

**GP Practice Address / Letterhead:**

**Contact telephone number:**

Dear \_\_\_\_\_

**Information about your Prostate Cancer follow-up care**

You have been having follow-up care for your GP since your care was transferred from the hospital. The Transforming Cancer Services Team Healthy London Partnership and Croydon Clinical Commissioning Group are working together with the GPs at your practice to see how good the care for patients with prostate cancer is and to look at ways to make it better.

**Your next check-up is due in:** --/-- (month/year)

When you attend your next appointment at the practice you may notice that the GP or the Practice Nurse will ask you more about your prostate cancer or the treatment you have had and how it might be affecting you.

We want you to have the opportunity to talk about anything that is worrying you about your cancer or any treatment you may have had. If you do not wish to discuss anything or are symptom free and have no concerns then that is ok.

We have included a Prostate Cancer Care Plan in this information pack that includes a list of common problems and worries that patients have reported in the past. If there, please select the 3 most important things on this that are affecting you and you need more support please tick the relevant things and bring the form with you to your appointment. Your GP or practice nurse will then be able to give you information about the supporting services available to you.

There has been a lot of information written for new patients who are now having their follow up at their GPs. We would like you to have the same information.

**Enclosed in this letter is:**

- Information about the signs and symptoms that you should look out for and what to do if you notice them (page 3).
- Information on local and national support organisations (page 4, 5 and 6).
- A short list of medical terms that you may come across (page 6 and 7).
- A Prostate Cancer Care Plan that you can use to help think about things that may be worrying you or that you would like to discuss with your GP at your appointment. (page 8)

If you have any concerns about your health before your prostate follow-up appointment, please book an appointment to see a GP in the usual way. We look forward to seeing you at the practice.

Yours sincerely

**GP name and signature**

## Signs and symptoms to look out for

There are certain signs and symptoms that may be a cause for concern in people with a history of prostate cancer. These symptoms can also be side effects of treatment or be caused by other things, such as an enlarged prostate or urinary tract infection. You may have had some of these urinary symptoms for some time, in which case if they are becoming more bothersome it would be a good idea to let your GP or practice nurse know.

**It's important that you see your GP if you develop or experience any changes to these signs and symptoms:**

- Needing to urinate more often, especially at night time, for example if you need to go again after two hours
- Blood in the urine or semen
- A weak flow of urine or feeling you need to strain to go
- Taking a long time to finish urinating
- A feeling you haven't emptied your bladder
- Needing to rush to the toilet, or leaking before you get there
- Dribbling urine
- Pain when urinating
- Persistent aches and pains in your bones for longer than one week
- Continuous pain in your pelvic region – the area below your stomach
- Unexplained weight loss
- Swelling in your legs.

## Further information and support

If you have questions about prostate cancer you can discuss this with a Prostate Cancer UK Specialist Nurse on **0800 074 8383**. Prostate Cancer UK is a UK charity that provides information and support on prostate cancer.

**Prostate Cancer UK helplines are open Monday to Friday 9am-6pm and Wednesday 9-8pm**

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Transforming Cancer Services Team for London



Croydon Clinical Commissioning Group



## Local Support Organisations

### South East Cancer Help Centre – telephone: 020 8668 0974

Cancer support services are available to men in South East London who have been affected by prostate cancer. The Centre offers a wide range of services including

- Counselling sessions
- Complementary therapies
- One-to-one and support group sessions.

Their services help men come to terms with a diagnosis of prostate cancer and provide an opportunity to meet other people in similar situations.

Based in Purley, the South East Cancer Help Centre strives to provide group support, complementary therapies and information to people who have been affected by cancer. The centre is open to anyone affected by cancer so partners and carers are welcome.

If you would like to attend the support group please speak directly to the **South East Cancer Help Centre** on **020 8668 0974**.

Please mention that you found the service via this Welcome Letter.

[www.sechc.org.uk](http://www.sechc.org.uk)

### Paul's Cancer Centre – telephone: 020 7924 3924

The Centre's services can be used by anyone over 18 years who can reach the Centre, which is less than 10 minutes' walk from Clapham Junction station in south London.

Services provided include:

- one-to-one services of counselling, various forms of massage and reflexology, hypnotherapy, healing and relaxation & visualisation
- groups and classes (including the creativity group, and meditation and qigong classes)
- support groups (the African-Caribbean, Asian, and Prostate Cancer support groups)
- a telephone support line, a lending library and our Macmillan Information Service which provides information about cancer, its treatments and advice on accessing practical help

The Centre is open to all people regardless of gender, race, sexual orientation or religious belief and the Centre's premises are accessible by people with disabilities.

If you would like any more information, please contact **Paul's** on **020 7924 3924**



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### **Cancer Black Care – telephone: 020 8961 4151**

To raise awareness of cancer within the black and minority ethnic communities and to influence the information, care and treatment of cancer to ensure it is appropriate and sensitive to ethnic and cultural diversity.

Core support services include dietary needs, befriending, counselling, advocacy, home/hospital/hospice visits, telephone/face-to-face contact, advice on general welfare benefits, community health awareness events and support throughout illnesses.

The groups runs on the first Saturday of each month between the hours of 2pm-4pm at **305-307 Camberwell Road, Camberwell, London SE5 0RZ.**

Please call **020 8961 4151** for more information.

[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

### **Metro Walnut Gay and Bisexual Support Group – telephone: 020 8305 5000**

The Metro Centre offers a prostate cancer support group for gay and bisexual men living in South East London. The Support group often provide a source of information and informal support for men and those they love.

The support group meet monthly in Greenwich, South East London and is open to anyone who lives in South London.

If you would like to attend a meeting, please speak directly to the **Metro Centre** on **020 8305 5000**

[www.metrocentreonline.org](http://www.metrocentreonline.org)

## **National Support Organisations**

### **Prostate Cancer UK – telephone: 0800 074 8383**

**(helpline open Monday to Friday 9am-6pm, plus Wednesday 9-8pm)**

Prostate Cancer UK (PCUK) work to help more men survive prostate cancer and enjoy a better quality of life. Their three priorities are:

- Supporting men and providing information
- Funding research
- Leading change to raise awareness and improve care

PCUK had a UK-wide confidential helpline staffed by specialist nurses, for anyone concerned about or affected by prostate cancer: For more information ring 0800 074 8383 or visit their website [www.prostatecanceruk.org](http://www.prostatecanceruk.org)



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**Macmillan Cancer Support – telephone: 0808 808 00 00  
(helpline open Monday to Friday, 9am-8pm).**

Macmillan is a great source of support, helping with all the things that people affected by cancer want and need. The service is not only for patients who live with cancer; it also helps carers, families and communities.

They can provide realistic advice on managing side effects, juggling financial problems and trying to come to terms with your emotions. Whether you've just been diagnosed, are going through treatment now, or have been told your cancer can't be cured, or if you finished treatment years ago, they are can you information [www.macmillan.org.uk](http://www.macmillan.org.uk)

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## Definitions of commonly used medical terms

### Follow-up:

If you've had treatment that aimed to get rid of your prostate cancer, such as surgery, radiotherapy or brachytherapy, you will have regular check-ups afterwards. This is often called follow-up.

The aim of your follow-up appointments is to:

- check how your cancer has responded to treatment
- deal with any side effects of treatment
- give you a chance to raise any concerns or ask any questions.

### Hormone treatment

Hormone therapy stops the hormone testosterone from reaching prostate cancer cells. It treats the cancer, wherever it is in the body.

Testosterone controls how the prostate gland grows and develops. It also controls male characteristics, such as erections, muscle strength, and the growth of the penis and testicles. Testosterone doesn't usually cause problems, but if you have aggressive prostate cancer, it can make the cancer cells grow faster. In other words, testosterone feeds the prostate cancer. If testosterone is taken away, the cancer will usually shrink, wherever it is in the body.

Hormone therapy alone won't cure prostate cancer but it can keep it under control, sometimes for several years, before you need further treatment. It is also used with other treatments, such as radiotherapy, to make them more effective.



## Watchful Waiting

Watchful waiting is a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to keep an eye on the cancer over the long term, and avoid treatment unless you get symptoms. The aim of any treatment given would be to control the symptoms of the disease.

## PSA Test

The prostate-specific antigen level blood test (PSA test) is often a good indicator of how effective treatment is or has been. Generally speaking, your PSA level should be very low after treatment but PSA results aren't always cut and dry. Your GP will contact your hospital consultant should anything abnormal appear in your results.

The level of PSA may fluctuate a bit on their own in some cases. The blood PSA level is an important tool to monitor the cancer, but not every rise in PSA necessarily means that the cancer is growing and requires treatment right away.

## Localised prostate cancer

Prostate cancer that is contained within the prostate gland.

## Locally advanced prostate cancer

Locally advanced prostate cancer is cancer that is starting to break out of the prostate, or has spread to the area just outside the prostate.

## Lower urinary tract symptoms (LUTS)

Problems passing urine, including leaking urine, needing to pass urine frequently or urgently, and needing to get up in the night to pass urine.

For a complete definition of medical terms in relation to prostate cancer, please call **Prostate Cancer UK** on **0800 074 8383** and ask for the "A-Z of Medical Words".

Alternatively, you can call **Prostate Cancer UK** on **0800 074 8383** or visit [www.prostatecanceruk.org/information](http://www.prostatecanceruk.org/information) for a full list of all PCUK's information booklets and leaflets that are free including:

- Follow-up after prostate cancer treatment and side effects
    - A guide to common prostate problems
    - Understanding the PSA test
    - Prostate Cancer treatments such as Watchful Waiting and Hormone therapy
    - Sex and prostate cancer
    - Urinary and incontinence problems
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### Prostate Cancer Care Plan (please bring this to your next prostate cancer appointment)

We have asked you to complete a Prostate Cancer Care Plan. This provides us with information to give you the best support to manage your condition. This document lists some issues / concerns. Please indicate if any apply to you and if so which you would like to discuss at your next prostate cancer review with your GP/Practice Nurse.

Physical Concerns	Yes	No	Discuss	Practical Concerns	Yes	No	Discuss	Relationship Concerns	Yes	No	Discuss
Problems when urinating or loss of bladder control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Caring for others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	With children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of Bowel control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Housing or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	With partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation or diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Parking or transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	With others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bleeding from the bowel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Work or education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Grocery shopping or making food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Indigestion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Bathing or dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Bone pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Laundry or housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Feeling tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Information needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Poor sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<b>Emotional Concerns</b>							
Problems getting or keeping an erection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loneliness or isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
No or loss of sex drive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sadness or depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Unplanned weight gain or feeling swollen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worry, fear or anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Unplanned weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Helplessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

**Please write down anything else you wish to discuss with the GP or Practice Nurse:**

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*With thanks to STAR Project Team Southampton University Hospital for allowing us to adapt their assessment tool.*

