

Prostate cancer supported self-management

A guide to your follow up care



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Your personal details and summary of your treatment

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 supported self-management

Your specialist cancer team will discuss supported self-management with you at a point in your care when this option might suit you.

Once you have agreed with your team that this is the right option for you, 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 S Madaan, 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 TrueNTH Online.
www.truenth.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
- Create a personalised care plan

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

Supported self-management workshop

You will be invited to attend a one-off four-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
- TrueNTH 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
- Moving forward and making good plans

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 TrueNTH 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 TrueNTH Online you will be able to send an email to your specialist cancer team who will respond within one working day. Emails sent at the weekend will be replied to the next working day. Alternatively you can call the team on **01322 428614** or **01322 428797**. 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 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 useful contacts

Many more are available via TrueNTH Online.

National contacts

Prostate Cancer UK

Telephone: **0800 0748383**
www.prostatecancer.org

Movember

http://uk.movember.com

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 2020**
Email: **cancerline@macmillan.org.uk**

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

RADAR national key scheme

Offers access to more than 6000 locked public toilets for disabled people in the UK. Keys can be obtained from **020 7944 2046**, and often from local social services offices, district council offices and some branches of Age Concern.
www.radar.org.uk

Local contacts

ProsPect Support Group

Fay Fawke, Lead Urology-oncology
Clinical Nurse Specialist, Darent
Valley Hospital
Contact: 01322 428614

Prostate Cancer Support Organisation Helpline

Contact: 0845 650 2555
www.pcaso.org

Kent Cancer Trust

Contact: 07792 111537

Quitters stop smoking services

Dartford Borough Council contact:
01322 343434

Dartford Citizen's Advice Bureau,

Contact: 01322 472979
www.dartfordcab.org.uk
Trinity Resource Centre, High
Street, Dartford DA1 1DE

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