



Salisbury  
NHS Foundation Trust

**information**

# **Salisbury Urology Department**

*Your guide to  
PROSTATE Supported  
Self-Management*

**Cancer Support Worker/  
SSMP coordinator  
01722 336262 ext. 2417**

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## Personal Details

Name:

Hospital Number:

Date you were diagnosed:

### PSA level at diagnosis:

*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*

Surgical consultant:

Oncology consultant:

Clinical nurse:

Care coordinator:

Health care support worker:

# **Introducing the Supported Self-Management Pathway (SSMP)**

In the past, it has been traditional for patients living with or after their prostate cancer treatment to have been seen at regular intervals by their clinical team for their follow up care. Although many patients find these pre-arranged appointments useful and reassuring, there are many that find them as a source of great anxiety and not particularly helpful, unless they have something specific they wish to discuss.

There is strong evidence to show that symptoms and concerns are addressed more quickly if patients report them as and when they occur, rather than waiting for a routine follow-up appointment. Like many other hospitals across the UK, Salisbury now has a system in place where you are able to arrange follow-up appointments as and when you need them and for 5 years following the transition to this system.

This booklet aims to explain what Supported Self-Management is and how it works. It contains all the information you need to contact the Urology (prostate) department and how to arrange any future follow-up appointments for yourself. It contains details of your cancer and the treatment you have received so far, as well as future tests you will need (your surveillance plan.) This booklet also covers some general information we think will be useful as you recover from your treatment for prostate cancer.

## **What is supported self-management?**

Supported Self-Management puts you in control of your own care and allows you to take an active and leading role in your recovery with help from your specialist cancer team. Once you have received this booklet you will no longer be given

routine follow-up appointments at regular intervals but you will still have all the surveillance tests that you would have on traditional follow-up.

You will be able to contact your cancer support worker/ SSMP coordinator directly to arrange a follow-up appointment with the urology (prostate) team as, when or if you feel concerned. The main aim of supported self-management is to enable you to develop the 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 (staying active, eating healthily).

## **Moving Forward Clinic**

To ensure a smooth transition from traditional follow-up to Supported Self-Management you will receive a date in the post to attend our Moving Forward Clinic. This clinic is a 2 hour session run by the Urology (prostate) Team which will cover medical topics such as: erectile dysfunction, continence, pelvic floor exercises and staying cancer aware. It will also cover the psychological impact of cancer such as: fatigue management, anxiety management, diet, exercise and information on other support services.

## **PSA tracking and surveillance**

PSA stands for prostate specific antigen, which is a protein found in the blood. A PSA test is a very effective way of monitoring your progress during or after treatment.

You will be notified by post when your blood test is due the

following month. The blood test can be carried out at your GP surgery or at the hospital. The urology team will check your result once it is available and inform you of the result.

If your PSA is within your normal limits you will receive a letter stating the result and the blood test form for your next PSA test and the month this will be due.

If your PSA is out of your normal limits you will receive a phone call from one of the team to explain the result and the plan going forward from this result.

## **Holistic needs assessment (HNA) and care planning**

Throughout your cancer diagnosis and treatment most patients will have been offered a Holistic Needs Assessment (HNA), you will also be asked to do one during the transition to self-supported management this is useful for identifying any issues or concerns that you may have living with or after prostate cancer. These may include practical issues such as work, or dealing with the practical and emotional effects of prostate cancer or concerns relating to your relationships or family life. The HNA will reflect your individual needs and a care plan will be created if appropriate. This can be useful for us to be able to provide you with any information or support you may need.

## **Getting back to 'normal'**

Reaching the end of your treatment can be a difficult time for many patients. Although you may feel relieved that it's finally over you may experience a feeling of "what now?" and find that you miss the security of being seen regularly at the hospital. Most patients will also find it takes longer than

expected to recover from their treatment. Below are some free activities available to you, which may be useful to assist you in moving forward.

## **Wellbeing programme**

The wellbeing programme is a 7 week course held for 2 hours a week. 1 hour is information and managing techniques session which is followed by an hour of gentle exercise. This programme is available to all patients during their treatment and up to a year post treatment. If you would be interested in attending please speak to your nurse or cancer support worker/SSMP coordinator.

## **Free swimming sessions**

Odstock Health and Fitness Centre (Salisbury Hospital) hold free swimming sessions for patients who have had a cancer diagnosis, these are held on a weekly basis. The pool and changing areas are closed for general use during this time. For more information call

**01722 336262 ext. 2085**

## **Finding support**

You may have already found that people have different ways of living with prostate cancer. There is no right or wrong way; it's just finding what works best for you. Some people prefer not to talk about it, while others find that it helps to discuss their experience. Contact your SSM coordinator and they can advise you on any other health and wellbeing sessions that may be of interest to you.

**01722 336262 ext. 2417**

## When should I contact the Cancer Support Team/SSMP co-ordinator?

**Bone pain lasting more than 6 weeks:** this may be general wear and tear on the joints/bones or it may be related to your prostate cancer. If your PSA is undetectable or very stable it is very unlikely that it is related to your prostate cancer.

Blood in your stools: this can be a late effect of radiotherapy. Most commonly it is related to haemorrhoids or piles, or straining if constipated. Sometimes it is due to an anal tear. Occasionally this could be due to an unrelated bowel disorder or may indicate a bowel cancer so needs to be reported and investigated promptly.

**Bowel problems: constipation or diarrhoea:** this may be a late effect of treatment but may also be related to your diet, fluid intake, level of physical activity or medications that you may take.

**Blood in your urine:** this could be caused by a urine infection or be related to a bladder or kidney problem which needs further investigation.

**New or worsening incontinence:** this may be a late effect of treatment, an enlarged prostate or bladder instability. If you have had surgery to remove your prostate, most likely this is due to reducing the frequency of performing pelvic floor exercises. In the first instance, increasing the frequency of performing these exercises usually improves things. In some instances you may be invited back to the hospital for urinary flow tests and an ultrasound scan.

**Changes in passing urine (hesitancy or slow flow):** may be due to a urethral stricture (a narrowing in the water pipe) or an enlarged prostate. Again, you may need to attend the hospital for urinary flow tests.

**Unplanned weight loss:** could be due to stress or related to dietary intake.

## **Who do I call to arrange a review?**

You can contact your cancer support worker/ Supported Self-management coordinator on

**01722 336262 ext. 2417**

Please leave a brief message and a contact telephone number on our answer phone. You will be contacted within 2 working days. We will briefly discuss the nature of your concern with you and if necessary arrange a clinic appointment with either your surgeon or your oncologist. We will aim to see you within 2 weeks of your telephone call. Your GP can also use this number to contact us if he or she feels you need to be seen by the urology (prostate) team.

## **Further information and useful contacts**

### **Prostate Cancer UK**

Telephone: 0800 074 8383

[www.prostatecancer.org](http://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](http://www.cancerresearchuk.org)

### **Macmillan Cancer Support**

Free information, practical and emotional support

Telephone: 0808 808 2020

Email: [cancerline@macmillan.org.uk](mailto:cancerline@macmillan.org.uk)

### **NHS Choices**

Includes all NHS online services and information, to help you make choices about your health

[www.nhs.uk](http://www.nhs.uk)

### **Citizens Advice Bureau**

[www.citizenadvice.org.uk](http://www.citizenadvice.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](http://www.radar.org.uk)

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If you need your information in another language or medium (audio, large print, etc) please contact the Customer Care Team on 0800 374208 or email: [customer.care@salisbury.nhs.uk](mailto:customer.care@salisbury.nhs.uk)

You are entitled to a copy of any letter we write about you. Please ask if you want one when you come to the hospital.

**The Friends and Family Test** - Please complete The Friends and Family Test to tell us about your experience at [www.salisbury.nhs.uk/FriendsFamily](http://www.salisbury.nhs.uk/FriendsFamily) or download our app to your smartphone from the Apple App Store and the Google Play Store.

The evidence used in the preparation of this leaflet is available on request. Please email [patient.information@salisbury.nhs.uk](mailto:patient.information@salisbury.nhs.uk) if you would like a reference list.

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