NHS
Oxford University Hospitals
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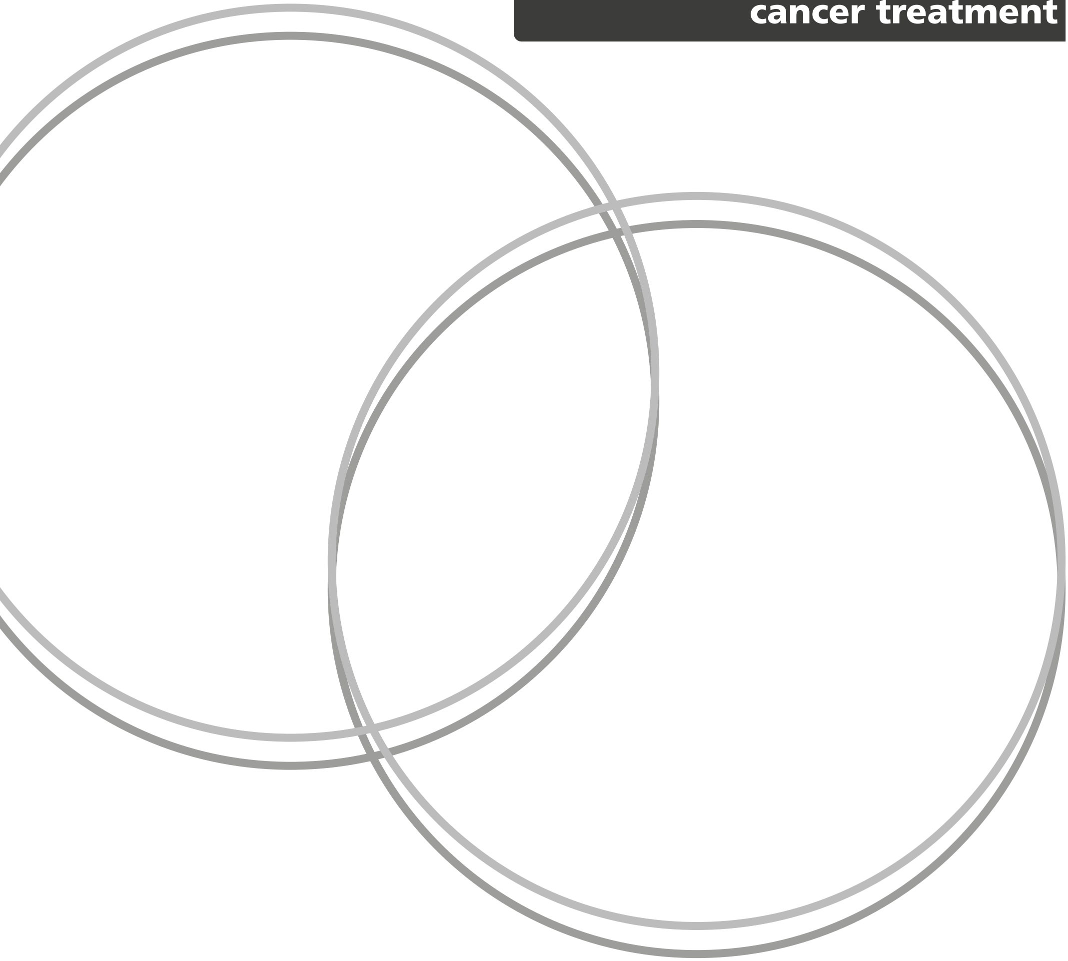
Colorectal cancer follow-up care

Patient Led Follow-Up (PLFU)
Information for patients following colorectal cancer treatment



This leaflet provides you with information about your colorectal cancer surveillance (follow-up care).

Follow-Up Programme

Patient Led Follow-up (PLFU) has been shown to improve patient experience, promote well-being, maintain quality of life, and empowers individuals to take an active role in their cancer care to improve outcomes. It ensures your symptoms and concerns can be addressed more quickly, as you can report them as and when they occur, rather than waiting for a routine appointment.

PLFU gives you the option to avoid unnecessary journeys, parking, time off from work, associated costs with visiting the hospital, and finding time for appointments. It also benefits the clinical team by freeing up clinics for patients that need face to face care.

Your follow-up plan will be created at an appointment with your consultant, at a point when it is recognised that your cancer is stable.

Further support that might be useful to you will be explored during a **Holistic Needs Assessment**. This is an assessment and a discussion which you will have with a member of the nursing team. Together you can talk through any needs and concerns you have about any area of your life, such as physical, emotional, practical, financial, and spiritual. You will then agree on a plan for your care and support needs.

For Patient Led Follow-Up:

- Your condition must be stable.
- You will be invited to attend and participate in a Health and Wellbeing Workshop

We will provide you and your GP with a treatment summary which will summarise your care and detail your schedule for ongoing follow-up. This includes frequency of follow up tests, symptom assessments and how to contact the department.

If you would like more information about follow-up, please ask us.

Components of Patient Led Follow-up:

- Blood tests at local GP
- Questionnaire to assess symptoms
- Hospital team review results
- Scans at hospital but NO regular hospital appointments, instead contact us if you need advice or have concerns
- Holistic Needs Assessment
- Receive information on supported self-care
- Invited to a Health and Wellbeing Workshop
- Access to Patient Portal

Patient Portal

Oxford University Hospitals have a Patient Portal called Health for Me. This enables you to access your own digital health record from a smart device such as a phone, tablet, or computer.

Here you can have access to your blood and scan results as soon as they are available rather than waiting for your letter. Completing health questionnaires through this platform will enable the clinical team to review them in the shortest time.

The departmental administrative team can give you access to the Patient Portal. You will then receive an access invitation to Health for Me for you to sign yourself up.

Access to the Patient Portal is optional. Alternative ways to complete or receive information can be provided if necessary.

How PLFU works

To respond quickly to any possible changes in your health we will arrange tests specific for you these may include:

1) CT scan of chest, abdomen, and pelvis.
This is a scan which uses x-rays linked to a computer to create detailed pictures of your body. The CT scanner is an open ring like structure, which looks a bit like a donut, rather than a tunnel. You will have had one of these before you received your treatment.

2) MRI scan pelvis and rectum (only for some types of follow up).
MRI scans use strong magnetic and radio waves to make pictures of the inside of your body. The scanner is like a tunnel, but you won’t need to go into it completely. During the scan there can be loud banging so you will wear headphones and if you prefer, we can play music through them to help.

3) Flexible sigmoidoscopy (short camera test into the bowel) or colonoscopy (full camera test into the bowel).

4) Blood test to check for the bowel cancer marker called Carcinogenic Embryonic Antigen (CEA).

We would also like to know about your general health, specifically asking you questions about your current symptoms and medication.

You **do not** need regular hospital appointments.

You **do** need to visit your GP practice to have blood tests.

You **do** need to fill in some short questionnaires regularly.

All results will be reviewed by your hospital team.

You can call your clinical team if you have any concerns. If at any point you need an appointment either because of new symptoms or the results of your investigations are abnormal, we will aim to see you within 2 weeks.

For any patients that PLFU is not suitable for we will instead offer regular appointments over the telephone or face to face.

How will I know when to have tests?

You will be given a personalised schedule of follow-up in your treatment summary. This will tell you how often you will need to book blood tests at your GP and how often we will arrange your scans and/or colonoscopies

You will be asked to log into the patient portal and respond to your questionnaires every 12 months

We will contact you by text or phone a few weeks before your test is due to remind you.

When will I know my results?

The hospital team will review your results and will send a letter usually within **3 to 4 weeks** of your scheduled test date. This will explain your results and any further actions needed. You may also choose to have your results sent by email.

We encourage you to check your results (these can be found on your Patient Portal, within your letter, or by contacting the Specialist Nursing Team).

If you have any concerns or think you may benefit from an appointment, please contact our team.

What you are responsible for:

- Arranging regular appointments to have blood taken at your GP surgery
- Contacting Radiology directly if you need to re-arrange your scans
- Contacting Endoscopy directly if you need to re-arrange your colonoscopies/flexible sigmoidoscopies
- Completing and returning questionnaires we send you
- Letting us know if you have any problems or concerns
- Being aware of your own results and discuss any concerns you have with us (these will also be reviewed by our hospital team)

What we are responsible for:

- Providing you with information to help you support yourself (supported self-care)
- Sending blood forms/stickers to allow you to have tests at your GP (Oxfordshire results will come straight to us)
- Requesting all investigations as required.
- Sending you appointments for your scans or colonoscopies/ flexible sigmoidoscopies
- Checking your blood tests/CT scan/MRI scan/endoscopy reports and questionnaire results and acting on these as appropriate
- Enabling you access to our clinical teams when you need us (by telephone, email or clinic appointments)

Supported Self-Management

We will support you to manage your condition yourself. This puts you in control of your care and allows you to take an active role in your healthcare. This is called supported self-management.

There are lots of things you can do to look after your own health during and after cancer treatment. Many of these can be done without the involvement of your clinical team, such as physical activity and healthy eating.

Health and Wellbeing Workshops

All patients will be invited to workshops to inform them more about their condition, explore areas of support and have opportunities to discuss any of this with their care team and other individuals with a similar diagnosis.

Workshops provide information on:

- Introduction to the service
- The importance of CEA monitoring
- Potential long term side effects arising from a colorectal cancer diagnosis, treatment, and how to manage these - mental health support/ sexual difficulties/ diet/ exercise/ fatigue/ bowel problems (including stoma) / social and/or financial difficulties /early menopause amongst others
- Survivorship (wellness and empowering you beyond cancer)
- Signposting to local and national support
- How to ask for advice or raise concerns with the clinical team
- Your responsibility in managing your well-being and blood tests etc.

What symptoms do I need to look out for?

Red flag symptoms to look out for are detailed in your treatment summary and will also be discussed at the Health and Wellbeing Workshop.

If you do get any persistent symptoms you are concerned about, please talk to your Specialist Nurse Team.

What support will I have?

You can contact your Specialist Nurse Team by phone or email if you have any concerns. We can offer:

- Advice and support for you, your relatives, and friends
- Advice on management of symptoms
- Someone to talk to about worries or problems
- Signposting for advice
- Arranging visits to clinic or remote consultations as needed

Our working days are Monday to Friday 8am to 4pm.

If you have not had your blood tests, scans, endoscopies or completed the health questionnaires, our administration team will be in contact with you.

Contact Details

Colorectal Cancer Specialist Nursing team

Telephone: 01865 221454 (answerphone service)

Email: colorectal.nursing@ouh.nhs.uk

CT Telephone: 01865 228944 / 235770

MRI Telephone: 01865 231144 / 235772

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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