

Supported self management follow up after treatment for Prostate cancer

This information is for patients in our Prostate cancer supported self-management programme

The Supported Self-Management/ Patient initiated follow up programme has been specially designed by your team to support you. It is a type of follow up, where you, the patient, are in control. It means that your normal routine will not be disrupted by regular hospital appointments; instead, you can quickly gain access to the Prostate cancer care team and hospital when you need to. It is based on evidence showing that there are no advantages to regular, fixed time follow up in hospital for well men after treatment for Prostate cancer.

Once you have entered your personalised Cancer follow-up programme you should contact us to talk about any new symptoms that you are concerned about or other issues you may have, you can do this via the My Health and Care Record Patient portal.

The aim of the My Health and Care record/ Patient Knows best Portal is to provide helpful advice and allow you to have access back to the Specialist team as required. The best way to contact the team is via the messaging section on the portal. Whilst this is NOT an emergency service, we endeavour to contact you within 48 hours of your query.

What are the alternatives?

The alternative to this Supported self-management programme (if you do not have access to the internet) is to keep your routine appointments with your Oncology specialist nurse until such a time as you can be discharged from the service.

If you feel that you are not able to manage your own condition, do not understand the information or cannot access the Online portal please let us know at your earliest opportunity. Whilst supported self-management is the best way to manage your condition out of a traditional outpatient setting, we understand that patients have varying needs, and this may not be appropriate for you at this time.

Our commitment to you:

The oncology Co-ordinator will be available to offer information and support via the My Health and Care record portal and escalate your concerns if you feel you need to speak to a clinician.

Please note this is not an emergency service, if you feel unwell or need urgent help you should call your GP, 111 or 999 for assistance.

If your specialist team feels that you should be seen back in one of our clinics because of any symptoms you are experiencing, we will make sure that you are offered an appointment within 14 days of contacting us. If necessary, further investigations may be organised and an outpatient appointment arranged to receive the results. Sometimes, verbal advice may replace the need for an outpatient appointment and may be supported by correspondence to you and your GP. We hope that this enhances and promotes your ability to care for yourself and enables you to benefit from the team's expertise as required.

Treatment Summary

Along with this document you will also be provided with a treatment summary, this will provide you and your GP information about your diagnosis and treatment as well as how your follow-up care will be organised.

This includes:

- PSA and Testosterone Monitoring regime
- PR25 and FRAX score questionnaire and schedule
- Details of your treatment
- Some of the common side effects of treatment
- if Prostate cancer returns, signs and symptoms to report to us or your GP
- Services available to patients who have completed treatment
- Further help and support and how to contact the Prostate cancer care team.

Information about the Supported self-Management/ Patient initiated follow up programme will also be sent to your GP.

PSA and testosterone monitoring regime:

Depending on your risk, your treatment, your current PSA and your age/comorbidities you team will assess when you require regular PSA and testosterone blood tests and questionnaire assessment, which is outlined in your care plan.

Questionnaire assessment and Side effects of treatment:

Patient reported outcome measures (PROMs) are a way of looking at vital symptoms which may affect your quality of life and how side effects of your treatment may be affecting you. These questionnaires can also pick up on symptoms which may warrant further investigation and are therefore vital to your overall assessment on this programme.

If you are experiencing side effects and they are distressing you, please contact your specialist nurse, consultant, or GP to discuss these further as there are treatments that can help. More detailed information on post treatment side effects can be found via the links at the bottom of this document.

Hormone therapy:

You may experience side effects that are particular to the drug you are taking. Side effects can include but are not limited to: Fatigue, erectile dysfunction, loss of libido, mood changes and chest swelling and tenderness.

Radiotherapy/ brachytherapy

Side effects include but are not limited to:

- Bowel disturbances – Diarrhoea, urgency, blood in stool.
- Bladder problems, increased frequency, or urgency on passing urine, urinary Incontinence.
- Sexual problems such as loss of libido and changes in erectile function.

If Prostate cancer returns - signs and symptoms.

Prostate cancer can sometimes return. There is no maximum time span as to when prostate cancer can return but the risk reduces over time. It is important that you are aware of what to look out for and what to do if you become concerned about anything.

Your PSA trend can give us the first indication of a change in your condition. We have given you a range which is personalised to you and your condition. If you were to exceed this range, please contact your specialist team which is outlined within this document.

If you experience any of the following or you are concerned, please call your specialist team who can support and advise you further:

- Bone pain
- New problems urinating.
- New bowel problems.

It is important to remember that physical problems will often be side effects of treatment rather than a sign that your cancer has come back, but it is important that you contact us if you are concerned.

Everyone has aches and pain, but when you have had prostate cancer, you may be more aware of them and may be concerned that any pain is related to cancer. If you experience any of these symptoms it does not necessarily mean that your cancer has returned as they can be caused by many other common conditions, but it may mean that you should get them checked out by the Specialist team.

Getting a recurrence or a new cancer can be frightening, but it is important to remember that if Prostate cancer returns, it can usually be treated.

Feelings and emotions:

Everyone will have different feelings when they no longer need to see their medical team regularly. Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment. Most people worry about the cancer coming back. This is very normal and usually these anxieties lessen with time.

Realising that there is a problem and getting help is the most important thing you can do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If you are finding it difficult to cope, your specialist nurse may be able to arrange an appointment for one-to-one support or counselling. It may also help to contact a local or national support organisation such as Prostate cancer UK, PCaSO or

Macmillan Cancer Support. Their contact details can be found at the back of this booklet.

Life after treatment

Once treatment is over people often want to know what they can do to stay healthy. You may have questions about your diet, exercise, and general well-being which we would be happy to address. We understand your need for support does not end when treatment finishes.

Brighter Outlook – Exercise and rehabilitation after cancer treatment.

Our Brighter Outlook physical activity sessions and support is there to help you through your cancer journey.

If you have been diagnosed with cancer, our specialist activity coaches can help you. You can self-refer via the website below, alternatively you can ask your Cancer Nurse/ Support worker to refer you.

Website: www.albioninthecommunity.org.uk

Welfare and benefits advice

If you are experiencing housing, employment, immigration, financial or welfare benefits issues, you can get help by contacting the Macmillan welfare and benefits advisor. The telephone number is included at the end of this booklet.

If there are other issues which concern you that are not offered here, please discuss them with your specialist care nurse who will be able to advise you on where to get help and support and information if you need it.

Macmillan Provide comprehensive financial advice and support if you are worried.
You can chat to an advisor online at

<https://www.macmillan.org.uk/cancer-information-and-support/get-help/financial-help>
alternatively Tel:0808 808 00 00

Finally

If you are worried about something to do with your Prostate cancer, or the treatment that you have had for it, please contact your key worker or specialist Nurse.

They would rather see you with something that turns out to be nothing, than for you to be at home worrying. They are there to help you, so please call if you have any questions or concerns. The contact numbers are in the useful contacts information below.

Useful contacts:

[Uro-oncology Co-Ordinator:](#)

Telephone: 07811581251

Email: esht.oncology.mhr@nhs.net

Hours: Monday to Friday 08:30-16:30

[My Health and Care Record:](#)

ESHT MHCR registration / log in:

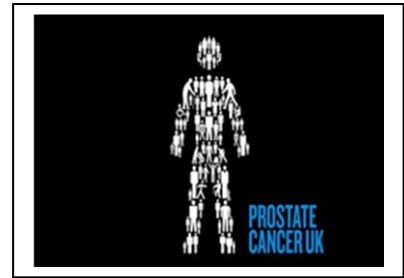
<https://my.patientsknowbest.com/?team=mhacr-sussex>

[ESHT website MHCR info:](#)

<https://www.esht.nhs.uk/my-health-and-care-record/>

Useful Contacts:

Prostate cancer UK
<https://prostatecanceruk.org>
Nurse helpline: 0800 074 8383



Macmillan Cancer Support
Free helpline: 0808 808 0000
www.macmillan.org.uk

Macmillan welfare and Benefits advice line:
01323635989



Prostate cancer support organization (PCaSO).
<https://pcaso.org>
Email: eastbourne@pcaso.org
Telephone 01323 638021
Christine Cutting – 01323 641513



LGBT Walnut
<https://www.lgbt-walnut.org.uk/>
Email: enquiries@lgbt-walnut.org.uk
Telephone: Simon Faulkner on 07947 826 853



Important information

The information in this leaflet is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: 0300 131 4731 (direct dial) or by email at: esh-tr.patientexperience@nhs.net

Hand hygiene

The Trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.

Tel: 0300 131 4434 Email: esh-tr.AccessibleInformation@nhs.net

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

Reference

The following clinicians have been consulted and agreed this patient information:
Dr Aspasia Soultati – Consultant Clinical Oncologist, Dr Sally Appleyard – Clinical Oncologist, Mark Collins – Lead Cancer Nurse, Imran Yunus – Oncology Service manager, Andrea Yardy – Oncology Advanced Nurse Practitioner, Gemma Ingram-Adams – Macmillan Senior Team Lead / Acute Oncology Advanced Nurse Practitioner.

The directorate group that has agreed this patient information leaflet:
Uro-oncology – Prostate team.

Next review date: August 2025
Responsible clinician/author: Kelly Smith – Kelly.smith35@nhs.net

© East Sussex Healthcare NHS Trust - www.esht.nhs.uk