



**University
Hospitals Sussex**
NHS Foundation Trust

Patient initiated follow-up (PIFU)

Information and advice
for patients with
long-term neurological
conditions such as epilepsy
and muscular dystrophy

Patient information

Following your outpatient appointment

We have changed the way we provide your care as an outpatient. Instead of having regular, routine appointments according to a timetable, we'll support you to manage your own care and to contact us only if you have worries or concerns. This is called Patient Initiated Follow Up (PIFU).

This leaflet explains how you can access support and advice about your health. If you have any concerns or questions that are not answered in this leaflet please speak to your healthcare professional.

How does my Patient Initiated Follow Up (PIFU) work?

You will have 'open access' to the clinic for 3 years from the date of your outpatient appointment.

If you are worried you have further problems related to your original appointment during the three years, contact us and a clinician will review your request and offer you a further if appropriate. If you have problems after this time, please contact your GP.

Why am I being offered Patient Initiated Follow Up (PIFU)?

The reason we offer follow-up this way is because we want to give you more choice and flexibility and reduce unwanted and unnecessary visits to the hospital. This will help improve patient experience, reduce cost of travel and parking and reduce waiting times for appointments.

When can I book an appointment?

You can make a follow up appointment if:

- you have on-going concerns about your condition;
- if your condition changes significantly beyond that expected; or
- if you require further information or clinical input that cannot be met by support organisations or your GP or local services.

We want to empower you to contact us when you need us.

How can I book an appointment?

You can telephone our Central Booking Team on **0300 303 8360** or email bsuh.outpatients.bookingcentre@nhs.net

A member of your clinical team will review your request. They may be able to offer you advice and guidance or decide that you need an appointment. Appointments may be virtual via telephone, video or face to face, if we need to physically examine you. We will send you a confirmation of your appointment.

When should I contact the service?

- If you have an increase in seizure frequency or severity
- If you have concerns about treatment side effects, dosages or changes
- If you have been seizure free for a significant time and wish to discuss coming off medication
- If you are planning or considering pregnancy or finding out that you are pregnant
- If you need to discuss something relating to your seizures such as driving, employment or travel
- For patients with other long term neurological conditions, such as muscular dystrophy, if you have a change in your disability that you need to discuss.

When is a Patient Initiated Follow Up (PIFU) appointment not appropriate?

PIFU is not appropriate for conditions or symptoms unrelated to the condition you were seen for originally: for these you will need to contact your GP or NHS111 for advice.

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

Frequently asked questions

Q. What if I cannot get through to make an appointment?

A. If you cannot get through using the phone lines, please contact the booking team via email bsuh.outpatients.bookingcentre@nhs.net

Q. How long will I have to wait for an appointment?

A. The service will contact you within 1 week to discuss a plan.

Q. Could I get lost in the system?

A. No. You will be clearly recorded as being on Patient Initiated Follow Up pathway on our internal systems. If you do not need to see the clinician at all within the three years after your last appointment, you will be discharged back to your GP who will refer you back to us if you need hospital care again in the future.

Q. Why have you set an end date for me to make an appointment?

A. Your clinician will decide how long you need to be on the PIFU pathway. It will depend on your condition and their clinical judgement of how long you will need before you can be discharged back to your GP. Our aim is to discharge you once you are well enough.

This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

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