The Royal Wolverha

Endocrinology Service - Prolactinoma Patient Initiated Follow Up (PIFU)

If you wish to access PIFU, please call the team on: 01902 485 316

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 endocrinology 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 Endocrinology 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, or if your regular blood tests show any unusual results.
- 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

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- aim to see you within a small number of weeks after you get in touch.
- You will be asked to have a blood test every year and will be sent instructions on how to do this by post. If your results are abnormal, we will contact you to arrange an appointment.

How do I make an appointment?

Making an appointment is easy; you just need to call the endocrinology 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 2 weeks. 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 endocrinology team, you must have previously agreed with your endocrinology specialist that this is the right pathway for you.

What symptoms should I get advice about?

The endocrinology 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 and important triggers are:

- Concerns or questions about treatment side effects or changes
- If you wish to return to regular follow-up appointments instead of PIFU
- If you become pregnant
- Any of the following new symptoms:
 - Visual disturbances
 - Headaches
 - o Loss of libido
 - Changes to your menstruation cycle
 - Breast discharge

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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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