

Epilepsy Service

Patient Initiated Follow Up (PIFU)

This leaflet is to provide you with useful information about what PIFU is and assist you with deciding whether you need to contact the Epilepsy team.

What is 'Patient Initiated Follow Up' (PIFU)?

- Patient initiated follow up empowers you the patient by allowing you to be in control.
- You or your carer can initiate your follow up appointment when you feel you need one due to symptoms which you may have, or when your circumstances may have changed.
- You will have direct access to guidance when you need it the most, as opposed to attending a follow up within a set timeframe which you may not need.
- Research has shown that regular interval follow ups are not effective at identifying new problems and can potentially cause unnecessary anxiety.

The Epilepsy PIFU service offers:

Open access to advice, support, and appointments as and when you need them. These may be via telephone or video call, or face to face, based on your individual needs and circumstances.

How is PIFU beneficial to you?

- You won't be making any unnecessary journeys to the hospital attending a follow up appointment which you may not really need. You will only have a consultation if you feel you need to be seen.
- You have more control over your care and how an appointment is initiated as opposed to attending your follow up appointments at fixed routine intervals. We will aim to see you within a small number of weeks after you get in touch.
- It gives you direct access to the clinic without needing to be referred by your GP.

How do I make an appointment?

Making an appointment is easy; you just need to call the epilepsy team on the number provided at the bottom of this leaflet. Please provide your NHS number when you call, which can be found at the top of any hospital letter.

Please note, to arrange a patient-initiated follow-up appointment with the epilepsy team, you must have previously agreed with your epilepsy specialist that this is the right pathway for you.

What symptoms should I get advice about?

Some of the more common symptoms to advise us about are listed below:

- Any increase in seizure frequency or severity - you could monitor this using the EpSMon monitoring app to look for any changes; more information can be found at the following link:

sudep.org/epilepsy-self-monitor

- Concerns or questions about treatment side effects or changes
- If you are pregnant, or are planning or considering pregnancy
- You need to discuss something relating to your seizures such as driving, employment or travel, or any other worries or concerns about your epilepsy
- If you are five years seizure free and wish to discuss a withdrawal of antiseizure medication

When you should NOT use PIFU

If you require urgent medical attention, you should contact your GP, NHS 111 or attend A&E if you are really unwell.

For medical problems that are not related to this speciality, your GP remains your first point of contact.

If you wish to access PIFU, please call the team on:

Telephone – 01543 576 283