

Cancer services

Open access follow-up (OAFU) for prostate 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 prostate 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 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 prostate 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 prostate, new symptoms you would like to report, questions about your treatment or other related issues.

OAFU also gives you access to a dedicated helpline for reporting worries or concerns with 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 specialist prostate nurse who will explain the service to you. They will discuss with you 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:

- how to be body and prostate aware
- 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 regular prostate specific antigen (PSA) blood tests, and how you will get the results

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

Contacting the OAFU helpline

You can contact the prostate service via the OAFU helpline or email if you have concerns about your prostate, 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 2348**. 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.openaccessprostate@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.

Will I need any routine follow-up tests?

Patients who have had prostate cancer are advised to have regular PSA blood tests for at least five years following treatment. Your PSA tests will be arranged for you by the hospital. You and your GP will receive the results of your PSA test by post within two to three weeks of having the test. If you do not receive your results within one month, please contact the helpline.

If your results are uncertain or abnormal, your letter will explain this and will include an appointment at the urology department within two weeks for further tests. If you are sent an appointment please try not to worry. You can contact the helpline if you are concerned and would like to talk to a nurse.

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

The following list is a reminder of the signs and symptoms to look out for if you have had treatment for prostate cancer. These symptoms could indicate a return or spread of the disease and need further investigation:

- persistent aches and pains in bones, lasting more than one week
- swelling in legs
- unexplained weight loss
- pain when urinating
- change in the controlling and passing of urine
- passing blood in urine or faeces
- numbness or pins and needles in legs or arms that does not go away
- weakness in arms or legs or difficulty in standing or walking
- back pain which may move to lower back or legs

If you experience any of these symptoms, you should contact the OAFU helpline (see page 2) without delay. A nurse 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 within two weeks.

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

Other reasons to contact the OAFU helpline

You should also contact the helpline if you:

- have questions about the side effects of your medication or treatment
- have changed address or telephone number - it is really important that the contact details we have for you are correct
- have not had an appointment for your PSA blood test and it is now overdue
- are finding it difficult to cope and/or if you would like some emotional support

If you are worried about anything to do with your prostate or treatment, please contact the helpline. 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

People 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, whilst 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 all very common and there are many organisations that provide help and support to people who have or have had cancer. Your specialist prostate nurse will give you information about these.

Alternatively, your GP may be able to arrange 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 OAFU helpline.

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 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

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

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk