



Information for
patients and
carers

**Personalised Stratified Follow Up
After Surgery for Prostate Cancer**

What is Personalised Stratified Follow Up?

Personalised Stratified Follow Up (sometimes shortened to “PSFU”) is a type of follow up that aims to reduce unnecessary hospital visits, helping you feel more in control of your recovery.

Your Prostate Cancer team will always be on hand to help and support you, but the main difference is that you won’t routinely come back to clinic for a face-to-face appointment. Instead, you will receive all your PSA blood forms through the post, and your results will then be given to you via letter. You will also be asked to complete health questionnaires relating to your recovery. Should the team need to see you, a clinic appointment will be arranged for you.

You will have a dedicated Prostate Cancer Support Worker who will be your first point of contact for any concerns you have during your follow up. They can be contacted via phone or email if you have any concerning symptoms or worries about any aspect of your cancer diagnosis, and, if necessary, will arrange for you to be seen urgently at the earliest appointment.

What test, when?

As part of PSFU you will continue to have regular monitoring which will include:

PSA blood tests

Your PSA will be checked regularly as part of your follow up. 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 when your blood test is next due.

Health Concerns Questionnaire

You will complete this at each PSA check to determine if you have any physical problems that may require further investigation. You can get in touch with your clinical team at any time if are experiencing new or worrying signs and symptoms. You don't need to wait for your regular PSA check and Health Concerns questionnaire.

The Health Concerns Questionnaire will also offer the opportunity to discuss any other concerns you may have (such as emotional, financial, relationships etc.) with a member of the team. This is sometimes referred to as a Holistic Needs Assessment (HNA). Your team will discuss with you what your concerns are, and together with you will make a plan for how best to address your needs. A HNA can be completed or reviewed whenever you feel it is necessary – you don't need to wait until your PSA check is due.

EPIC 26 Questionnaire

This questionnaire is designed to measure quality of life issues in patients with Prostate Cancer. To help us get the most accurate measurement, it is important that you answer all questions honestly and completely.

Signs and symptoms of disease recurrence

It is important to tell your clinical team if you are experiencing any of the symptoms listed below:

- New or worsening urine leakage.
- Difficulties in urinating.
- Blood in your urine or stools.
- Bowel problems.
- New and persistent pain.

- Unplanned weight loss.

These symptoms do not necessarily mean the prostate cancer has returned. They may be due to side effects of treatment or completely unrelated to your condition. By contacting your clinical team by phone, they will be able to advise and reassure you. If necessary, they can arrange any investigations that might be required.

Finding your new normal after surgery

Reaching the end of your treatment can be a difficult time for many patients.

Although you will feel relieved that your treatment is finally over, you may also experience a feeling of “what now?” and find that you miss the security of being seen at the hospital on a regular basis. Some patients will also find that it takes longer than expected to recover fully from their treatment.

Central to PSFU is that your self-management is supported by us; therefore we need to know if we can help. It is essential that you get in touch with us should you require support at any time. Your Prostate Cancer Support Worker is available as your first point of contact.

Emotional impact

Your emotional wellbeing is equally as important as your physical health. Taking time out for yourself and doing things you enjoy is key to supporting your recovery from cancer treatment.

There is no right or wrong way to feel – everyone is different. After treatment, some people will put their cancer experience to the back of their mind and hardly ever think about it. Uncertainties may not bother them. Others think about cancer often and find that those thoughts are overwhelming. Some people find it useful to have additional support in dealing with these feelings.

Please let us know if you feel that you would benefit from some extra help.

Ways to manage worry and uncertainty

- Talk to family and friends about your concerns.
- Join a support group (ask your clinical team for details).
- Write a diary about your fears and feelings.
- Get involved with an interesting hobby or other things you enjoy doing.
- Review your priorities and direct your time towards interesting and meaningful activities.
- Remember that as time goes by, these worries will fade.
- If depression, anxiety or any part of the cancer journey becomes overwhelming seek advice from your clinical team or GP.

Relationships and sexual activity

Being diagnosed with and treated for prostate cancer is a complex and completely individual experience that can have far reaching effects throughout all aspects of your life.

Relationships can be very difficult during this time, both emotionally and physically. Adjusting to these changes is often difficult. There are a number of explanations for symptoms you may be experiencing.

Please talk either to your Clinical Nurse Specialist or your GP, who will be able to help you access any additional support that may be available.

Incontinence

If you are having/have had surgery to remove your prostate the risks of this procedure will have been discussed with you. One of these risks is urinary incontinence post-surgery.

This is because surgery can damage the muscles and nerves that control when you urinate. These include the pelvic floor muscles, which stretch below the bladder and help support it. The sphincter muscle at the opening of the bladder, which normally stops urine leaking, may also be damaged.

You might just leak a few drops when you exercise, cough or sneeze (stress incontinence) or you might leak larger amounts. Leaking urine usually improves with time. This can be hard to deal with, but there are things that can help.

Regular pelvic floor muscle exercises can help strengthen the muscles that control when you urinate and may help if you leak urine. You will receive information on how to perform pelvic floor muscle exercises after you have had your prostate operation. If you are unsure how to perform these or need any further support, you can be referred to the specialist physiotherapist at the Continence Team by your clinical team or GP.

Practical tips for incontinence:

- Plan ahead when you go out. For example, find out where there are public toilets before leaving home. Pack a bag with extra pads, underwear and wet wipes. Some men also find it useful to carry a screw-top container/travel urinal in case they can't find a toilet (see below for more details).
- Get an 'urgent' toilet card to show to staff in shops, restaurants and other public places. They should then let you use their toilets without asking awkward questions. You can order a card from Prostate Cancer UK by visiting the website at prostatecanceruk.org or calling 0800 074 8383.
- A National Key Scheme for anyone who needs access to locked public toilets across the UK because of a disability or health condition is available.

- If you often need to use the toilet at night, leave a light on in case you're in a hurry, or keep a container near your bed.

Your local Continence Team

The Lancashire Care NHS Continence Team is made up of specialist continence nurses, a specialist continence physiotherapist and an assistant practitioner.

This team provides continence advice, assessment and treatment to patients registered with a GP in the Preston or Chorley & South Ribble areas. If you are registered with a GP outside these areas, please contact your GP practice who should be able to refer you to the right service for your area.

The objective of the continence team is to promote continence by providing high quality advice and specialised treatments.

If you're dealing with urinary problems, you might feel embarrassed, isolated or stressed. It can affect your self-esteem and your independence and can have an impact on your work and social life. Many men find that seeking advice about their urinary problems helps them to feel more in control and build their confidence. The continence team can offer you practical support.

Exercise

You should follow the advice from your consultant who will advise you when the right time to start is.

Getting regular physical exercise and staying active is a great way to boost your overall health. The type of physical activity you do isn't really important – the main thing is to get active when it is the right time to do so. Regular physical activity of 30 minutes, at least five times a week has been shown to help prevent and manage over 20 chronic conditions – including cancer. Physical activity:

- Improves low mood or depression.

- Improves your quality of life.
- Improves bone health.
- Improves heart strength.
- Helps maintain a healthy weight.
- Reduces cancer-related fatigue.
- Reduces stress and anxiety.

You should try to gradually increase your daily activity with the aim of trying to build up to at least three 20 minute sessions of moderate activity each week. Walking daily and building up the distance you walk is a good starting point.

You can talk to your GP, practice nurse or Prostate Cancer Support Worker about how best to get started and to find out about local activities.

Fatigue

Fatigue is being tired – physically, mentally and emotionally. It means having less energy to do the things you need or want to do. Cancer related fatigue is one of the most common side effects of cancer treatment and often occurs without warning. Everyday activities such as talking on the phone, shopping and even eating a meal can be overwhelming.

Cancer related fatigue is worse than everyday tiredness. It lasts longer and sleep does not make it better. People have described it as overwhelming and affecting every part of their lives. Cancer related fatigue can last from months to years. It often continues after treatment has finished.

There may be a medical reason as to why you are experiencing fatigue such as anaemia, pain, anxiety, stress or the consequences of cancer

treatment. If you are concerned ask for advice from your clinical team or GP.

Fatigue - tips to help

- Take it easy. Set aside time in the day to rest. Take a short nap – no longer than an hour
- Conserve your energy for important activities. Ask for help when needed
- Maintain your energy. Drink lots of fluid and eat a well-balanced diet. Limit caffeine and alcohol and drink plenty of water.
- Get moving. When you feel up to it, light exercise throughout the week may help you preserve your energy level.

Diet and fluid management

As a general rule you should try to eat a good, balanced diet. Enjoying a healthy diet is especially important if you have had cancer. There are conflicting theories about diet and cancer, which can be confusing. Most experts would agree that a healthy diet is balanced and varied and provides all the right nutrients needed.

The main part of your diet should come from fresh fruit and vegetables and starchy, preferably wholegrain foods such as rice or pasta or potato. A smaller part of your diet should come from proteins such as meat, fish, nuts and seeds, dairy or alternatives. You should limit foods that are high in fat and sugar as they are high in calories and usually cholesterol as well.

In the long term, this diet may reduce the chances of getting heart disease and diabetes as well as certain types of cancer. This diet can also be used by members of your family.

The main things to consider in a healthy diet include:

- Eat the right amount to maintain a healthy weight.

- Eat plenty of fresh fruit and vegetables.
- Eat plenty of foods rich in fibre and starch.
- Avoid eating too much fatty food.
- Avoid sugary food and drinks.
- Avoid alcohol or only drink in moderation.

Avoid constipation: straining to empty your bowels can put pressure on your pelvic floor muscles.

Eat plenty of fibre. This would be at least 5 portions of fruit and /or vegetables a day. You may find pears or prunes particularly helpful.

Aim for a fluid intake of 1.5 - 2 litres (3-4 pints) a day. This usually works out at 6-8 drinks a day from an average sized mug. You may worry about drinking if you're leaking urine, but it can help prevent bladder irritation and infection and help prevent constipation. If your urine is dark, this could be a sign that you need to drink more.

Avoid fizzy drinks and drinks that contain caffeine (tea, coffee and cola), as these can irritate the bladder.

Be aware that alcohol can increase the number of times you need to visit the toilet so you may want to limit your intake.

Financial concerns

A cancer diagnosis can have an effect on your income, but you may be able to get help with NHS costs, grants and certain benefits. There are a number of people you can talk to for information to see if you are entitled to any additional help if financial issues are causing you to worry. Ask your Prostate Cancer Support Worker or Clinical Nurse Specialist to refer you to Macmillan Cancer Support for more information.

Returning to work

If you are going back to work, it will help to first meet with your employer, human resources department or occupational health staff. It can be useful to have someone else there (such as a work colleague or union rep) to take notes.

If you're still having some side effects from the cancer treatment, discuss any reasonable changes that can be made to help you get back to work, including a staged return to work.

Some questions that might be helpful to ask before returning include:

- Can you reduce your hours, work flexibly or work more at home?
- Will you be able to rest at work during the day?
- Is there any counselling available if you want it?

Telling friends and work colleagues about your cancer is the best way to overcome any uneasiness they may have about what has happened to you.

Finding support

The most important thing to remember is that you're not alone. You may have already found that people have different ways of coping following prostate cancer treatment. There is no right or wrong way, just what works for you. Some people prefer not to talk, while others like to get support from talking about their experience. Your Prostate Cancer Support Worker and Clinical Nurse Specialist are there to help you with support.

Our Macmillan Cancer Information and Support Centre has branches at both Royal Preston Hospital and at Chorley Hospital and offers high quality cancer information, emotional support, and practical advice to patients, relatives and carers at any stage of the cancer journey and beyond.

They aim to give you time away from the clinical environment, where you can find a listening ear and information on everything from local support groups to help for the financial problems cancer may create.

The Macmillan website and helpline are also great sources of information and support.

Contact details

Should you require further advice or information please contact:

Clinical Nurse Specialist: Katie Wass: Tel: 07590 626 657

Support Worker: Emma Meadows Tel: 07526 178 907

Email: You can send an email to our dedicated Prostate Cancer Support inbox at prostate@lthtr.nhs.uk which is monitored by the clinical team.

Lancashire Care NHS Continence Team Tel: 01772 777480

Macmillan Information and Support Centre Tel: 01772 523709

Macmillan Helpline: Tel: 0808 808 00 00

Macmillan website: www.macmillan.org.uk

Sources of further information

www.prostatecancer.org

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.patient.co.uk

www.accessable.co.uk

All our patient information leaflets are available on our website for patients to access and download:

www.lancsteachinghospitals.nhs.uk/patient-information-leaflets

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On 31 May 2017 Lancashire Teaching Hospitals became a smoke-free organisation. From that date smoking is not permitted anywhere on any of our premises, either inside or outside the buildings. Our staff will ask you about your smoking status when you come to hospital and will offer you support and advice about stopping smoking including Nicotine Replacement Therapy to help manage your symptoms of withdrawal.

If you want to stop smoking you can also contact the Quit Squad Freephone 0800 328 6297.

Please ask if you would like help in understanding this information. This information can be made available in large print and in other languages.

Gujarati:

આ માહિતીને સમજવામાં સહાયતા જોઇતી હોય તો કૃપા કરીને પૂછો. આ માહિતી મોટા છપાણ માં અને અન્ય ભાષામાં ઉપલબ્ધ કરી શકાય છે.

Romanian:

Vă rugăm să întrebați dacă aveți nevoie de ajutor pentru înțelegerea acestor informații. Aceste informații pot fi puse la dispoziție în format mare și în alte limbi.”

Polish:

Poinformuj nas, jeśli potrzebna jest ci pomoc w zrozumieniu tych informacji. Informacje te można również udostępnić dużym drukiem oraz w innych językach

Punjabi:

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਸਮਝਣ ਵੱਲੋਂ ਮਦਦ ਲੈਣੀ ਚਾਹੋਗੇ ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਇਸ ਬਾਰੇ ਪੁੱਛੋ। ਇਹ ਜਾਣਕਾਰੀ ਵੱਡੇ ਪ੍ਰਿੰਟ ਅਤੇ ਹੋਰਨਾਂ ਭਾਸ਼ਾਵਾਂ ਵੱਲੋਂ ਮੁਹੱਈਆ ਕੀਤੀ ਜਾ ਸਕਦੀ ਹੈ।

Urdu:

دو سر ی زبانوں او ر بڑی اگر آپ کو ہی معلومات سمجھنے کے لیے مدد کی ضرورت ہے تو ییچھیہا جس ییہ ابی دست ہو یسکت ہے براے مہر یبان پوے یچھہی۔ معلومات

Arabic:

مطبوعة بأحرف كبيرة وبلغات إذا كنت تريد مساعدة في فهم هذه المعلومات يرجى أن تطلب الأخرى يمكن تو فیر هذه المعلومات

Department: Urology

Division: Surgery

Production date: December 2022

Review date: December 2025

Document Code and version: CA146 V1