

Introduction to supported self-management for urology patients

Information for patients

Your specialist cancer team will discuss supported self-management with you, at a point in your care when this option suits you. Once you have agreed with your team that this is the right option for you, you will no longer need to travel to 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 when you need it. Your team will review any blood results and contact you if they have any concerns.

What is supported self-management?

Supported self-management puts you in control of your care. It allows you to take an active 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 skills, knowledge, and expertise to:

- make positive choices about your health care.
- manage the physical and emotional impact of prostate cancer and its treatment.
- make long-term positive changes to health behaviours (such as staying active and eating healthily).

What is the Prostate Portal?

As part of your follow-up care you will be given secure and confidential access to an online resource called the Prostate Portal. The Portal is accessed using the internet, and you can use it to:

- view your prostate specific antigen (PSA) test results.
- send messages to your specialist cancer team.
- take assessments to monitor issues related to your prostate cancer and treatment.
- create and review your personalised care plans.



What is PSA tracking and surveillance?

PSA (prostate specific antigen) 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 sent a letter reminding you when you need a blood test. The test can be carried out at your GP surgery. You and your specialist cancer team at the hospital will be sent the results. You will receive your results via letter and can also view them on the Prostate Portal.

Your specialist team will contact you if they need to discuss your PSA result with you. You may also contact your specialist cancer team if you have any questions or concerns about your PSA results.

What is the supported self-management workshop?

You will be invited to a one-off supported self-management workshop, which lasts two to three hours. The workshop is run by your specialist cancer team. It aims to give you with the skills and confidence to:

- monitor yourself for symptoms and signs that your cancer has returned.
- manage any lifestyle changes.
- set your own goals for recovery and rehabilitation.

At the workshop you will learn about how we will keep track of your PSA level and how surveillance is planned for you.

Topics covered include:

- Introduction to supported self-management
- Prostate Portal demonstration
- What is PSA tracking and surveillance?
- Coping with the physical and emotional effects of prostate cancer
- Healthy lifestyle tips, for example healthy eating, physical activity / exercise, and bone health
- Moving forward and making good plans.

How am I assessed and my care plans arranged?

You will be asked to complete regular assessments using a Health MOT checklist and a patient symptom questionnaire. You can access these via the Prostate Portal, or ask for a paper copy.

The checklist is a way of raising any concerns or problems you may have living with or after prostate cancer. These might include practical issues such as work, dealing with the physical and emotional effects of prostate cancer, financial concerns, or concerns relating to your relationships or family life. The checklist will show your needs with a clear care plan or action plan. This can help you to self-manage your care or see when other help or resources could be useful.

What happens if I do not have access to the internet?

We feel confident that with our support we can provide you with the necessary knowledge to use the custom-built systems for this self-management pathway. However, we understand that not everyone feels comfortable with technology or has easy access to a computer or smart device (such as a smart phone or tablet). If you are one of these patients you can continue to follow the nurse / clinician led follow-up pathway. If you wish to discuss this further, please speak to a member of your specialist cancer team.

How do I contact my specialist cancer team?

You can use the Prostate Portal to send messages to your specialist cancer team. They will get back to you within 48 hours (if you leave a message at the weekend they will respond the next working day).

If you wish to speak to a member of your specialist cancer team, you can contact them on:

- Telephone: 01227 86 86 66
- Email: ekhuft.uro-onccns@nhs.net

The above telephone number is the Cancer Care Line number, which is used for all patients with cancer in East Kent. Response times may vary depending on demand for the service at the time of your phone call.

The phone line is open Monday to Friday 9am to 5pm, and Saturday and Sunday 9am to 4pm. Trained cancer care co-ordinators will triage (decide how urgent) your call is and arrange the next available telephone appointment for you.

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation