



Prostate Easy Access Support Service (PEASS)

A guide for patients and their carers



Personal Details

Name: _____

Christie number: _____

NHS number: _____

Date of diagnosis: _____

Diagnosis: _____

Gleason score: _____

Treatment: _____

End of treatment date: _____

My consultant is: _____

Consultant's secretary: _____

Contact phone number: _____

Named clinical nurse specialist (CNS): _____

Contact phone number: _____

Named cancer support worker (CSW) : _____

Contact phone number: _____

Contact email: **the-christie.psamonitoring@nhs.net**

My PSA parameters _____

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The Christie website

For more information about The Christie and our services, please visit www.christie.nhs.uk or visit the cancer information centres at Withington, Oldham, Salford or Macclesfield.

The PEASS workshop

Welcome

Thank you for attending a PEASS (Prostate Easy Access Support Service) workshop. During and following treatment for prostate cancer, we are encouraging patients who have a stable Prostate Specific Antigen (PSA) to self-manage their care with the support of the PEASS team. This workshop will cover all the information you need to do so.

Housekeeping

Please feel free to step away from the workshop to use the toilet as necessary. Please respect others' opinions and privacy. We ask that you do not share any personal details of any group attendees outside of the workshop.

Please speak up, ask questions, and give others in the group space to speak. We ask that mobile phones are switched off during the workshop to minimise distractions for you and others.

Aims of the workshop:

1. Ensure you have the information you need, about your follow up care and supported self-management.
2. Provide you with the skills to increase confidence to monitor your symptoms and look for any sign of cancer spread or recurrence.
3. Increase your awareness of services which can help you to manage the physical and emotional impact of prostate cancer and its treatment.
4. Encourage positive long-term changes to your health behaviours.
5. Signpost you to information and support, so that you can live as full and active life as possible.

What is The Christie PEASS (Prostate Easy Access Support Service)?

The Christie PEASS is a supported self-management follow up pathway, for patients following their prostate cancer treatment or who remain on hormone therapy treatment. Supported self-management pathways are being introduced nationally as part of NHS England's long-term plan.

Previously patients living with, or after, a diagnosis of prostate cancer were reviewed at regular intervals by their clinical team at a hospital or community clinic. Some patients find these appointments useful and reassuring, however many more find them unhelpful and a source of anxiety, unless they have something specific they wish to discuss.

There is strong evidence that symptoms and concerns are managed more quickly and effectively if patients report them as and when they occur, rather than waiting for a routine appointment. The Christie have therefore changed the way we follow up some of our prostate cancer patients, and this new pathway is known as The Christie PEASS.

Patients who have been enrolled onto The Christie PEASS pathway will no longer have routine follow-up clinic appointments. You will be able to contact your PEASS team directly as and when you need to if you have any symptoms or worries.

There are lots of things you can do to look after your own health during and after cancer treatment. Many of these can be done without the involvement of your clinical team, such as physical activity and healthy eating.

It is important to remember that you are not yet being discharged and that you will have easy access to your PEASS team if you have any worries or concerns.

What are the benefits of moving onto The Christie PEASS pathway?

- You will not have to make trips to a clinic appointment or pay travel and parking charges when you are feeling well – this will also reduce your carbon footprint.
- You will not need to take time off work for unnecessary routine appointments.
- Your PSA blood test results and side effects from treatment will continue to be monitored and you will be supported with these.
- You can contact your PEASS team, as and when you need to, with any concerns relating to your prostate cancer or side effects from treatment, instead of having to wait for your next clinic appointment.

We have left space at the front of this booklet for you to add your own diagnosis details and the treatment you have received. It also contains all the information you need to contact your team if you have any questions or worries.

What is Prostate Specific Antigen (PSA)?

A PSA blood test measures the amount of PSA in your blood. PSA is a protein produced by normal cells and by prostate cancer cells and you will continue to have regular PSA blood tests, usually every 6 to 12 months, for the rest of your life.

It is essential that you and your PEASS team are aware of your exact PSA result as this is the most effective way to monitor your prostate cancer during and after treatment.

Your prostate cancer support worker will monitor your PSA schedule and remind you when you are due a PSA blood test. This reminder will be sent to you by email, text message or letter 2 weeks before your PSA test is due.

Your PSA test result will be recorded in your clinical notes, reviewed by a clinical nurse specialist and if necessary, they will arrange a clinic appointment for you.

We will send your PSA test result to you and to your GP by email. We understand that not everyone feels comfortable with technology or has access to a computer, so you will be able to continue to receive information from us by letter if you prefer.

We encourage you to keep a record of your PSA schedule and levels at the back of this booklet.

Where can I have my PSA blood test done?

The bloods closer to home (BCTH) service enables patients under the care of The Christie to have a blood test at a location closer to home, at a time and date convenient to them.

Local BCTH clinics are facilitated by The Christie staff. The PSA blood sample will be transported back to The Christie on the same day and the results will be available to your PEASS team.

To book a blood test appointment closer to home, visit www.christie.nhs.uk/bloodtest or telephone **0161 918 7654**.

To book a blood test appointment at The Christie Withington, email your PEASS team using the following email address the-christie.psamonitoring@nhs.net or telephone **0161 956 1087**.

Please ensure that your PSA is requested when you have your blood test.

It may be helpful to take your reminder text, letter, or email with you to your appointment.

What to expect from the PEASS

Health Questionnaires:

As well as being able to report any urgent concerns you may have to the PEASS team, you will also be asked to complete a health questionnaire each time your PSA test is due. These are sometime referred to as Patient Reported Outcome Measures (PROMs).

Your questionnaire will be sent electronically (ePROMs) or posted out to you at the same time as your PSA reminder. You will be asked several questions which will cover your current health and wellbeing.

This is an essential part of your follow up care. A clinical nurse specialist (CNS) and your cancer support worker (CSW) will look at your completed health questionnaire after you have submitted it online or posted it back to us. We will then telephone you to discuss any issues you have asked us to contact you about.

Important signs and symptoms to report

If you experience any of the symptoms below it is important that you report them to the PEASS team. These symptoms do not necessarily mean your prostate cancer is more active or has returned but they may be due to side effects of treatment or completely unrelated to your cancer diagnosis.

- Bladder problems – including blood in urine, pain when passing urine, new or worsening incontinence, difficulties in passing urine (hesitancy or slow flow) or passing urine more frequently than is normal for you, especially at night.
- Bowel problems – including blood in your poo, difficulties opening the bowels or incontinence, pain when you poo or pooing more frequently.

- New bone pain lasting more than 6 weeks.
- Unplanned weight loss.

Managing the side effects of prostate cancer treatment

Bowel side effects

Radiotherapy for prostate cancer (external beam radiotherapy and brachytherapy) can cause bowel problems for some people. Radiation can cause the lining of the bowel to become inflamed (proctitis) which can lead to symptoms such as:

- loose and watery bowel movements (diarrhoea)
- passing more wind than usual
- needing to go to the toilet more often, or having to rush to the toilet
- feeling an urge to have a bowel movement, but then not being able to go
- a feeling that your bowels haven't emptied properly
- pain in the stomach area (abdomen) or back passage
- bleeding from the back passage

Some people find that changes to their bowel habits settle down a few weeks after finishing treatment. For others, the changes last longer. Some people get bowel problems months or years after treatment.

Living with bowel problems can be distressing, and for a lot of people it's not an easy thing to talk about. The Christie PEASS team are here help people with these issues and they are used to discussing the problem and finding ways to deal with it.

How can I help myself?

You may find it helpful to plan ahead and find out where toilets are before you go out and carry absorbent pads. Information about **toilet cards and radar keys** are available at the back of this booklet.

If you are having problems with diarrhoea, eating less fibre for a short time may help.

Foods such as beans and pulses, cabbage, broccoli, and cauliflower, fizzy drinks and beer can all cause wind and bloating so you may want to avoid these. Chewing your food slowly can also help.

If you're gay, bisexual or a person who has sex with men, and are the receptive partner ('bottom') during anal sex, then bowel problems after radiotherapy may be a particular issue. **Read the information for gay and bisexual men produced by Prostate Cancer UK.**

Macmillan Cancer Support, Prostate Cancer UK and the Bladder and Bowel Foundation also produce detailed information about coping with bowel problems.

Lower Urinary Tract Symptoms (LUTS)

Many people get urinary problems as a side effect of their treatment. This is because prostate cancer treatment can damage the nerves and muscles that control passing urine.

Side effects depend on the treatment you have and on whether you had urinary problems before treatment.

Urinary problems can affect your self-esteem and independence and your work, social and sex life.

How can I help myself?

Making some changes to your lifestyle may help, and there are some practical steps that can make things easier.

- Drink plenty of fluids. Aim to drink about 1.5 to 2 litres (3 to 4 pints) a day. You may worry about drinking lots if you're leaking urine, but it can help prevent bladder irritation and infection. If your urine is dark, this could be a sign that you need to drink more.
- Cut down on fizzy drinks, alcohol and drinks that contain caffeine (tea, coffee, and cola), as these can irritate the bladder.
- Regular pelvic floor muscle exercises can help strengthen the muscles that control when you urinate and help if you leak urine.
- Try to maintain a healthy weight. Being overweight can put pressure on your bladder and pelvic floor muscles.
- If you smoke try to stop as this can cause coughing, which puts pressure on your pelvic floor muscles.
- 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.
- 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 people find it useful to carry a screw-top container in case they can't find a toilet.
- Get an **Urgent toilet card** to show to staff in shops, restaurants and other public places. They should let you use their toilets without asking questions.
- There is a National Key Scheme (**Royal Association for Disability and Rehabilitation – RADAR**) for anyone with a disability or health condition who needs access to locked public toilets across the UK.

Erectile Dysfunction (ED)

Dealing with prostate cancer and living with the side effects of treatment can have an impact on your sex life. Many people with prostate cancer say that the changes to their sex lives and relationships are some of the biggest issues they deal with.

Treatments for prostate cancer can affect:

- How you feel about yourself sexually
- Your desire to have sex (libido)
- Your ability to have children (fertility)
- How your body looks
- Your relationships
- Your ability to get an erection, ejaculate or have an orgasm

There is no right or wrong way to deal with changes to your sex life. Some people will want to try treatments for erection problems, while some will prefer to find other ways to be close to their partner. What's important is that you find what's right for you and don't be afraid to ask for support if you want it.

It can be difficult talking about sex and erection problems, but talking to your doctor, nurse or cancer support worker will mean you can get treatment and support.

How can I help myself?

Some people find that sexual counselling can be beneficial, and you can ask your GP to refer you for this.

Ask for a referral to an ED clinic:

- Post prostatectomy – speak to your PEASS team

- Post internal or external radiotherapy and/or hormones – speak to your GP and ask to be referred to your local ED clinic

Lifestyle changes such as staying a healthy weight and being physically active can help improve your sex life. Physical activity can help you stay a healthy weight and lowers the risk of some health problems that can cause erection problems.

Smoking may increase the risk of erection problems and treatments may not work as well if you smoke. Stopping smoking isn't easy but there is help available. The NHS website has information, advice, and support for giving up smoking, including quit kits.

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 sometimes 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 PEASS team or GP.

How can I help myself?

- Take it easy.
- Set aside time in the day to rest, take a short nap if you feel the need.
- Conserve your energy for important activities.
- Ask for help from friends and family when needed.
- Maintain your energy by drinking lots of water-based fluids and eating a well-balanced diet. Limit caffeine and alcohol, especially before bed.
- Get moving. When you feel up to it, light exercise throughout the week may help to improve your energy level.

Though fatigue is a common symptom when you have had cancer, there are steps you can take to reduce or cope with your symptoms. Contact your PEASS team or GP who can advise you on how you can find more information.

Hormone therapy side effects

Hormone therapy affects people in different ways. Some people have fewer side effects than others. This doesn't mean that the treatment is any less effective.

There are treatments and support to help manage side effects. Some people find that their side effects get better or become easier to deal with over time. The risk of getting each side effect depends on your type of hormone therapy and how long you take it for. If you have hormone therapy alongside another treatment, you may get side effects from both treatments.

The side effects of hormone therapy are caused by lowered testosterone levels. Side effects will usually last for as long as you are on hormone therapy. If you stop your hormone

therapy, your testosterone levels should gradually rise again, and side effects should reduce. Your side effects won't stop as soon as you finish hormone therapy, it may take several months.

Some of the side effects you may experience because of hormone therapy are listed below. If you are experiencing any of these, we recommend that you look at the information available from Prostate Cancer UK and Macmillan. You can also contact your GP or your PEASS team for help and advice.

- Hot flushes
- Weight gain
- Weakness of the muscles
- Changes to your memory and concentration
- Breast swelling and tenderness
- Loss of body hair
- Bone thinning
- Mood change

How can I help myself?

- Eat a healthy balanced diet
- Get plenty of rest
- Reduce alcohol intake
- Wear light clothing if hot flushes are troubling you
- Keep physically active

Bone health

Hormone therapy treatments can sometimes lead to bone thinning (osteopenia or osteoporosis) which may mean you have an increased risk of fracture. It is important to keep

your bones as healthy as possible if you are on hormone treatment.

How can I help myself?

You can make changes to your lifestyle to improve your bone health and reduce your risk of osteoporosis.

- eat a healthy, balanced diet
- get some sunshine, Vitamin D, but stay safe in the sun
- keep physically active
- do some weight bearing exercise e.g. walking, dancing, hiking, jogging
- try doing some resistance exercises to strengthen muscles, bones and joints e.g. hand weights, resistant exercise machines, resistance bands

These changes are helpful for everyone, not just people affected by cancer.

Emotional impact

After treatment, some people will put their cancer experience to the back of their mind and hardly ever think about it. Some people will focus on the positive changes cancer has brought, such as a new purpose and strength in life. Others think about cancer often and find that those thoughts are overwhelming. They may live with fears about whether their cancer will come back, get worse, or how it will affect their future. It is important to understand that everybody reacts in a different way.

How can I help myself?

Everyone has their own way of dealing with prostate cancer, but you may find some of the following suggestions helpful.

- Be as active as you can be. Physical activity such as gentle walking can improve your mood.
- Think about what you eat and drink. Some people find they manage better by aiming for a healthy, balanced diet.
- Share what you're thinking – find someone you can talk to. It could be someone close, or someone trained to listen, like a counsellor.
- Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like listening to music or breathing exercises.
- Set yourself goals and things to look forward to.
- Find more strategies in the PCUK booklet, *Living with and after prostate cancer: A guide to physical, emotional and practical issues*
- Get more ideas about how to look after yourself from local cancer support centres as well as Macmillan Cancer Support, Maggie's Centres and Look Good Feel Better.

When to ask for help from a professional:

- If you are finding it difficult to rebuild your life because of uncertainty about prostate cancer.
- If you constantly worry that the prostate cancer is going to come back or is going to spread or get worse.
- If you worry about prostate cancer before you go to bed at night and the first thing in the morning.
- If you are having problems sleeping that have lasted for a few weeks or more.
- If you have little or no appetite.
- If you have no desire to spend time with friends.
- If you have little or no interest in carrying on with your normal routine.

Please speak to your GP if you are experiencing any of these issues.

Smoking

Research suggests that smoking makes prostate cancer more likely to grow and spread to other parts of the body. Smoking may also make prostate cancer more likely to come back. However, if you stop smoking your risk of prostate and other cancers should start to drop and after 10 years it could be as low as for people who have never smoked.

There is lots of support available to help you to stop smoking. Contact one of the stop smoking services available at the back of this booklet or speak to your GP.

Exercise and healthy eating

Physical activity

There are many benefits of physical activity. Exercise and keeping physically active has shown to be beneficial both during cancer treatment and following a cancer diagnosis.

Being physically active has many benefits such as:

- Reducing tiredness and fatigue
- Reducing anxiety and depression
- Improving your mood
- Strengthening your muscles, bones and joints
- Improving heart health
- Reducing the risk of other health problems such as diabetes, heart disease, kidney disease and strokes
- Reducing your risk of a cancer recurrence

Exercise tips

Keep in mind the benefits of becoming more active and what that is going to do for you.

Throw away the old tracksuit/jogging bottoms... and the memories too. It's normal to have a mental image of yourself when you last exercised. Starting today, make new memories.

Prepare. If you feel that you do not have time, write it down like an appointment every day. You would not cancel an appointment, would you? Why would you cancel on yourself? You are important too.

Start slowly. Do much less than what you think you are capable of. Take a 20-minute walk if you are returning to exercise. You might feel like it is not enough, but it is a good start.

Get the family or friends involved and go walking together. Share your plans to exercise with people you know are supportive. Celebrate with a little something special every time you manage to exercise.

Ask for advice from your GP or PEASS team if you are unsure about any aspect of exercise and your health.

Try not to feel too bad if you do not manage to exercise as planned. Think about why you did not get round to it and what you could do differently next time to change that.

Healthy eating

A healthy diet and regular physical activity are important for general health and can help you stay at a healthy weight. This may be particularly important if you have or have had prostate cancer, as there is strong evidence that being overweight raises the risk of aggressive (more likely to spread) or advanced prostate cancer.

We don't recommend any set diet or exercise programme. Instead, we suggest some changes to improve your overall

Useful information

Bladder and Bowel Foundation

0845 345 0165

www.bladderandbowelfoundation.org

Cancer Research UK

Cancer Research UK patient information resources

Helpline: 0808 808 2020

www.cancerresearch.org

Citizens Advice Bureau

www.citizensadvice.org.uk

LGBT Foundation

A national charity delivering advice, support and information services to lesbian, gay, bisexual and trans communities.

www.lgbt.foundation

Look Good, Feel Better

Free supportive workshops both virtually and at cancer care centres and hospitals across the UK.

www.lookgoodfeelbetter.co.uk

Macmillan Cancer Support

0800 808 0000

www.macmillan.org.uk

Maggie's Centre

0300 123 1801

www.maggies.org

Men's Health Forum

020 7922 7908

www.menshealthforum.org.uk

NHS Choices

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

www.nhs.uk

Orchid – Fighting Male Cancer

020 4655 766

www.orchid-cancer.org.uk

Prostate Cancer UK

0800 074 8383

www.prostatecanceruk.org

Prostate Cancer Support Federation

0845 601 0766

www.tackleprostate.org

Prostate Cancer Support Organisation

0845 650 2555

www.pcaso.org

Quit Now Smokefree NHS

0300 123 1044

www.quitnow.smokefree.nhs.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 **0207 944 2046** and often from local social services offices and district council offices.

www.radar.org.uk

The Christie cancer information centre

0161 446 8100/8107

the-christie.informationcentre@nhs.net

Toilet cards

Available from Macmillan Cancer Support and Prostate Cancer UK

UK Movember Foundation

020 7952 2060

www.uk.movember.com

Conclusion

We thank you for attending the workshop today. The information from today's workshop is also available online at www.christie.nhs.uk

You may wish to watch this with your family, or in the future to refresh your memory about what you can do to self-manage your follow up care.

We hope that this workshop has explained what the PEASS pathway means for you and has given you the knowledge, skills and confidence for you to be involved in your supported self-managed follow up care.

If you have any questions or concerns, please do not hesitate to contact us via the contact details on page 2.

My PSA results

Please ensure that when you attend for your blood test that your PSA is requested on the blood form, prior to your blood sample being taken from you.

Next blood test due	Appointment date	Appointment location	PSA requested	PSA result

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact the-christie.patient.information@nhs.net

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

The Christie at Macclesfield **0161 956 1704**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

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0161 446 3000

www.christie.nhs.uk



The Christie Patient Information Service
August 2023 – Review August 2026

CHR/URO/1561/02.08.23 Version 1