

As part of your cancer care, you have been referred into the Patient Initiated Follow-Up pathway. This information leaflet explains how this pathway works and who to contact if you have any concerns.

What is Patient Initiated Follow-Up (PIFU)?

Instead of having regular follow-up appointments arranged by your cancer team, this pathway allows you to arrange follow-up appointments with the appropriate member of your cancer team when you feel you need them, if you have any symptoms, or if you have any general worries or concerns.

There is good evidence to show that having regular follow-up appointments does not help prevent cancer returning or identify any new problems related to the cancer.

There is strong evidence that symptoms and concerns are addressed more quickly if patients report them when they occur rather than waiting for a routine follow-up appointment with the cancer team.

How does PIFU work?

If your cancer team feel that PIFU will be suitable for you, they will discuss this with you and if you agree, you will be placed on the PIFU pathway.

This means that you will no longer receive regular follow-up appointments and will need to contact your cancer team if you feel that you need an appointment.

What are the benefits of PIFU?

This pathway allows patients to manage their own condition with the following benefits:

- You are able to schedule follow-up appointments when you need them

- A follow up appointment can be arranged quickly with a member of the cancer team
- You are informed about the concerning symptoms associated with cancer recurrence
- You are able to call your cancer team directly with any concerning symptoms
- You won't have to come to hospital as often meaning less disruption for you.

When should I call my cancer team?

You should call if you have any of the following symptoms:

- Vaginal bleeding including bleeding after sexual intercourse
- Unusual vaginal discharge
- Rectal bleeding (bleeding from the back passage)
- Abdominal (tummy) or pelvic pain that doesn't go away
- Abdominal (tummy) bloating or swelling that doesn't go away
- Loss of appetite or feeling full quickly when you eat
- Persistent (more than 2 weeks) nausea or vomiting not obviously related to another cause
- Unexplained weight changes (loss or gain)
- Persistent changes (more than 2 weeks) in bowel habit (diarrhoea or constipation)
- Persistent changes (more than 2 weeks) in bladder habit (e.g. urinary incontinence or passing urine frequently)
- Shortness of breath or a persistent cough
- Persistent (more than 2 weeks) leg swelling (lymphedema)
- OR if you feel generally unwell / excessively tired.

These are some of the common symptoms women experience if their cancer has returned, BUT remember that any of these problems can be caused by a number of reasons, not everyone will experience these symptoms, and it does not necessarily mean your cancer has returned.



If you are experiencing any of these symptoms however it is always sensible to contact the cancer team.

We would also recommend that you call your cancer team if you are experiencing the following:

- You have any on-going problems or side effects after your treatment
- You need emotional support. It is normal to feel emotional for a while after your treatment has ended.

You can call the cancer team if you have any of the following worries:

- Low mood
- Depression
- Feelings of isolation
- Sexual concerns
- Money worries
- Have any general worries or concerns.

Who should I contact if I have any concerns?

If you experience any of these symptoms then please contact:

The Gynaecology-Oncology Clinical Nurse Specialists:

- **01302 642813** (answerphone service available).

They will try to return all calls as soon as possible but please be aware that this may be the next working day.

Consultant Gynaecologists Medical Secretary:

- Mr El-Hadidy/ Mr Barani: **01302 642197**.

They will try to return all calls / emails as soon as possible but please be aware that this may be the next working day.

If you experience any symptoms not listed or your call is urgent:

- Contact your own GP
- Phone 111 for advice



- Or go to your nearest Emergency Department.

What happens when I contact the cancer team?

They will discuss your concerns with you and recommend one of the following:

- An appointment to see a member of the cancer team
- An ultrasound scan or CT scan followed by an appointment to see a member of the cancer team with the results.
- Arrange an appointment with your GP
- No action is required and reassurance will be given.

Patient Advice & Liaison Service (PALS)

The team are available to help with any concerns, complaints or questions you may have about your experience at the Trust. Their office is in the Main Foyer (Gate 4) of Doncaster Royal Infirmary. Contact can be made either in person, by telephone or email.

The contact details are:

Telephone: 01302 642764 or 0800 028 8059.

Email: dbth.pals.dbh@nhs.net

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