Ashford and St. Peter's Hospitals
NHS Foundation Trust

Epilepsy Nursing Service
Adult Neurology Department

Patient Information

Epilepsy nurse's role

The Epilepsy nurse can support you with:

- Understanding your epilepsy diagnosis
- Seizure triggers and management of seizures
- First aid in epilepsy
- Documenting seizures - seizure diaries
- Support and advice with daily living after diagnosis - driving, employment, education, safety at home, travel.
- Keeping healthy
- Contraception, pre-conception, and pregnancy advice for women with Epilepsy
- Review of anti-seizure medication - side effects and management, including support with complex drug changes
- Advice re use of emergency medications in cluster and, prolonged seizures, including formulation of guidelines.
- Refer / signpost to other services / agencies as required - e.g., Adult Social Care, dietician, Community Team for People with a Learning Disability, Community Mental Health Services, Epilepsy society / Epilepsy action, Action for carers, telecare.
- Communication with - GP's; neurologists, therapists, and other involved professionals

The Epilepsy Team

The team at Ashford St Peters consists of an epilepsy nurse, a team of neurology consultants, and an administration team.

After your initial diagnosis you will be reviewed either by the epilepsy nurse or your consultant; this may be yearly, six monthly or more frequently and will depend on several factors including seizure control, toleration of epilepsy medication, and if you have any other health conditions.

The Epilepsy team will write to your GP after your appointments to ensure they are up to date with your treatment and management of your epilepsy.

Role of the GP

Your GP will be involved in ongoing prescriptions of your anti-seizure medication alongside monitoring of your epilepsy. They are your first point of contact in relation to your health, and it is helpful to book annual reviews with them so that they can get to know about you and your epilepsy.

Taking Medications / Prescriptions

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

You are entitled to free prescriptions for your epilepsy medications, 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 or live alone it would be beneficial to have a monitor to alert others, should you have a seizure. There are many 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 MedicAlert bracelet. Further information on this can be found at https://www.medicalert.org.uk

You could consider using an app, such as ICE on your mobile this will provide details of your condition, medication, and emergency contacts.
https://www.epilepsy.org.uk/living/safety-equipment/medical-id-products

SUDEP (Sudden Unexplained Death in Epilepsy)

Very rarely seizures can also have effects on the heart of breathing, which is probably the basis of the small risk of sudden unexpected death in epilepsy (SUDEP). The risk overall in the epilepsy population of SUDEP is around 1% over a 10-year period, but for most patients, particularly if their epilepsy is well controlled and/or their attacks are minor, the risk is almost certainly much lower than this, probably no higher than one in several thousand. Frequent convulsions, especially at night in patients who live alone, may carry slightly higher risks in this context. Although the cause of SUDEP is unknown, a clear understanding of your epilepsy and

taking your medication regularly can reduce the risk. For more information about SUDEP, visit https://epilepsysociety.org.uk/living-epilepsy/sudden-unexpected-death-epilepsy-sudep

There are certain things that you can do to help manage your seizures and reduce the risk of SUDEP.

It is important to attend your epilepsy reviews and make sure that you let health professionals know if you notice changes to the frequency, length, or appearance of your seizures. Make sure that you take your medication as prescribed, do not miss doses, and take it at the same time every day. Identify triggers to your seizures; common triggers are, a lack of sleep, intake of alcohol or recreational drugs, having a raised temperature, and missing meals.

You could download an app called EpSMon (https://www.sudep.org/epilepsy-self-monitor) which can help you to keep a record of your seizures and wellbeing.

There are also paper epilepsy diaries available: https://www.epilepsy.org.uk/living/seizure-diary

Water Safety

People with Epilepsy should not bathe alone; showering is advised and the safest option, the bathroom door should be kept unlocked.

Do not swim alone and make sure that the lifeguards are informed that you are epileptic. It is not recommended for people with epilepsy to scuba dive. Other water sports can be carried out with suitable buoyancy aids, but again ensure that you are not alone, and that the instructor is aware that you have epilepsy.

Home Safety

Take care when using equipment in the house such as the kettle, the hob, hair straighteners etc. There are devices available which can help to reduce the risk when using everyday equipment. 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.

When riding a bike, you must wear a helmet to protect you from head injury if you were to fall. Ensure you use recognised crossings when transversing the road.

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

Make sure that you are in good health before carrying out an activity. If you are feeling unwell it may be best to take extra

precautions and if necessary, delay participation until you are better.

Vitamin D

It is recommended that you take a Vitamin D supplement if you take medicines for epilepsy. This will help to maintain 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.

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 and hold luggage.

You should take out medical insurance.

You should 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 advise.

Driving

The DVLA state that you must be seizure free for 12 months before driving.

If you have a license and have a seizure you have a legal obligation to stop driving and let the DVLA know.

If you continue to drive, you would be breaking the law; and you could cause injury to others as well as yourself if you had a seizure whilst driving.

The DVLA states that you cannot drive whilst weaning off epilepsy medications for a further six months.

There are different rules, if you only have nighttime seizures, you can speak to your epilepsy team for further advice.

Further information on driving rules can be found at https://www.epilepsy.org.uk/living/driving

Alcohol / Recreational Drugs

Alcohol and recreational drugs can make epilepsy medications work less well. This is not only at the time of intake but for several days afterwards.

Everyone reacts differently to the ingestion of alcohol and drugs and what would be safe for one, may not be for another.

It is best to not drink to excess and to stay within the government's recommended limits.
https://www.epilepsy.org.uk/living/daily-life/information-on-alcohol-and-epilepsy

Planning a Family / Sex

If you are sexually active, it is important to use contraception. Speak to your GP about this.

Certain epilepsy medications can affect the way some contraceptives work and so you may not be protected from pregnancy.

Hormonal contraceptives may affect the way some epilepsy medications work; this can mean that they are not as effective in controlling your seizures.

Your GP and epilepsy team will be able to provide advice.

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 medicine on pregnancy; birth defects in the unborn baby or issues with your sex life or fertility, please speak to your GP or epilepsy team.

It is very important NOT to stop taking your epilepsy medication until you have spoken to your GP or epilepsy team.

Benefits PIP / Universal Credits

If your seizures affect your day-to-day living, you may be entitled to Personal Independence Payments (PIP) and Universal Credit.

Further information on this can be found on:

- https://www.gov.uk/health-conditions-disability-universal-credit
- https://www.gov.uk/pip

Employment

You are protected under the Equality Act 2010, even if your seizures are controlled or you don't consider yourself to be 'disabled'.

Employers are expected to make reasonable adjustments in the workplace, so that a person with a disability is not put at a disadvantage. For example, this could be time off work for medical appointments.

Employers cannot legally refuse to give you a job just because you have epilepsy. However, they do need to consider your epilepsy, and what the job involves, to ensure your safety and that of other employees.

Often employers and work colleagues feel more comfortable with epilepsy if they understand it and know what to do if you have a seizure at work. See the link below for further advice.

Access to Work is a scheme that supports people who are disabled, who are in a paid job, or about to start a job. If you have particular needs at work, Access to Work may be able to help fund solutions. For example, an Access to Work grant could pay for equipment or extra support at work or help with the cost of getting to and from work if you are not able to drive or use public transport. Contact your Job Centre Plus for details or visit https://www.gov.uk/access-to-work

If you do not drive because of your epilepsy, you can apply for a rail card to get discounted rail fares. You can also apply for a free national bus pass to travel around the UK.

For further information see https://www.epilepsy.org.uk/living/work

Wellbeing

Wellbeing is about feeling good and functioning well.

Looking after your wellbeing when you have seizures can help you to have less seizures and improve how you feel about your seizures.

Eat a well-balanced diet; be active; have a good sleep routine and limit the amount of alcohol you drink will all help.

When you look after your wellbeing your memory can improve, your mood can lift, sleep can improve, and stress can be reduced.

In 2008, the UK government's Foresight Project did some research about wellbeing and from this came.

5 ways to wellbeing for everybody

1. **Connect** - With family, friends, colleagues, and neighbours.

2. **Be active** - Go for a walk or run, step outside, cycle, play a game, garden, dance.

3. **Take notice** - be curious, notice things around you, enjoy the moment.

4. **Keep learning** - Try something new, rediscover an old interest, sign up for that course, learn to play an instrument or how to cook your favourite food, set a challenge you will enjoy achieving.

5. **Give** - do something nice for a friend or a stranger, volunteer, join a community group.

There are various online resources that you may find helpful if you are feeling low, stressed, or anxious. The most important thing is to tell someone how you feel.

https://www.epilepsy.org.uk/support-for-you/talk-and-support-virtual-groups

https://www.mindmattersnhs.co.uk

Support Groups

Epilepsy Action https://www.epilepsy.org.uk

Epilepsy Society https://epilepsysociety.org.uk

What to do if you have a seizure?

Make sure that your friends, family, work colleagues, teammates, know that you have seizures.

Share your Epilepsy plan with those who care and support you,

The plan will include:

- Any emergency medication that you are prescribed and when and how to take this.
- A description of your seizures, what is normal for you; how long a seizure usually lasts and what is likely to happen before and after you have a seizure.
- Advice on how to support you during and after a seizure.
- When to call for an ambulance

If you don't have an Epilepsy plan, please contact your epilepsy team and then will be able to help you.

Epilepsy Team

Dr Kirsten Kamman
Consultant Neurologist specialising in Epilepsy
Email - asp-tr.neurologyqueries@nhs.net

Nicola Ridgway
Specialist Epilepsy Nurse
asp-tr.epilepsy@nhs.net;
Telephone - 01932 723669

Neurology Admin team
asp-tr.neurologyqueries@nhs.net
Telephone - 01932 722383

Further Information

We endeavor 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

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