

## Cancer services

# Open access follow-up (OAFU) for colorectal cancer

## Information for patients, relatives and carers

### Introduction

This leaflet provides information about open access follow-up (OAFU) for patients who have received treatment for bowel cancer at Imperial College Healthcare NHS Trust. We hope it will answer many of the questions that you or those who care for you may have at this time. It is not meant to replace the consultation between you and your specialist nurse, but aims to help you understand more about what is discussed.

### What is OAFU?

OAFU is the type of aftercare service used at Imperial College Healthcare NHS Trust for patients who have received treatment for bowel cancer. Routine follow-up appointments are replaced with an arrangement that allows you to contact us at any time if you have concerns about your bowel function, any new symptoms you would like to report or questions about your treatment or other related issues.

OAFU also gives you access to a dedicated helpline for reporting worries or concerns. You will receive a response within 24 working hours if no-one is available to answer immediately. If we think that you need to be seen, you will be offered an appointment within two weeks.

OAFU gives you the freedom to get on with your life with the reassurance of fast advice and a prompt clinic appointment should you need one.

### How does OAFU work?

Before joining the OAFU programme, you will have a consultation with a colorectal nurse specialist who will explain the service to you. They will discuss your diagnosis, treatment and any possible side effects, and provide advice on related health, lifestyle and wellbeing issues. The nurse will also tell you about further sources of help and support and explain:

- the signs and symptoms to look out for that might indicate a return or spread of the disease
- the helpline you can contact if you have any symptoms, concerns or queries
- the arrangements for any follow-up tests such as CT scans, blood tests and colonoscopies, why these are important and the process for getting the results
- what patient information is available to you and your family

We will also send your GP full details of your treatment plus any monitoring tests they may need to arrange for you.

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## Will I need any routine follow-up tests?

Yes - these will be offered to you at an agreed time. The follow-up programme will involve:

- carcino-embryonic antigen (CEA) blood tests every six months for five years – these measure how much CEA there is in the blood
- CT scans every six months for the first two years, then every year for a further three years
- a colonoscopy which will be booked every three years (or within six months of surgery if it wasn't possible to look at the end of your large bowel before surgery) – colonoscopies often continue until the age of 75 (this will depend on each individual case)

It is important that you follow this programme. Studies have shown a higher number of patients with recurrent disease that could be acted upon were identified if they followed an intensive follow-up programme, compared to those who did not.

You may find the table below helpful to keep a record of your investigations\*

Type of test	Year 1	Year 2	Year 3	Year 4	Year 5
CEA blood test					
CT abdomen, chest and pelvis					
Colonoscopy					

\*insert the date into the relevant box once the test is completed

If after any of the tests we feel that you need to be seen, the colorectal nurse specialist will call you to arrange an appointment with the doctor within 14 days. This will also be communicated to you and your GP in writing.

## Are there any signs and symptoms I should look out for?

It is important to remember that survival rates and treatments for bowel cancer are improving all the time and that recurrence (the cancer returning) is unusual. As bowel cancer can return or spread to other parts of the body, however, it is important to be aware of the signs and symptoms to look out for.

You know better than anyone how your bowels normally work, so if you do notice any changes, or you are concerned in any way, please contact us via the OAFU helpline (see page 3).

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Listed below are some of the symptoms you should report via the OAFU helpline **immediately**:

- any new bleeding from your back passage, stoma, or in your urine
- continuing pain that does not go away with your usual painkillers
- any unexplained lumps, bumps or swelling around your scar or stoma
- a change in your bowel habit that lasts for six weeks or more – especially if you are waking in the night with loose stools
- unexplained weight loss, lack of appetite, a constant feeling of nausea or increase in waist measurement
- bleeding or discharge from your operation site
- any physical problem that interferes with your daily life, e.g. fatigue, difficulty sleeping or any new problem with sexual function

The colorectal nurse specialist will talk through your symptoms with you and agree the best course of action. If the nurse thinks that you need to be seen or have any diagnostic tests, you will be given an appointment as soon as possible and certainly within two weeks.

Getting a symptom that could indicate a recurrence or a new cancer can be frightening but it is important to remember that having one of these symptoms does not necessarily mean that your cancer has returned, as they can all be caused by many other common conditions.

**Please note:** if your symptoms are particularly worrying, especially in the case of sudden, heavy bleeding or severe and persistent abdominal (tummy) pain, you should contact your GP immediately or go straight to your nearest A&E department.

### Contacting the OAFU helpline

You can contact the specialist colorectal service by telephoning or emailing the OAFU helpline if you have concerns about your bowels, any new symptoms you would like to report or if you have questions about your treatment or any other related issues.

OAFU telephone helpline: **020 3312 5362**. The helpline is open between 09.00 and 17.00 from Monday to Friday. If no-one is available to answer immediately you can leave a message.

OAFU email address: **ICHC-tr.openaccesscolorectal@nhs.net**

Please note that all emails will be responded to by phone.

When leaving a message or emailing please give a brief description of your query or concern, along with your name, hospital number and telephone number, and someone will call you back within 24 working hours. If we think that you need to be seen in the clinic or have any diagnostic tests, you will be offered an appointment within two weeks.

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## Other reasons to contact the OAFU helpline

You should also contact the helpline with any of the following:

- questions about the side effects of your medication or treatment
- changes to your address or telephone number - it is really important that the contact details we have for you are correct
- if you have not heard about an appointment you were expecting
- if you are finding it difficult to cope and/or you would like some emotional support
- any concerns you would like to talk through

We are here to help you and would prefer if you got in touch with any concerns you may have rather than worry about it on your own.

## Further help and support

Patients experience different feelings when they no longer need to see their medical team following treatment for cancer. Some feel relieved that their lives are no longer disrupted by appointments, while others are concerned about the future and anxious about losing contact with the hospital. Most people also worry that the cancer may return. These feelings are very common and there are many organisations that provide help and support to people who have or have had cancer. Your colorectal nurse specialist will give you information about these.

Alternatively, your GP may be able to arrange appropriate counselling for you. If it would be helpful, we can put you in touch with our hospital multi-faith chaplains who would be happy to talk to you about any spiritual questions you may have. Please let us know by contacting the helpline. Below are some other useful contacts:

- **Macmillan patient information and support service at Charing Cross Hospital (020 3313 0171) and Hammersmith Hospital (020 3313 4248)**
- **Maggie's Cancer Caring Centre (based at Charing Cross Hospital)**  
Telephone: 020 7386 1750  
[www.maggiescentres.org](http://www.maggiescentres.org)
- **Beating Bowel Cancer**  
Nurse advisory helpline: 020 8973 0011  
Email: [nurse@beatingbowelcancer.org](mailto:nurse@beatingbowelcancer.org)  
[www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)
- **Bowel cancer UK**  
[www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)

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## How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at [imperial.pals@nhs.net](mailto:imperial.pals@nhs.net) The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street  
London W2 1NY

Email: [ICHC-tr.Complaints@nhs.net](mailto:ICHC-tr.Complaints@nhs.net)

Telephone: **020 3312 1337 / 1349**

## Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:  
[imperial.communications@nhs.net](mailto:imperial.communications@nhs.net)

## Wi-fi

Wi-fi is available at our Trust. For more information visit our website: [www.imperial.nhs.uk](http://www.imperial.nhs.uk)