

Prostate cancer patient initiated follow-up

Your guide to supported self-management
and surveillance of prostate cancer



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Your personal details and summary of your treatment

Name:

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

Treatment/s:

Surgical consultant:

Oncology consultant:

Clinical nurse specialist:

Health care support worker:

Prostate surveillance plan:

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Introducing patient initiated follow-up (PIFU)

In the past, patients living with or after prostate cancer have been seen at regular intervals by their clinical team for follow-up care. Some patients find these pre-arranged appointments useful and reassuring, but many others find them a source of great anxiety and not particularly helpful, unless they have something specific they wish 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.

We have therefore changed the way we manage the care of patients and this system is called patient initiated follow-up (PIFU). This booklet explains what PIFU (a combination of supported self-management and a personal surveillance plan) is and how it works. It contains space to record your details about your cancer and the treatment you have received so far, as well as the tests that you will need in the future (your surveillance plan). It also contains all the information you need to contact your team and arrange to be seen if you are worried.

What is supported self-management?

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. 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.

During your treatment and care, a member of your team will discuss supported self-management with you. Once you and your doctor have agreed this is the right option for you, you will no longer have routine follow-up appointments at the hospital. Instead you will be able to contact your team at the hospital directly to arrange a follow-up appointment, if you have any concerns.

My Medical Record

To help you self-manage you will be provided with secure and confidential access to an online resource called My Medical Record. You can access this via the internet to share information between you and your clinical team in order to support the management of your healthcare. My Medical Record can also be used to access information on living with or after prostate cancer.

Getting started on PIFU

To take part in PIFU and self-management, you will be required to join an introduction session. The session will be run by a member of our prostate cancer nursing team and will be either face-to-face, online or by telephone. Please see your appointment letter for more details. You will be provided 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. During this session, you will learn about how we will keep track of your prostate specific antigen (PSA) level and how surveillance is planned for you.

What will the introduction session cover?

- Introduction to supported self-management
- My Medical Record demonstration and training
- What is PSA tracking and surveillance?
- Coping with the physical and emotional effects of prostate cancer
- Healthy lifestyles - healthy eating, physical activity/exercise and bone health
- Fear of recurrence and stress
- Moving forward and goal setting

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 be notified when your blood test is required via My Medical Record and by letter. The test can be carried out at your GP surgery or possibly local hospital, and your clinical team at the hospital will be notified of the result. You will be able to view your results on My Medical Record.

If you have any concerns about your PSA result, you can contact the PIFU team by telephone or send an email to the team via My Medical Record.

The hospital will contact you directly if they need to discuss your PSA result with you.

Holistic needs assessment

Through My Medical Record you will be able to access a holistic needs assessment (HNA). On the My Medical Record system this is known as the Health MOT. If you do not have access to the online system, we will supply you with paper copies of this. This 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 HNA will reflect your individual needs which can then be discussed with the PIFU team who will offer advice appropriately. This can help you to manage your care or identify when other help or resources could be useful.

How do I arrange a review?

Using My Medical Record, you will be able to send an email to the PIFU team who will respond within two working days. Emails sent at the weekend will be replied to the next working day. Alternatively, you can call the PIFU team on **023 8120 1309**.

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 one working day.

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 nursing team is there to help you with support so ask them if you would like details of local support groups.

Further information and useful contacts

Many more are available via My Medical Record™.

National contacts

Prostate Cancer UK

Telephone: **0800 074 8383**
www.prostatecanceruk.org

Movember

<http://uk.movember.com>

Cancer Research UK

Cancer Research UK's patient information resources
Helpline: **0300 123 1022**
www.cancerresearchuk.org

Macmillan Cancer Support

Free information, practical and emotional support.
Telephone: **0808 808 0000**
www.macmillan.org.uk

NHS

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

RADAR national key scheme

Offers access to more than 6000 locked public toilets for disabled people in the UK. Keys can be obtained from **01395 265543**, and often from local social services offices, district council offices and some branches of Age Concern.
Email: sales@radarkey.org
www.radarkey.org

Local contacts

PCaSO

Prostate Cancer Support Organisation Helpline: **0800 035 5302**

www.pcaso.org

Patient and Family Support Hub

B level, Southampton General Hospital

Telephone: **0800 484 0135**

Jane Scarth House

Local charity providing emotional and practical support to anyone who is affected by cancer. Telephone: **01794 830374** **www.janescarthhouse.co.uk**

Wessex Cancer Trust

Local charity providing information, counselling, complementary therapies

Telephone: **023 8067 2200** **www.wessexcancer.org.uk**

NHS Better Health - every mind matters

Mental wellbeing advice. **www.nhs.uk/every-mind-matters**

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For help preparing for your visit, arranging an interpreter or accessing the hospital please visit **www.uhs.nhs.uk/additionalsupport**

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