

Parkinson's Disease Service

Patient Initiated Follow Up (PIFU)

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

Wolverhampton and Cannock: 01543 576 042

Telford and Shropshire: 01952 800 135

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

- Patient-initiated follow-up (PIFU) puts you, the patient, in control of when you are supported by the neurology team. It means spending less time attending hospital appointments, but still having access to specialist clinical input when you need it.
- You or your carer can initiate your follow up appointment when you feel you need one due to a change in your condition or circumstances, or if your symptoms are causing you trouble.
- 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.
- If your condition is stable, you may not find it helpful to attend regular outpatient appointments scheduled by the hospital. Sometimes, these appointments may not result in any change to your treatment, but you'll have spent time and energy putting arrangements in place to attend your appointment.

The Parkinson's Disease 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 or want one.
- 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.

- We will write to you regularly between appointments to make sure that we still have up to date contact information for you, and that you are still happy to remain on a PIFU pathway.
- If you do not need to access the PIFU pathway within 24 months, you will be discharged back to your GP who can refer you back to a Consultant Neurologist or Clinical Nurse Specialist if a future review is needed.

How do I make an appointment?

Making an appointment is easy; you just need to call the Parkinson's disease team on the number provided at the start and end of this leaflet. Please provide your NHS number when you call, which can be found at the top of any hospital letter. Please briefly explain your symptoms and situation and that you need some clinical advice and are on PIFU.

The team will review your message and a clinician will decide whether you need immediate clinical advice for your symptoms or if you need an appointment, and which member of the team will best be able to address your needs. This might be a consultant, specialist nurse, or specialist therapist. If you need immediate advice, someone will call you back as soon as possible.

If the team think you need an appointment, we will contact you to agree an appointment date and time. In most cases we will arrange an appointment for you within 10 working days. Sometimes it will be most appropriate to support you by having a remote consultation over the telephone or video link, but an in-person appointment may also be arranged if necessary.

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

What symptoms should I get advice about?

The Parkinson's disease team will outline the most important situations that should prompt you to contact them by PIFU. That does not mean that you cannot contact them at other times if you think you need to. Some of the most common queries are:

- Concerns or questions about treatment side effects or changes
- If you wish to return to regular follow-up appointments instead of PIFU

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.

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