

Your Local Adult Epilepsy Nursing Service – Reference Guide

Reference Number: ULHT-LFT-3719 v2

Issued: March 2025

Review Date: March 2027

Introduction

The epilepsy nursing service provides a service for people who live in Lincolnshire. Referrals are made either by the consultant neurologist or from an obstetrician for people with epilepsy who are pregnant.

The service is offered Monday to Friday between 9.00am and 5.00pm.

Epilepsy nurses are experienced nurses who have undertaken additional training in epilepsy. Your epilepsy nurse may also have been trained to prescribe epilepsy medication.

Telephone

Secretaries:

Pilgrim Hospital Telephone: 01205 446764

Lincoln County Hospital Telephone: 01522 421742

What your epilepsy nurse can offer you

- ✓ Nurse-led epilepsy service. You may not always have to continue to be seen by a consultant neurologist as your nurse can provide full support.
- ✓ Assessment of your epilepsy and medications including history of your epilepsy.
- ✓ The opportunity to negotiate dates, times and type of appointments to suit your individual needs and the availability of epilepsy nurse clinics.
- ✓ Telephone access in-between your appointments for advice.
- ✓ Information to help you understand your epilepsy such as safety, driving regulations, preconception and epilepsy management during pregnancy, coping with your diagnosis, any fears you may have around dying and explanation about your seizure types and medications.
- ✓ Prescribing new medications or changing doses of current medications with full guidance on how to take your epilepsy medications, including side effects.
- ✓ Rescue medication care plan if you experience prolonged seizures.
- ✓ Referrals where applicable for blood tests, ECG, EEG and other professionals.
- ✓ Helping you understand relevant epilepsy investigations.
- ✓ Use of translation and interpretation services for appointments and written communications in the language you prefer.
- ✓ You will be able to agree on the type of follow up appointments available to you. This could be face-to-face clinic appointment, telephone appointment or video consultation.

- ✓ You can expect that you or your designated carer to be involved in all decisions about your epilepsy and treatment.
- ✓ You will receive copies of clinic letters which will be shared with your GP and other relevant professionals.

Who to contact about my epilepsy and why

Contacting my epilepsy nurse

At any time between your appointments with the epilepsy nurse you can contact the service secretary to leave a message for your nurse for:

- Significant increase in seizure frequency.
- Significant deterioration in the seizure quality such as lasting longer than usual or you are taking longer to recover.
- To inform your epilepsy nurse if you have recently had to call for an ambulance, attended Accident and Emergency Department due to your epilepsy or have been admitted to hospital.
- You are not tolerating your epilepsy medication and side effects (any new onset i.e. rash see below).
- Should you become pregnant and need to make contact ASAP.
- To notify of change in address or telephone numbers.

Contacting my GP

- Repeat prescriptions.
- Urgent advice when your epilepsy nurse is not available.
- If your call is of a health matter unrelated to your epilepsy.
- When invited for any annual health checks.
- Rash and/or flu like symptoms after starting new epilepsy medications (urgent medical advice required for a rash).
- To notify your GP of any changes in address or telephone contact number.

Calling for ambulance, 111 and/or attending A&E

- Attend A&E if you have failed to seek medical advice for new onset body rash, facial and lip swelling and flu like symptoms after having started new epilepsy medication within recent 6 weeks. Follow advice on the medication as recorded in your clinic letter.
- If you experience a first ever generalised tonic clonic seizure (your nurse will explain what this is).

- If you experience a prolonged generalised tonic clonic seizure which lasts 5 minutes with no signs of stopping and do not have any rescue medication (Buccal Midazolam).
- If your carer/relative has followed your rescue medication care plan and the Buccal Midazolam has failed to control your seizures as recorded in your plan (and/or breathing is compromised on recovery from a seizure) always refer to your rescue medication plan documented in your clinic letters.
- If you sustain an injury during or post seizure which causes your carer/relative concern such as head trauma, burns or scalds, fractures. Please note this is not an exclusive list.

Contacting for general information about epilepsy

You can make contact with National Epilepsy Associations such as Epilepsy Action or National Society for Epilepsy, details are on page 12.

Making contact with my epilepsy nurse

Contact the epilepsy nursing service on the telephone numbers on page 2. Please note out of hours there is an answer messaging service.

When leaving a message and you are the person with epilepsy, you need to leave the following information:

- Your full name and date of birth
- Your NHS number if known
- Your phone contact number
- Name of the nurse you want to leave a message for
- Outline of the reason for your call i.e. increased seizures

When leaving a message on your behalf the caller will need to leave the following information:

- The caller's name
- The name and date of birth of the person they are calling about and include NHS number if known
- Their relationship to the person they are calling about
- Their phone number
- The contact number of the person they are calling about if different to theirs

- Name of the nurse they wish to leave a message for
- Outline of the reason for their call

You can be reassured that your message will be relayed to the epilepsy nurse or you will be informed if the nurse is not going to be available within the following five working days. If considered a priority call, it will be passed to a consultant neurologist to respond.

Your epilepsy nurse will prioritise your call depending on clinical need such as; if you have unexpected or significant changes in seizure control, unexpected epilepsy medication side effects or if you have become pregnant.

What if you can't attend your appointment?

If you cannot attend the appointment and wish to make another appointment, you should contact appointments booking on the number provided on the appointment letter as soon as possible rather than contacting the epilepsy nurse secretaries.

If you need to cancel the appointment on the actual day of the planned appointment please contact the secretaries (see numbers on page 2).

If you wish to keep the appointment but the appointment is in a clinic and you can't get to clinic that day please contact the secretaries to ask if you can have a phone appointment instead.

Your epilepsy nurses understand that there will be times when you can't attend appointments and unforeseen circumstances can occur so you should feel free to discuss any problems attending with the nurse.

If you have not contacted the epilepsy nurses and fail to attend two consecutive appointments or frequently do not attend (clinic or telephone) you may need to be discharged back to your GP.

If you have a learning disability and rely on carers for appointments then your carers have a duty of care to respond to appointments. If your carers are not able to respond to a planned telephone contact appointment they will need to cancel and rearrange as your appointments are allocated a specific time slot.

Discharge from the epilepsy nursing service

You will be discharged from the Epilepsy Nursing Service if:

- ✓ You have been seizure free for one year and not at significant risk of recurrence. If there is a risk of recurrence then you may be offered a “patient initiated follow up”. This option can be discussed with your nurse.
- ✓ If you or your carers and epilepsy nurse consider your epilepsy to be optimally controlled and no further medication changes planned.
- ✓ You have moved outside of the Lincolnshire locality (please ask your new GP to refer you to local services. Your new GP will have access to your old neurology letters).
- ✓ You wish and request to be discharged.

Following discharge you should contact your GP in regards to your epilepsy. Your GP can refer directly back to the epilepsy nurse service within 6 months after discharge. After this time your GP will need to refer back to neurology. Your GP will be aware of the referral process at any given time.

What can you expect from your epilepsy appointment?

You will be:

- ✓ Invited to discuss anything relating to your epilepsy causing you concern and given time to ask questions.
- ✓ Asked about driving (if applicable) and lifestyle issues relevant to epilepsy.
- ✓ Asked about your current and past epilepsy medication.
- ✓ Asked what other medications you take including herbal or over the counter medications.
- ✓ Able to inform your nurse if you are experiencing side effects to your epilepsy medications.
- ✓ Asked for a description of your seizures, frequency and duration you may have experienced between your appointments.
- ✓ Able to receive information on how to self-manage your epilepsy and support to make informed decisions about your care.
- ✓ Given relevant referrals to other services with your agreement.
- ✓ Involved during the appointments even if you rely on carers.
- ✓ Receive a copy of your clinic letter with a care plan.

Do you get support with your epilepsy medications?

Your nurse will be able to inform you about any potential side effects of your epilepsy medications and what action(s) you should and can take, if side effects occur. This will include information on possible interactions with other medications.

Your nurse will be able to prescribe epilepsy medication and/or guide on the dose including when to increase, lower or withdraw medications. They will be able to advise on different formulations to suit you such as tablets or liquid. If necessary the nurse will discuss this with a consultant if there is a clinical need.

Your nurse will be able to ask the GP and/or pharmacist for a device which will help you to take your medication safely if you experience any difficulties (Dossette box).

You will be able to share your concerns about taking medications and if a number of medications have failed to control your seizures you will be able to discuss alternative treatment options if applicable to the type of epilepsy you have.

Do you need any blood tests?

Routine blood tests are not always necessary but occasionally blood tests can be useful; it will depend on your individual health needs and type of epilepsy medication. Some of these tests may include U&Es (this looks at your kidney function), LFT (this looks at your liver function) and FBC (this looks at your blood cells). A vitamin D test is quite important so this may be requested.

Generally epilepsy medication levels are not routinely monitored apart from during pregnancy. If you take Carbamazepine, Phenytoin, Phenobarbitone you are more likely to need blood tests.

If your nurse requests any blood tests the nurse will either phone or write to you with the results and copy any letters to your GP. Please notify the epilepsy secretary if you do not hear about your results 4 weeks after having them taken.

You can always discuss any concerns regarding blood tests with your nurse during your appointments.

Having a blood test at the hospitals

All blood tests are by appointment only at Pilgrim Hospital, Boston and Grantham and District Hospital and Lincoln County Hospital.

To book an appointment please use the online booking tool link below or scan the QR code, this takes you to a booking website provided by our pathology partners.

www.ulh.nhs.uk/services/blood-testing-phlebotomy/



Lincoln County

- If you are unable to use the online service, please call **01522 573754** and one of our schedulers will create the appointment on your behalf. This phone line is available **Monday to Friday: 2.30pm to 3.30pm.**

Grantham Hospital

- If you are unable to use the online service, please call **01476 464706** and one of our schedulers will create the appointment on your behalf. This phone line is available **Monday to Friday: 2.30pm to 3.30pm.**

Pilgrim Hospital

- If you are unable to use the online service, please call **01205 446333** and one of our schedulers will create the appointment on your behalf. This phone line is available **Monday to Friday: 2.30pm to 3.30pm.**

What treatment is available if you have prolonged seizures

Your epilepsy nurse should have asked if you have ever experienced Generalised Tonic Clonic Seizures (GTCS) of over five minutes duration. If you are not asked by the nurse please raise it with them.

If you have experienced a prolonged GTCS, your nurse may discuss rescue medication which is most likely to be Buccal Midazolam (either Epistatus or Buccolam). If a plan is agreed, the nurse will draw up guidelines and ask your GP to prescribe this medication. The nurse will offer a full explanation about Buccal Midazolam.

If you need rescue medication and live with relatives, the nurse could invite up to two adult members of your family to demonstrate how to administer rescue medication during a seizure.

If you live in residential care, your carers should access external training on how to administer rescue medication. Many home managers have trainers already; if not they should contact Epilepsy Action.

Can you name a family member/partner/carers with whom your epilepsy nurse can discuss and share information about your epilepsy?

With your consent yes, but your nurse will need to know that you have given consent.

This can be achieved by:

- ✓ Inviting the person to attend appointments with you.
- ✓ Write to the nurse giving the name of the person the nurse can speak with about your epilepsy providing secure contact details.
- ✓ If your nurse is not confident with whom they are talking with they will decline to share any information. It may be possible to set up a password for contact. Please explore this with your nurse.
- ✓ The nurse will listen to any callers but if not known to them they will need to contact you.

What support can I expect during pregnancy?

Ideally it is best if you receive pre-conception advice and optimisation of your epilepsy medications prior to becoming pregnant and have a base line epilepsy medication level done when your seizures are best controlled. This is used to make comparisons of levels during pregnancy as levels can significantly fall during pregnancy. It is important that you plan for pregnancy.

During pregnancy you should expect to have:

- ✓ Telephone contact within two weeks of informing your nurse that you are pregnant or the nurse having received a referral.
- ✓ Two monthly formal telephone appointments interlaced with ad hoc calls to update on blood medication levels.
- ✓ You can have blood tests at your GP practice. For hospital blood tests please see page 8.
- ✓ Written and verbal advice on what happens to medication levels during pregnancy, risk of seizures, pain control during labour and care of new-born.
- ✓ Post-partum epilepsy plan (what you need to do with medication post-delivery).

- ✓ Agreed appointments for one year post delivery of baby and only discharged if seizure free at that time.

What if you are feeling really low?

You should talk to any professional person involved in your care but especially your GP to assess if you are feeling depressed.

Discuss with your epilepsy nurse who can assess if any of the epilepsy medications are contributing to low mood and give you time to discuss what is concerning you. Also, you can refer to the other sources of support section (in this booklet).

If you should ever feel suicidal you should let a trusted person you know be aware of how you are feeling.

What you can do to get the most from the epilepsy nursing service?

- ✓ Attend appointments or cancel if not able to attend.
- ✓ Have someone who has seen your seizures available during your appointments.
- ✓ Have your medication or repeat prescription slip available during appointments.
- ✓ Keep a diary of seizures and share with the nurse during appointments.
- ✓ Write a list of questions you may need to ask the nurse.
- ✓ Let your nurse know if you are unhappy or concerned about your epilepsy care.
- ✓ Attend for any investigations you may have agreed to be referred for.

What can you contribute to the epilepsy nursing service?

You can:

- offer feedback by completing service patient surveys.
- share concerns directly with your epilepsy nurse.
- feel confident that any suggestions for service improvement will be gratefully received.

If you do not feel confident to raise concerns with your nurse, you can contact Patient Advice & Liaison Service (PALS).

Further source of support or information

- ✓ Epilepsy Society helpline 01494 601400
- ✓ Epilepsy Action helpline 0808 800 50 50
- ✓ Driving and Vehicle Licensing Agency (DVLA)



Mental Health contacts:

- ✓ **Lincolnshire Mental Health helpline**

Telephone: 0800 0014331 (open 24/7) if you are feeling low, anxious or stressed.

- ✓ **Steps to Change self-referral**

Single Point of Access Contact Centre by calling 0303 123 4000 (available 24/7).

Online via



- ✓ **Samaritans**

Telephone: 116 123

- ✓ **Automatic Triggered Fall Alarms**

Telephone: 0300 303 4430 LinCare life line system at Lincoln Council

Email: LinCare@lincoln.gov.uk

- ✓ **Alzheimer's Society**

Telephone 03331503456

- ✓ **Non-Epileptic Attacks Epilepsy Attack disorder website**



Epilepsy and pregnancy contacts:

- ✓ **Epilepsy Action**

Freephone: 0808 800 50 50



- ✓ **Epilepsy Society**

Helpline: 01494 601 400



- ✓ If you wish to register your pregnancy with the **UK Pregnancy Registry**. Please visit their website at <http://www.epilepsyandpregnancy.co.uk/> or could call free phone 0800 389 1248 or text 'join' to 07585 509789. * You will only be able to join the registry in pregnancy.



- ✓ **Vagal nerve stimulation (VNS)**



- ✓ **SUDEP (Sudden Unexpected Death in Epilepsy) Action support line**

Telephone: 01235 772850



- ✓ United Lincolnshire Hospital Trust Epilepsy Nursing Service online survey or you can request a hard copy from the Pilgrim epilepsy secretary



United Lincolnshire Hospitals NHS Trust has worked with AccessAble to create detailed Access Guides to facilities, wards and departments at our sites. www.accessable.co.uk/united-lincolnshire-hospitals-nhs-trust

United Lincolnshire Hospitals NHS Trust endeavours to ensure that the information given here is accurate and impartial.

If you require this information in another language or alternative format. please email the Patient Information team at ulth.patient.informattion@nhs.net