Testicular cancer
Information for patients
This booklet has been given to you to help you have a better understanding of your diagnosis of testicular cancer.

There are two main types of testicular cancer: teratoma and seminoma. These two cancer types, sometimes referred to as germ cell cancers, occur most frequently between the ages of 15 and 50 and are by far the most common cancers in young men. Rarely germ cell cancers can start in the chest, or abdomen, without involvement of the testicles.

Initial treatment for testicular cancer may involve surgery (an operation) to remove the affected testicle (orchidectomy) or cancer at other sites, chemotherapy (drug treatment), radiotherapy (x-ray treatment) or a combination of these.

1. Follow-up after treatment

All patients, however treated, will require follow up, generally for three to five years after finishing treatment. Some patients will be followed up for the rest of their lives. Although most patients with testicular cancer will be cured by their initial treatment, in some the cancer will recur and require additional treatment. The purpose of follow-up is to detect any reoccurrence of your testicular cancer at an early stage, so it can be successfully treated. It also provides an opportunity to identify and correct (where possible) any after effects of treatment.

A recurrence of your testicular cancer is likely to be detected by one or more of the following investigations: blood tests (measuring serum marker levels), chest x-ray or computerised tomography (CT) scan. See below for more information on these tests. During your follow up period, you will need to have one or more of these investigations at regular intervals and we will give you a schedule for these tests. We will give you the results as soon as possible after the tests have been done. You will only need to attend the outpatient clinic if your test results are abnormal or if you have a problem or concern that you wish to discuss.

If you have any symptoms or concerns you can telephone a member of the team to discuss these and if necessary we will arrange to see you urgently, usually within the next week (see contact details on page 2).

2. Symptoms to watch for

If you experience any of the following symptoms persistently for more than two weeks without improvement you should contact us:

- Testicular swelling or pain
- Shortness of breath
- Cough
- Lower back pain
- Unexplained weight loss
- Abdominal pain or swelling
- Headache
- Loss of interest in sex
- Unexplained fatigue
3. Contact details

If you have any of the above symptoms, or any other concern related to your condition, please contact Gus Seebaran, clinical nurse specialist (CNS) on:

Tel 07795 506790
Email info.urologyCNS@suht.swest.nhs.uk

You can also contact the secretary for Dr Simmonds or Dr Wheater on:

Tel 023 8079 8657 or 023 8079 8639

4. Follow-up investigations

It is vitally important that you have these tests done as set out in your personal schedule. Blood tests and chest x-rays should be performed as close to the schedule date as possible. CT scans are booked appointments. If you cannot make the scheduled date please let us know so this time is not wasted. If necessary we can always reschedule an appointment to a more convenient time.

It may be possible to have blood tests performed at your GP’s surgery, but x-rays and CT scans will need to be performed at a hospital. Whenever feasible we will try to ensure that these are at the hospital nearest to where you live. In most hospitals you do not need to book an appointment for blood tests or x-rays, but at many GP surgeries it is necessary to book an appointment for a blood test. Please discuss this with your team.

We will review the results of your tests and scans and send a summary of these to you by post. We will also send a copy to your GP. When tests are abnormal and require urgent action we may discuss these with you by telephone. You will always be given a clinic appointment to discuss the results in person within the next week.

We will give you request forms for your first scheduled follow-up blood test and x-ray at your last routine clinic appointment. Each time we write to you about the results of these tests we will send you a new set of request forms for your next routine follow-up as per your schedule. We will request CT scan appointments directly and send you an appointment by post.

The tests and scans we may ask you to have as part of your routine follow up include:

**Tumour markers**

Tumour markers can show us whether there is active testicular cancer or not. They are proteins that are normally present in small amounts in the blood, but can be produced by testicular cancers, resulting in higher than normal levels. If your tumour marker levels are persistently raised it suggests that you have active cancer and will require further treatment. It is important to be aware that not all testicular cancers produce raised markers so some patients can have active cancer with normal tumour marker levels.

The tumour markers we are looking for are:

**HCG** (this stands for Human Chorionic Gonadotrophin): This can be raised in both pure seminoma and teratoma. The normal range is 0 to 5 iu/L.

**AFP** (this stands for Alpha Fetoprotein): This can be raised in patients with teratoma or mixed tumours containing both teratoma and seminoma. The normal range is 0 to 10 ku/L.

**Chest x-ray**

Testicular cancer can spread to the chest, and a chest x-ray is a simple test that can help to detect this. Using a very low dose of radiation, a picture is taken of your chest and is examined to look for any abnormalities.

We keep the number of chest x-rays to a minimum so that you are not exposed to too much radiation.

**Computerised tomography (CT) scan**

A CT scan is another type of x-ray that helps us to see what is happening inside your body. The pictures produced from the scan show more details than a normal x-ray (such as a chest x-ray), but they do expose you to higher levels of radiation. A CT scan is the same as having hundreds of x-rays at the same time. For this reason we will only scan the area of your body where we think you have the most risk of having a recurrence of testicular cancer and will keep the number of scans performed to the minimum required, based on published research.
5. **Testicular self examination**

Men who have had testicular cancer have an increased risk of developing a new cancer in the other testicle. It is therefore important to check your remaining testis on a regular basis. If you feel a new lump or notice any change in size or texture you should see your GP as soon as possible so that further investigations can be arranged if necessary.

6. **Sexual function**

Removal of one testicle should not affect sexual function. Usually the healthy testicle that is left will produce more testosterone and sperm to make up for the testicle that has been removed. However, sexual problems do sometimes occur in men with testicular cancer. In most cases they result from the emotional reaction to the experience of being diagnosed and treated for cancer and often resolve if you are able to discuss them openly with your partner. Occasionally sexual problems may occur as a consequence of treatment or because the remaining testicle is not producing adequate testosterone (see below).

You might experience any of the following:

- Loss of interest in sex
- Inability to have an erection
- Inability to keep an erection during sex or intimacy
- Ejaculation without producing semen

If you have ongoing problems it is important to let us know so that we can assess these to determine whether the cause is likely to be physical or emotional. If appropriate you can be referred to a counsellor.

7. **The remaining testis is not working properly (hypogonadism and infertility)**

Most men will have no problems with the remaining testis after diagnosis. But sometimes it does not work as well as it should.

Hypogonadism is when the testicle produces less testosterone than normal and can lead to a combination of any of the following symptoms: loss of interest in sex, difficulty having or maintaining erections, unexplained tiredness, weight gain, decreased beard and body hair, tender nipples, development of breasts, mood changes and hot flushes/sweats.

Testosterone levels can be measured by a blood test and testosterone replacement can be given if required to correct testosterone deficiency.

**Infertility** may occur because the testicle is producing less sperm than normal or because the sperm produced are abnormal. This may happen because the remaining testicle has always been abnormal, or because it has been damaged as a result of treatment (chemotherapy or radiotherapy).

Infertility caused by chemotherapy is usually temporary. The rate at which the sperm count recovers varies from person to person. It generally starts to return to normal around 18 months after treatment. Because of the small risk of permanent infertility all patients, other than those needing to start treatment as an emergency, are offered the opportunity to undertake sperm banking before starting treatment. Sometimes successful treatment with chemotherapy improves sperm production in men with a low sperm count at the time of diagnosis.

A rare cause of infertility is retrograde ejaculation. This means that semen goes backwards into the bladder instead of coming out through the penis (it is passed out harmlessly when you pass urine). This occurs rarely as a result of nerve damage after abdominal operations to remove residual masses following the completion of chemotherapy. The operation doesn’t stop you from getting an erection but your orgasm will feel different because it’s dry (dry climax).

If you think you may be experiencing any of these problems please contact us. We may need to see you in clinic to assess this more fully.

In some men the remaining testicle may not be functioning normally because there are changes within the testicle that could eventually develop into cancer. If we think that you are at risk of this we may recommend that you have a biopsy of the testicle performed under anaesthetic.
8. Long term side effects/ late effects of treatment

Most men with testicular cancer will be cured by removal of the affected testicle, but some will require additional treatment with radiotherapy or chemotherapy. Some men with teratoma that has spread beyond their testicle will also require further surgery to remove residual masses left after completion of their chemotherapy treatment.

Some side effects that develop during treatment may take a long time to improve or may occasionally become permanent (long-term effects). Other effects can develop many years after treatment has finished (late effects). You may not experience any after effects at all or they may range from being mild to more serious.

Possible long-term effects of combination chemotherapy can include:

- Changes in the feeling (sensation) in your hands or feet (peripheral neuropathy)
- Hearing changes (particularly for high pitched sounds)
- Lung problems
- Infertility

These changes are most commonly temporary but may take up to 12 months to resolve. Occasionally they are permanent.

Some men who have had chemotherapy for testicular cancer find that when their hands are cold their fingers become white, with pins and needles or numbness. This is known as Raynaud’s Syndrome and is due to spasm of the blood vessels that supply blood to the skin. If you have this you may have altered sensation in your hands or feet.

Possible late effects of chemotherapy can include:

- A greater likelihood of becoming overweight
- Raised blood pressure
- Raised cholesterol
- Diabetes
- An increased risk of heart disease

Taking regular exercise, eating healthily, watching your weight and stopping smoking are important ways you can help yourself.

It’s important to let us know if you have symptoms that could be linked with treatment effects.

9. Having children after treatment

Most men who have been treated for testicular cancer go on to have children when they have recovered.

There is no evidence that cancer treatment can harm children fathered after treatment is over. However, if you wish to try to have children after having chemotherapy or radiotherapy we recommend that you wait for at least 12 months after completing treatment. This gives your sperm time to recover from any damage that treatment may have caused. Until this time has passed it’s important to carry on using contraception to avoid getting your partner pregnant.

10. Returning to work or college

You can go back to work or college as soon as you feel able to and your doctor says it’s ok. If you are a student then try and talk to your personal tutor first about any worries you might have and the best way for you to return to college.

If you are going back to work, it will help to have a meeting first with your employer, human resources department or occupational health staff. It can help 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.

You may want to ask for time or training to catch up with any changes you may have missed when you were off sick. Any changes to your contract should be agreed in writing with you. This could include a change to your working hours, either temporary or permanent. Read through your organisation’s sickness policy carefully. Health and safety regulations mean employers have a duty of care and need to put processes in place to ensure your health and safety wellbeing.

The Disability Discrimination Act (DDA) covers all types of cancer and exists to protect against unfair treatment compared to others, harassment and victimisation, and unfair dismissal. If you think you are been treated unfairly when you’re trying to get back to work, it’s there to protect you. Disability employment advisors are based at Job Centres and Job Centre Plus.
Some questions that might be helpful to ask before returning include:

- What adjustments can your employer arrange that would make work easier for you?
- Can you reduce your hours, work flexibly or work more at home?
- Will you need 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.

11. Money matters

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 CNS to refer you to Macmillan, CAB or social work department for more information.

The Department for Work and Pensions provides information about benefits that you might be entitled to. You can also find out more at your local Citizens’ Advice Bureau or social security office, which will also be able to advise you about how to claim. Find out if Statutory Sick Pay, and occupational or company sick pay is relevant to your situation. Employment and Support Allowance (or Incapacity Benefit) is paid to people of working age who cannot work due to illness or disability. Income support is a means-tested benefit for people under 60 on a low income, and is intended to cover basic living expenses.

12. Insurance

After having treatment for cancer, it can be more difficult to get life insurance, travel insurance and mortgages. To find life insurance, it is helpful to contact an independent financial advisor (IFA), who can find the best deal for your particular situation. You can find a local IFA by referral from family or friends, looking in your phone book, or by contacting The Personal Finance Society or IFA Promotions.

The British Insurance Brokers’ Association (BIBA) may be able to find you a broker. BIBA can also help with travel insurance.

You may find it difficult to get life insurance for two to three years after a cancer diagnosis. This will depend on the type and extent of the cancer you had, and the length of time since your treatment. When life insurance is granted, the first premiums are likely to be high. If you’re already covered, you may find it difficult to increase the value of your policy for some years.

13. Other sources of support you may find useful

Cancer Research UK
Information about treatments, research and clinical trials.
www.cancerresearchuk.org
Helpline: 0808 800 4040

Carers UK CareLine
Freephone 0808 808 7777
(Wednesday and Thursday, 10am to 12pm and 2pm to 4pm).
www.carersuk.org

Macmillan Cancer Support
Emotional and practical support.
www.macmillan.org.uk
Helpline: 0808 808 0000

NHS Choices
NHS Choices gives the information you need to make choices about your health.
www.nhs.uk

Orchid
Support and information for people affected by male cancers.
0203 465 5766
info@orchid-cancer.org.uk
www.orchid-cancer.org.uk

Portsmouth Macmillan Centre
Queen Alexandra Hospital, Portsmouth.
023 9228 3323

Relate
Advice, relationship counselling, sex therapy, workshops, mediation, consultations and support.
www.relate.org.uk
Tel: 0300 100 1234

Southampton Macmillan Cancer
B level, Southampton General Hospital.
023 8079 6037
mary.weavers@suht.swest.nhs.uk
www.suht.nhs.uk/macmillan

Teenage Cancer Trust
Helping young people fight cancer.
020 7612 0370
www.teenagecancertrust.org

Turn2us
UK charity helping people access money that may be available to them.
0808 802 2000
www.turn2us.org.uk

Wessex Cancer Trust
Local charity providing information, counselling, complementary therapies.
www.wessexcancer.org
023 8067 2200
If you would like to make a donation to support our work please contact:

**Southampton Hospital Charity Uro-oncology Fund**  
Mailpoint 135  
Southampton General Hospital  
Tremona Road  
Southampton  
SO16 6YD  
Telephone: 023 8079 8881  
Charity registration number: 1051543

Some of the sections in this leaflet have been adapted with permission from information by Macmillan Cancer Support.

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone 023 8079 4688 for help.