

# **Epilepsy Nurse-Led Service**

Neurology

# Introduction

This leaflet is aimed at those recently diagnosed as having epilepsy or are new to the Epilepsy Nurse-Led Service. The clinical nurse specialists for epilepsy are part of an NHS team of health care professionals based in the Neurology Department at the Royal Wolverhampton Trust. We cover a large geographical area including Wolverhampton, South Staffordshire, Telford, Shropshire, and part of Powys. We have tried to address the most common questions asked by patients, their families and friends. Further sources of information are listed at the end, together with details of the Nurse Specialist team. Most importantly, if you have any concerns or unanswered questions, please let us know.

## The Nurse Specialist Role:

- To provide information, expert advice, and support around epilepsy, its management and care to adults with epilepsy, their families, carers and other professionals
- To provide expert treatment to adults with epilepsy
- To develop epilepsy services to meet people's needs and improve quality of life
- To support epilepsy research in order to enhance the care of people with epilepsy

# The Royal Wolverhampton Epilepsy Service at a glance

#### First seizure Clinics:

- Fast track evaluation for those whom the possibility of a first epileptic seizure has been raised
- Availability of a Consultant Neurologist or Consultant Nurse for the Epilepsies
- Some patients may be offered EEG and/or an MRI scan at the clinic

#### **Specialized Epilepsy Clinics:**

- Long-term expert treatment of epilepsy
- Support and advice

#### **Transition Clinics:**

 Run in conjunction with Paediatricians for young people in transition from paediatric to adult services, in order to ensure continuity of treatment

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available
- If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111
- Keep the environment clean and tidy
- Let's work together to keep infections out of our hospitals and care homes.

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#### **Antenatal / Pregnancy Clinic:**

• For women of childbearing age with epilepsy who require special advice with regard to contraception, pregnancy, breast feeding and medication adjustments

# **Joint Learning Disability Clinics:**

 Run alongside learning disability psychiatrists to ensure holistic management in a specialist format

#### **Nurse Led Clinics:**

- Currently covering a large geographical area including Wolverhampton, South Staffordshire,
  Telford, Shropshire, and parts of Powys
- Follow up and also new patients to the service with long standing or newly diagnosed epilepsy.

## **Investigations:**

- Standard and sleep deprived EEG
- Genetic testing
- Ambulatory and Video-Ambulatory EEG
- Radiology: MRI brain with Epilepsy Protocol

# Safety Advice

Family, friends and work colleagues need to know how to respond to a seizure. They should be advised of the following simple measures:

Do	Do Not
Try to stay calm, a good way to do this is by timing the seizure	Try to restrain the person
Remove any surrounding objects that are likely to cause injury	Put anything in their mouth
When the seizure has finished put the person into the recovery position	Try to move them unless they are in danger
Be reassuring and explain to the person what has happened	Give them anything to drink until fully recovered

## When to seek emergency help:

- If the seizure lasts more than 5 minutes
- If seizures recur without recovery in between
- If the person is injured
- If the person has possibly hit their head and has not recovered 15 minutes after the convulsion has stopped (but note, some people do sleep following a seizure; a sleeping person responds when gently shaken)
- If the seizure has occurred in water, and it is unclear if any water was inhaled
- If the person stops breathing for longer than 10 seconds after the seizure finishes (it is normal to stop breathing for a few seconds after a tonic-clonic (convulsive) seizure)

There is a potential risk of injury and a small risk of mortality relating to seizures. Please visit https://sudep.org for more information. You'll find you can still do things you enjoy, with some simple measures to reduce risk. The Epilepsy Action Website gives advice on how to stay safe inside and outside the home and do your own safety checks.

# **Our Trust Vision**

'To deliver exceptional care together to improve the health and wellbeing of our communities'.



# Contact Details

The Epilepsy Nurses work Monday to Friday during office hours.

If you wish to contact the Epilepsy Nurses based in Wolverhampton and Cannock you can call our Epilepsy Co-Ordinator on: 01543 576283.

If you wish to contact the Epilepsy Nurses based in Shropshire and Telford, you can call our medical secretaries on: 01952800135 or 01743261105.

Please leave a brief message with your name, contact details, NHS number and a brief message for the nurse. Please do not send text messages to the telephone line as they are not audible. This is not an emergency service. Although we endeavour to reply within 2 working days, it can occasionally take longer for a nurse to respond. In an emergency please seek urgent medical advice from your GP, NHS 111 or 999.

Alternatively, the epilepsy nursing team can be contacted by email at rwh-tr.epilepsy-nursing-team@ nhs.net

The Epilepsy Nurses aim to respond as soon as practicably possible, excluding weekends and Bank holidays.

# **Additional Support**

- Lots of information is available at Epilepsy Action (www.epilepsy.org.uk) and SUDEP Action (www.sudep.org) websites
- The benefits you can claim and how much you might get depends on your individual circumstances
- To find out what benefits you and your family are entitled to, you can contact a specialist service such as your local Citizen Advice Bureau.
- You are entitled to free prescriptions due to your epilepsy diagnosis. To apply for a medical exemption certificate, you need to complete an FP92A form from your GP surgery. This needs to be signed by your GP. The certificate lasts for five years, and then you need to renew it. The certificate means that all medications that you get on prescription will be free of charge, whatever they are for (not just your anti-seizure medication). A medical exemption form is not needed in Scotland, Wales and Northern Ireland, as all prescriptions are free in these countries.

## **Driving / Bus Passes:**

Most people need to be seizure free for 12 months before being legally able to drive (in some circumstance, driving is allowed after 6 months following an isolated seizure). In the meantime, you would be entitled to a free travel pass. In some areas, this only covers buses. In others, local trains and trams are included. You may be able to apply online. Further information is available from www.gov.uk/apply-for-disabled-bus-pass and enter your postcode. Alternative methods depend on where you live.

- Staffordshire Take a copy of your clinic letter, passport, and a recent utility bill to your local Staffordshire County Council run library
- West Midlands Take a copy of your clinic letter to your local bus station
- Powys You can apply online or through your local library or council office
- **Telford** To apply, you will need to either download an online application form or attend your local library to arrange for one to be printed. The form will need to be completed, together with a suitable photograph and your last clinic letter
- Shropshire Take your last clinic letter and a utility bill to Shropshire Local Authority (Shrewsbury) or Shropshire Local Authority (Ludlow) where your photo will be taken, or you can apply online for your first disability bus pass. For this you will need an email address and be able to upload a photo of yourself, along with a photo of required eligibility documents

# **English**

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

#### Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

#### **Polish**

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

# **Punjabi**

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

#### Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

#### **Traditional Chinese**

如果您需要以其他方式了解信息,如易读或其他语种,请告诉我们。 如果您需要口译人员或帮助,请告诉我们。