

Patient Information



Hospital number:

Prostate Cancer Team contact details

Telephone: 01270 612011

Email: PCT@mcht.nhs.uk

Uro-Oncology Nurse Specialist (Keyworker)

Lorraine Javle

Karen Hatch

Vanessa Adamson

Prostate Navigator

Linda Green

Calls and emails in-boxes are monitored Monday to Friday, 9.00am to 4.00pm (except bank holidays). One of the team will aim to contact you the same day or the next working day.

Please note these help-lines are not for emergencies. If you need urgent care, please phone your GP Surgery or NHS 111.

Please let us know if you change your address or GP.

Introducing Supported Self-Care

Your Prostate cancer team will discuss supported self-management with you and you will no longer need to travel to hospital for routine follow up appointments. Instead you will be able to contact your team at the hospital directly if you have any questions or concerns via telephone or e-mail. Your team will contact you when your blood test is due and review your blood results. They will inform you by letter with the results.

The Support Package

The supported self-care package includes the following:

- Access to the Prostate Cancer Team
- Access to telephone and email helplines
- Holistic Needs Assessment (HNA)

The Prostate Navigator

The Prostate Navigator's role involves co-ordinating the different components of the support package. They have the knowledge and access to a wide range of resources that may be available to you, for example financial advice, complimentary therapies and counselling.

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 Prostate Cancer Team at the hospital will be notified of the result. You will receive your results via a letter. If you have any concerns about your PSA result you can contact your Prostate Cancer Team by telephone or send an email to the team directly. The hospital will contact you directly if they need to discuss your PSA result with you.

Holistic Needs Assessment (HNA)

The HNA helps to identify on-going problems or concerns you may have living with, or after, prostate cancer. These might include practical issues such as work, dealing with the physical and emotional effects of prostate cancer, managing the side effects of treatment, or possible concerns relating to your relationships or family life.

You will be offered the opportunity to complete a HNA when you are transferred to self-supported management. You will be given the choice of discussing the completed questionnaire with your Keyworker or the Prostate Navigator, either face-to-face, or by telephone. If areas of needs or concerns are identified your Keyworker or Prostate Navigator will offer advice, strategies, support and information to deal with these. You can request to have a HNA at any point by contacting the team either by telephone or email.

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 them about details of local support groups if you think it may be helpful.

Important Signs and Symptoms

You should contact the Prostate Cancer Team if you experience any of the following symptoms:

- **Bone pain lasting for more than 6 weeks:** this may be general wear and tear on the joints/bones or it may be related to the prostate cancer. If your PSA is undetectable or very stable it is very unlikely that it is related to your prostate cancer.
- **Blood in poo:** this can be 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, the level of activity or medications you may take.
- **Blood in 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 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 test and ultrasound scan.
- **Changes in passing urine:** hesitancy or slow flow may be due to a narrowing of the water pipe or an enlarged prostate. This might mean you need to attend the hospital for assessment and urinary flow tests.
- **Unplanned weight loss:** could be due to stress or related to dietary intake.

Emotional Impact

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. They may live with fears about whether their cancer will come back, get worse, or how it will affect their future. Some people will focus on the positive changes cancer has brought, such a new purpose and strength in life. They may more easily accept and adapt to changes and challenges. Any one of these reactions is normal. Some degree of worry is quite normal. It would be uncommon not to be worried about these issues at some point.

When to ask for help

If you:

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

Ways to manage worry and uncertainty about prostate cancer:

- Learn to focus on the ways prostate cancer has made you a stronger person.
- Talk to family and friends about your concerns.
- Join a support group, details of which can be provided by your Prostate Cancer Team.
- Write a diary about your fears and feelings.
- Get involved with an interesting hobby or others 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 Prostate Cancer Specialist or GP.

Some friends and family members may be uncomfortable talking about cancer. If that is the case, it is very important to remind yourself:

- You have done nothing wrong by bringing the subject up – the other person may be responding to his or her own experience and fear of cancer.
- The other person may not know how to discuss the subject.
- Although what they said may not be what you wanted to hear, it may be that this person is doing the best he or she can right now.

Find a cancer support group

- Support groups can provide a safe environment to share experiences with other people who have gone through similar experiences. You can also learn new ways to handle difficult situations and talk about emotional issues that only other people like you will understand. These groups can offer an opportunity to learn different ways of coping. Macmillan Cancer Support are examples that can help. Your Prostate Cancer Team can signpost you to local support groups in your area.
- Talk with a professional therapist if worry or low mood overwhelms you. Counsellors are trained to listen and can help you to find your own ways to deal with things. Your Prostate Cancer Team or your GP could refer you to a counsellor or you can pay for one and arrange yourself.

Further information and useful contacts

National Contacts

Prostate Cancer UK
Telephone: 0800 0748383
www.prostatecancer.org

Movember
<http://ukmovember.com>

Cancer Research UK
Cancer research UK's patient information resources
Tel Helpline: 0808 800 4040
www.cancerresearch.org

Macmillan Cancer Support
Free information, practical and emotional support
Telephone: 0808 808 2020

NHS Choices
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 telephoning 020 7944 2046. You can also try your local social services offices, district council offices and some branches of Age Concern.

Local contacts

Mid Cheshire Hospital Macmillan Cancer Information and Support Services
Tel: 01270 273603/278343

Leighton Hospital Prostate Cancer Support Group
Provide an opportunity to meet people who have been affected by prostate cancer.
Tel: 07773 968842
www.prostateleighton.org.uk

This information is available in audio, Braille, large print and other languages. To request a copy, please ask a member of staff.