.

Why do I need to move?

You may find that as you get older there are certain aspects that the adult team may be more used to dealing with the questions you have.

There may be questions you may want to ask.

- Finding out more about your epilepsy
- Questions about your medications
- How to get support for exams?
- Can I drive?
- About sex, alcohol and drugs?
- What job can I do?
- Who will look after my epilepsy care?
- How do I keep myself healthy?

There may be other questions you may have which we would be happy to discuss with you. This is about you and how we can help support you.

Role of the GP

You may find that your GP becomes more involved in your care. It may be helpful to book annual reviews with them as a way of them getting to know about you and your epilepsy.

Taking medications / Prescriptions

It is important to take your medicines as set out by your epilepsy team.

It would help you to know what to do if you miss a dose of your medication or are sick.

Whilst in full-time education you receive free prescriptions up to 18 years. Beyond this and with a diagnosis of epilepsy you will need to fill out a FP92A form at your GP. You will receive a medical exemption card which means you do not pay the cost of your prescription. This needs to be renewed every 5 years.

Monitors / Medic Alert / ICE (In case of Emergency) or Health App

If you have nighttime seizures it would be beneficial to have a monitor to alert others, should you have a seizure. There are also many other monitors available.

Further information can be found at:
https://www.epilepsy.org.uk/living/safety-equipment/alarms-and-monitors

If you wish you could wear a medic alert bracelet.
Further information on this can be found at:
https://www.medicalert.org.uk/

Update your health app / ICE on your mobile with details of your condition, medication and emergency contacts

SUDEP (Sudden Unexplained Death in Epilepsy)

This is a rare phenomenon. Around 1 in 1000 people each year die from SUDEP.

Anyone having seizures could be at risk of dying prematurely because of them. The frequency and severity of someone's seizures may be a sign they are more at risk. However, SUDEP also occurs in people who have infrequent seizures too.

Try to avoid triggers that may make you have seizures such as drinking alcohol, getting extremely tired or not taking your medicines.

Keep a diary of your seizure activity and get in touch with your epilepsy team if you have concerns about your seizures happening more frequently or your seizures appear different. From 18 years old you can download an app called EpSMon https://sudep.org/epilepsy-safety/ which may help you with keeping a record of what is happening.

Other information on keeping a seizure diary can be found on: https://www.epilepsy.org.uk/living/keeping-a-seizure-diary

If you have epilepsy and especially if you have overnight seizures or live alone it is recommended to have a monitor.

If you want to find out more on SUDEP this can be found at https://sudep.org/

Water Safety

It is important to shower rather than bathing, and to keep the door unlocked. If swimming, do so with someone else, and inform the lifeguards. It is not recommended for people with epilepsy to scuba dive. Other water sports can be carried out with suitable buoyancy aids.

Home Safety

Take care when using equipment in the house such as the kettle, hobs, hair straighteners. There are safety devices available if required.

Further information can be found at:
https://www.epilepsy.org.uk/living/safety

Sports / Activities

It is important to keep healthy, to exercise and to eat a varied diet which includes fruit and vegetables.

Should you ride a bike, wear a helmet to protect you from head injury if you were to fall.

Ensure you use recognised crossings when crossing the road.

It is not recommended to climb unharnessed above your shoulder height. Activities where you are harnessed are fine to do.

Before carrying out any activity, if you are feeling under the weather then on that occasion it may be best to take extra caution and if necessary, not participate.

Vitamin D

It is recommended that if you take medicines for epilepsy, you should also take vitamin D. This is to help improve your bone health. Other ways to do so would be to exercise; spend time outside and to eat healthily. Vitamin D can be bought from a chemist or supermarket.

Exams

Sometimes your epilepsy may make it harder for you to learn. You can request your school to do an assessment and if they feel you need support during exams, you may be entitled to extra time or breaks.

Holidays

If you are travelling abroad, it is important to make sure you have more than enough medications to last you for your trip. If you are flying these can be split between your hand luggage. You should take out medical insurance. You can take copies of previous clinic letters and your care plan if you have these.

If flying, check with your airline before you go to find out if they have any special requirements. Some require you to have a letter outlining the medications you will be travelling with. Should you fly long haul you may need to change the times of taking your medicines before you go, if this is the case speak to your epilepsy team who will be able to help.

Driving

The DVLA state that you must be seizure free for 12 months before driving. If you have a license, then have a breakthrough seizure you have a legal obligation to stop driving and let the DVLA know. If you continue to drive, you will be breaking the law; you could cause injury to others as well as yourself if you then have a seizure whilst driving.

Should you be weaning off medications, the DVLA states that you cannot drive whilst weaning off your medications plus 6 months after this.

If you only have night-time seizures, there are slightly different rules, you can speak to your epilepsy team. Further information on driving rules can be found at:
https://www.epilepsy.org.uk/living/driving

Alcohol / Drugs

Alcohol and drugs can make epilepsy medications work less well. Not just at the time of consumption but for several days afterwards. Everyone is different and it is difficult to say what would be safe, so don't drink too much.

Further information can be found at:
https://www.epilepsy.org.uk/living/information-on-alcohol-and-epilepsy

Moving away from home

As you get older you may start thinking about moving away from home, this may be to go to university or for a job. If you do, it would be important to register with a new local GP to ensure that

your epilepsy care is transferred, and you can continue to get your medications. You can find a GP by entering your postcode on the following webpage, you will get a list of local GPs https://www.nhs.uk/service-search/find-a-GP

Planning a family / Sex

When you are older you may wish to have a family. It is important to plan pregnancies. If you are sexually active, it is important to use contraception. Speak to your GP about this. Further information can be found at https://www.epilepsy.org.uk/living/sex-and-contraception

If you have concerns about the possible effects of your epilepsy medicine on causing birth defects on the unborn baby; issues with your sex life or fertility concerns. Speak to your GP or epilepsy team. There are ways to help you. It is important not to stop taking your medication if you have concerns.

DLA / PIP / other benefits

If your seizures affect your day-to-day living, you may be entitled to benefits either Disability Living Allowance (DLA) or from 16 years, Personal Independence Payments (PIP). Further information on this can be found on https://www.gov.uk/disability-living-allowance-children and https://www.gov.uk/pip

If you are going to university or college, you may be entitled to financial and practical support. Further information can be found on: https://www.epilepsy.org.uk/living/education-and-epilepsy/going-to-college-or-university

If you want to find out if you are entitled to benefits you can text 'SUPPORT' to 60002 where you can speak to someone from the citizen's advice bureau about this. This service is supported by the Roald Dahl Marvellous Children's Charity https://www.roalddahlcharity.org/

Mental Health & Well-being

It is important to look after yourself and spend time doing things that you enjoy. If you are feeling worried about things, speak to a responsible adult. There are various online resources that may also help:

- https://www.mindworks-surrey.org/
- https://www.youngepilepsy.org.uk/i-have-epilepsy
- https://www.epilepsy.org.uk/support-groups
- https://www.mindmattersnhs.co.uk/

Support Groups

There are some good epilepsy charities which have a wealth of knowledge they can be found at:

Epilepsy Action	https://www.epilepsy.org.uk/
Epilepsy Society	https://epilepsysociety.org.uk/
Young Epilepsy	https://www.youngepilepsy.org.uk/

Transition Leaflets

https://www.youngepilepsy.org.uk/blog/young-voices-shape-nhs-transition-booklets

Epilepsy Team:

Paediatric Consultants: Dr Hill & Dr Browne

Epilepsy Nurses: Lisa Smith & Natalie Baines

Paediatric Secretary: 01932 722329 - Julia

Paediatric Team email:
asp-tr.paediatric.epilepsy.service@nhs.net

Adult Secretary: 01932 722383 - Chloe

Adult Team email:asp-tr.neurologyqueries@nhs.net

Further Information

We endeavour to provide an excellent service at all times, but should you have any concerns please, in the first instance, raise these with the Matron, Senior Nurse or Manager on duty.
If they cannot resolve your concern, please contact our Patient Experience Team on 01932 723553 or email asp-tr.patient.advice@nhs.net. If you remain concerned, the team can also advise upon how to make a formal complaint.

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We can provide interpreters for a variety of languages, information in larger print or other formats (e.g. audio) - please call us on 01932 723553.

You can use Text Relay to turn telephone communications into text.
Use the Relay UK app on your phone, tablet or PC.
You can also use Relay UK via Minicom or Uniphone.

اگر نیاز به ترجمه دارید، لطفا با شماره 01932 723553 تماس بگیرید.

ਜੇ ਤੁਹਾਨੂੰ ਤਰਜਮੇ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਇਸ ਨੰਬਰ ਤੇ ਫੋਨ ਕਰੋ: 01932 723553

اگرآپ اِس کا اُردو زبان میں ترجمہ چاہتے ہیں، تو براہِ کرم اِس فون نمبر 01932 723553 پر رابطہ کریں

Se precisa de uma tradução por favor contacte: 01932 723553

আপনার অনুবাদের দরকার হলে এখানে যোগাযোগ করুন : 01932 723553

यदि आपको अनुवाद की ज़रूरत है तो कृपया इस नंबर पर फोन करें: 01932 723553

Jeżeli chcemy, aby te informacje w innym języku, proszę zadzwonić 01932 723553

Ashford Hospital
London Road
Ashford, Middlesex
TW15 3AA
Tel: **01784 884488**

St. Peter's Hospital
Guildford Road
Chertsey, Surrey
KT16 0PZ.
Tel: **01932 872000**

Website: **www.ashfordstpeters.nhs.uk**