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NHS
Sherwood Forest Hospitals
NHS Foundation Trust

Personalised follow-up after treatment for prostate cancer

Information for patients and carers

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Introduction

This personalised follow-up programme has been specially designed by cancer specialists to support you when you have completed your primary treatment for prostate cancer.

The programme is based on evidence demonstrating that for well people after treatment, there is no advantage to scheduling appointments at fixed intervals where you have to attend a hospital appointment.

The period of fixed interval appointments you require will therefore be tailored to you, based upon your individual treatment plan and needs. When a cancer nurse specialist feels it is clinically appropriate, you will then be discharged under the care of your GP.

Personalised follow-up involves you, as the patient, being in control of your follow-up care. It means you will be offered opportunities to identify any additional specific needs you may have, so these can be addressed.

It also means that your day-to-day life will not be disrupted by regular hospital appointments – instead, you will be provided with information to help you identify when you may need to see a healthcare professional, so you can sort out contact with them as and when you need them.

The following sections provide a summary of what you can expect when on the personalised follow-up pathway.

Treatment summary

At the end of your treatment, you will have received a treatment summary (generated following your nurse follow-up appointment).

Your treatment summary provides information about your diagnosis and treatment(s), as well as how your follow-up care will be organised. This is an important document which will help you to effectively manage your follow-up care.

This includes:

- The dates of future PSAs (if applicable).
- Your planned anti-cancer treatments following surgery.
- The timescales in which you started and should complete your anti-cancer medication.
- Some of the common side effects of treatment.
- Signs and symptoms to look out for and to report to us or your GP.

- Holistic needs assessment information.
- Further help and support, and how to contact the urology team.

Your treatment summary will have been copied to your GP, so they have access to information about your personalised pathway.

Cancer recurrence and PSA surveillance

Prostate cancer can recur locally in the tissue next to the prostate or in the seminal vesicles (two small sacs next to the prostate).

It may also affect lymph nodes inside/outside of the pelvis area, or it can travel through the bloodstream and recur distantly in bones or other organs (known as metastasis).

If cancer returns in the prostate, the first sign is likely to be a rise in your PSA level rather than any specific symptoms, which is why PSA surveillance is used to identify cancer recurrence. If you require PSA monitoring, the frequency of these will be included within your treatment summary.

At each appointment, you will be given a bloods request form. You will be required to use this form to ensure you have had a blood test approximately one week before your next follow-up appointment.

By having your blood test approximately one week before your next appointment, this will allow us to inform you of your results at this appointment.

Should you have not had your bloods taken around a week before the appointment, we will ask you to have these done afterwards. We will then send you a letter with your results.

It is important you let your GP or nurse know if you do get any new symptoms or side effects, or if you are worried your cancer may have returned.

You should contact the cancer nurse specialist team or your GP if you experience any of the following:

- Lower urinary tract symptoms, e.g. hesitancy, poor and/or intermittent stream, feeling of incomplete bladder emptying, dribbling etc.
- Bone pain.
- Visible haematuria (urine that is visibly discoloured by blood).
- Weight loss.

Living with prostate cancer

Following treatment, you may experience some side effects:

Fatigue

Three in every four men will experience tiredness, which is not relieved by sleep. Potential causes can include sleep problems, hormones, nocturia (waking in the night to urinate) and hot flushes.

In order to try and help manage any fatigue symptoms, it is important that you plan your day so that priority things are completed first. Incorporate plenty of rest periods, eat well, and stay active. Taking part in exercise or finding a new hobby can help you to lift your mood and feel more alert.

Hot flushes

These are a common side-effect of hormonal treatment. Not everyone experiences these, but if they do, they may get easier over time.

Key things you can do to help with hot flushes are:

- Stop smoking.
- Maintain a healthy weight.
- Drink plenty of water (7-8 glasses per day).
- Cut down alcohol and caffeine intake.
- Eat less spicy foods.
- Maintain a cool room temperature.
- Cotton bed sheets with cotton towel on top.
- Lukewarm showers/baths.
- Keep a diary to identify any particular patterns, e.g. food/drink/situations which increase symptoms.

If these changes don’t work, there are medications to try.

Urinary problems

Bladder muscles and nerves work together to let you control when you urinate. Prostate cancer treatments can damage the muscles and nerves, causing leaking of urine or retention.

The likelihood of experiencing such symptoms depends on your treatment and whether you've had problems before. For patients who have undergone prostatectomy, it is common to leak urine.

Patients who have had radiotherapy treatment may struggle with bladder irritation, resulting in needing to urinate more frequently, sudden urges to urinate, or difficulty urinating.

There are a number of support options for urinary problems, therefore if you experience these, it is important you contact your cancer nurse specialist team when under the care of the hospital, or your GP if you have already been discharged.

You can also help yourself by:

- Drinking plenty of fluids (1.5-2 litres per day prevents bladder irritation and infection).
- Cutting down on fizzy drinks, alcohol and caffeine intake.
- Regularly performing pelvic floor exercises.
- Maintaining a healthy weight and level of fitness (there will be less pressure on bladder and pelvic floor muscles).
- Eating plenty of fibre (to avoid constipation).
- Trying to stop smoking.
- Planning ahead if going out; knowing where public toilets are.
- Having a toilet card/key.
- Packing a bag with extra pads/underwear/wet wipes.
- Leaving a light on or keeping a container next to the bed if you are getting up in the night.

Changes physically and mentally

Hormone therapy can change body image, e.g. cause weight gain, breast swelling and tenderness, and loss of body hair. It can also cause changes to memory and concentration.

Some top tips to help manage this include:

- Staying active – physical activity can improve energy levels, lift your mood and help with some side-effects.
- Staying a healthy weight.

- Stopping smoking.
- Not putting too much pressure on yourself – it takes time to come to terms with your diagnosis and side-effects.

Erectile dysfunction

Dealing with prostate cancer and living with the side-effects can have an impact on your sex life, and for many people, sex is an important part of life.

Staying a healthy weight, stopping smoking, and doing pelvic floor muscle exercises can help with erection problems.

Some key facts to be aware of:

- You can't pass cancer on through sexual activity.
- Having sex has no effect on your cancer or the chance of recurrence.
- It is safe to have an erection if you have a catheter in situ.

Late effects of treatment

Most patients will leave cancer treatment behind and continue life with few or no health problems, but for others there may be ongoing physical and/or emotional challenges that they will experience daily for the rest of their lives.

These are known as the late effects of treatment and include any side effects resulting from radiotherapy or chemotherapy treatment that take several months to settle. Some people may also develop side effects many months or sometimes years after treatment has finished.

Late effects vary from person to person; everyone experiences side effects differently and an assessment of your needs as an individual may be required. It is not always possible to predict if or when late effects from radiotherapy treatment will occur. If you feel you may be experiencing late effects from your treatment, it is important to seek help from the late effects team or your medical team.

Some late effects might improve or go away with time, whereas others could be permanent. If late effects of treatment do occur, it does not mean that your medical team did anything wrong. In most cases, the effects could not have been avoided.

Radiotherapy is excellent at treating cancer cells, however, over time the cells in the treatment area that have been exposed to the radiotherapy can become damaged due to what is known as radiation induced fibrosis. This is a build-up of fibrotic tissue, just like scar tissue, that makes tissues less stretchy.

Fibrosis is often irreversible and as it builds it can cause hardening, restriction and tightening, along with shrinkage of tissues and muscles. It can therefore cause pain and affect the normal functioning of that part of the body.

It is important to remember that radiotherapy only affects the area of the body being treated. Changes to a part of the body outside the treatment area will not have been caused by the radiotherapy treatment.

If you feel that you are experiencing a late side effect from your radiotherapy or chemotherapy treatment, then the Nottingham Late Effects Service can help.

This is a clinic dedicated to helping patients (who are six months past their treatment) manage and live well with the late effects from treatment.

This is a self-referral service, and you can contact them via the Radiotherapy Information and Support number:

Telephone: 01159 627976
Email: LateEffects@nuh.nhs.uk

Late effects from radiotherapy/ chemotherapy treatment to the pelvis

This involves issues with the functioning of your bowel and bladder. Patients can experience:

- An increase in urinary output, pain and discomfort, bleeding and altered flow.
- Looser bowel motions, increased frequency, wind, pain on opening your bowels, bleeding, and difficulty passing motions.
- Some patients may also experience problems with the skin around the pelvic area, and in and around your back passage.

Other commonly reported effects include:

- The altered ability to have and maintain a physical sexual relationship. This can be a lack of desire, or the inability to get and maintain an erection, along with feeling different about how your body looks.
- Fatigue can also be very common and some patients report that this is still a problem for them up to 10 years after treatment has ended, along with associated psychological and emotional issues.

For patients that have had chemotherapy, you can experience whole body effects such as:

- Gastrointestinal problems, such as problems with constipation and diarrhoea.
- Peripheral neuropathy, which is tingling in your hands and feet.
- Headaches and memory/cognitive problems.

Feelings and emotions

Everyone will have different feelings when they no longer need to see their medical team regularly.

Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment.

Many worry about the cancer coming back. This is very normal and usually these anxieties lessen with time.

Realising that there is a problem and getting help is the most important thing you can do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If you are finding it difficult to cope, your urology nurse or GP may be able to arrange an appointment for counselling. It may also help to contact a local or national support organisation such as Prostate Cancer UK.

The open access telephone service

Until the point you are discharged back to the care of your GP, you should call the urology cancer nurse specialists about any new symptoms that you are concerned about, or other issues you may have. The aim of the telephone service is to provide helpful advice and allow you to have rapid access back to the urology team as required.

You can call the telephone service Monday-Friday, between 8am-4pm on 01623 622515, extension 6284.

The telephone service may be answered by a support worker, a cancer nurse specialist, or go to the answering machine which is checked routinely throughout the day. If your call is not answered immediately, please leave your name, hospital number and a short message and your call will be returned by the end of the next working day.

Our commitment to you

If the urology nurse feels the symptoms you are experiencing may represent a new cancer diagnosis or be related to your previous cancer diagnosis, an appointment will be arranged at one of our clinics within two weeks of you telephoning us. If necessary, further investigations may be organised and an outpatient appointment may be arranged to receive the results.

For patients continuing to experience side effects of treatment, there are a number of other clinics and support services which you can be referred or signposted to.

Sometimes, verbal advice (via the telephone service) may replace the need for an outpatient appointment. In these cases, a written letter will be sent to you and your GP. We hope that this enhances and promotes your ability to care for yourself once treatment has been completed and enables you to benefit from the team's expertise as required.

Life after treatment

Once treatment is over, people often want to know what they can do to stay healthy. You may have questions about your diet, exercise, and general well-being which we would be happy to address. Some of the specialist services we can offer are:

- Mindfulness courses.
- Counselling and support.
- Lymphoedema services.
- Support with managing
  - ➲ Fertility/sexual issues.
  - ➲ Body image issues.
- 'Look good, feel better' workshops.

Spring into Action

Spring into Action is a clinic organised by physiotherapists which offers individual advice about making positive changes to levels of physical activity and/or diet after cancer treatment.

If you wish to attend, you can self-refer by telephoning 01623 622515, extension 3221 or 6030, or speak to the urology team.

HOPE course

The six-weekly Macmillan Help to Overcome Problems Effectively (HOPE) course concentrates on focusing and rediscovering inner strengths and resilience to help individuals cope emotionally, psychologically and practically.

Referrals can be made via the urology team or Macmillan Information Support Hub at King's Mill Hospital (01623 622515, extension 6499).

Maggie's Nottingham

Located at Nottingham City Hospital Campus, Maggie's Nottingham offers a range of cancer support, from courses, casual classes, self-help, support groups and help with money worries, or just a calming space with friendly faces.

Contact number: 0115 924 6210
Email: nottingham@maggies.org

Welfare and benefits advice

If you are experiencing issues with housing, employment, immigration, financial or welfare benefits, you can get help by contacting the urology team or Macmillan Information Support Hub (01623 622515, extension 6499) who can complete a referral to the Macmillan Money and Work Advisors.

Medicines information

If you have any questions or concerns about medication started by your cancer doctors, please contact the urology team for advice.

If you have any questions or concerns regarding medications started by your GP or holistic/complementary medications, please contact your GP or a local pharmacist.

Finally

If you are worried about something to do with your prostate cancer, or the treatment that you have had for it, please contact the cancer nurse specialists.

They would rather see you with something that turns out to be nothing, than for you to be at home worrying. They are there to help you, so please call if you have any questions or concerns.

Further sources of information

NHS Choices: www.nhs.uk/conditions
Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

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