The Clatterbridge
Cancer Centre
NHS Foundation Trust

Prostate Patient Directed Open Access (PDOA) - Follow-up guide

General information

A guide for patients and carers

Contents

Hospital number:

Date you were diagnosed:

PSA level when you were diagnosed:

PSA stands for prostate specific antigen, which is a protein found in the blood

Gleason Score:

this gives an indication of how aggressive the cancer is likely to be

Tumour Staging:

this shows how far the cancer has spread

T – Stage:

this shows how far the cancer has spread in and around the prostate

N – Stage:

this shows whether the cancer has spread to the lymph nodes

M – Stage:

this shows whether the cancer has spread to any other areas of the body

Introducing Patient Directed Open Access (PDOA)

Your specialist cancer team will refer you to PDOA and you will no longer need to travel to the hospital for routine follow-up appointments. Instead you will be able to contact your team at the hospital directly to arrange a follow-up appointment if you have any concerns.

Your team will also review any blood results at fixed points and contact you if they have any concerns.

“In the past, men living with or after prostate cancer have been seen at regular intervals by their clinical team. Some men find these pre-arranged appointments useful and reassuring, however many more find them a source of great anxiety and of little benefit, unless they have something specific to discuss. There is strong evidence that symptoms and concerns are addressed more quickly if patients report them as and when they occur, rather than waiting for a routine appointment.“

Mr J McCabe, Consultant Urological Surgeon

Supported self-management puts you in control of your care and allows you to take an active and leading role in your recovery, with help from your specialist cancer team. The main aim of supported self-management is to enable you to develop the skills, knowledge and expertise to:

1. Make positive choices about your health care
2. Manage the physical and emotional impact of prostate cancer and its treatment
3. Make long-term positive changes to health behaviours (staying active, eating healthily)

We know from work with people with other long-term medical conditions that supported self-management can improve physical health and well-being.

Online health records

As part of your follow up care you will be provided with secure and confidential access to an online resource called MMR Online. **https://livinglongerlivingbetter.uhs.nhs.uk/**

This resource can be accessed via the internet, and you can use it to:

- View your prostate specific antigen (PSA) test results
- Message your specialist cancer team
- Access information on living with or after prostate cancer
- Take assessments to monitor issues related to prostate cancer and its treatment

We understand that not everyone feels comfortable with technology or has access to a computer on a daily basis. To help support you, the team will offer you information on how to obtain free-of-charge guidance on access to internet skills training, if needed. If you choose not to register to use MMR online, you can continue to take assessments and receive information in paper format.

PSA tracking and surveillance

PSA stands for prostate specific antigen, which is a protein found in the blood. A PSA blood test is a very effective way of monitoring your progress during or after treatment. You will receive a letter to remind you when your blood test

is required. The test can be carried out at your GP surgery and your specialist cancer team at the hospital will be notified of the result. You will receive your results via letter and may also view them on MMR Online. If you have any concerns about your PSA result you can contact your specialist cancer team by telephone or send an email to the team via MMR Online. The hospital will contact you directly if they need to discuss your PSA result with you.

PDOA Workshop

You will be invited to attend a one-off two-hour workshop. The workshop is run by your specialist cancer team, and aims to provide you with the skills and confidence to self-monitor for symptoms and signs of recurrence, manage lifestyle change, and set your own goals for recovery and rehabilitation. At the workshop you will learn about how we will keep track of your prostate specific antigen (PSA) level and how surveillance is planned for you.

Topics covered include:

- Introduction to supported self-management
- MMR Online demonstration

- What is PSA tracking and surveillance?
- Coping with physical and emotional effects of prostate cancer
- Healthy lifestyles e.g. healthy eating, physical activity/exercise and bone health

Men who attend these workshops often give very positive feedback:

“I didn’t know what to expect before I came along to the workshop, I was sceptical as to what good it would do me to attend, but I have to say it was superb! I give it 100/100, I feel it was well worth going, I came away feeling more positive.”

Robert N

“It was lovely to chat to other men , I felt that I could relate to them all which felt really good and I realised I’m not an island on my own there are other people with the same issues and worries as me”

Michael D

Assessment and Care Planning

You will be asked to complete regular assessments in the form of a “Health MOT checklist”. You can access this via MMR Online, or in paper format. This checklist is a way of identifying any concerns or problems you may have living with or after prostate cancer. These might include practical issues such as work, or dealing with the physical and emotional effects of prostate cancer, or concerns relating to your relationships or family life. The checklist will reflect your individual needs with a clear care plan or action plan. This can help you to self-manage your care or identify when other help or resources could be useful.

How do I arrange a review?

Using MMR Online you will be able to send a message to your specialist cancer team who will respond within two working days. Alternatively you can call the team on **0151 556 5769**. You can leave a message on the answer machine, which is checked every working day (please note: it is not an emergency phone line). One of the team will aim to contact you within two working days.

Finding support

You may have already found that people have different ways of living with prostate cancer. There is no right or wrong way, just what works for you. Some people prefer not to talk about it, while others find it helps to discuss their experience. Your prostate cancer specialist team is there to help you with support. Ask the team about details of local support groups if you think this may be helpful.

Further information and contacts

Many more are available via MMR online.

National contacts

Prostate Cancer UK
Telephone: 0800 0748383
www.prostatecancer.org

Cancer Research UK
Cancer Research UK’s patient information resources
Helpline: 0808 800 4040
www.cancerresearchuk.org

Macmillan Cancer Support
Free information, practical and emotional support.
Telephone: 0808 808 00 00 (7 days a week, 8am-8pm)
Email: via the online support line through Macmillan cancer support or online chat open 8am-8pm seven days a week

NHS Choices
Includes all NHS online services and information, to help you make choices about your health.
www.nhs.uk

Citizens Advice Bureau
www.citizensadvice.org.uk

Local contacts

The Clatterbridge Cancer Centre Prostate Cancer Support Worker
Contact: 0151 556 5769
ccf-tr.cccpatientdirectedopenaccess.prostate@nhs.net

Maggie's Merseyside - Maggie's Centre
Contact: 0151 334 4301
clatterbridge@maggiescentres.org

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Notes

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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