Testicular Cancer

Information for patients
This leaflet aims to help you have a better understanding of your diagnosis of testicular cancer.

There are two main types of testicular cancer:
• Seminoma
• Non-seminoma, these are sometimes referred to as Germ Cell Tumours.

Testicular cancer occurs most frequently between the ages of 15 and 50 and is the most common cancer in young men. In rare cases germ cell cancer can start in the chest or abdomen without involving the testicles.

The treatment for testicular cancer may involve:
• surgery to remove the affected testicle (orchidectomy);
• chemotherapy (drug treatment);
• radiotherapy (using high energy x-ray treatment);
• or a combination of these.

For more information, see the links at the end of the booklet.

Follow-up after treatment
All patients, however treated, will need follow-up, generally for three to five years once treatment is finished. Some patients may be followed up for the rest of their lives. Although most patients with testicular cancer will be cured by their first treatment, in some, the cancer will come back and need more treatment. The purpose of follow-up is to detect any recurrence of your testicular cancer at an early stage so
it can be successfully treated. It also gives an opportunity to identify and correct (where possible) any after effects of treatment. It can also help with any uncertainties or stresses caused by having had testicular cancer.

If you are unfortunate enough to have your cancer return, this is likely to be detected by symptoms you get, blood tests called tumour markers, or radiology tests such as Chest x-rays or CT scans.

During your follow-up we will need you to:

• report any symptoms you have;
• have regular blood tests;
• have regular chest x-rays;
• have CT scans at a few key times.

The results of these tests will be given to you as soon as they are available. You will only need to attend the outpatient clinic if your test results are abnormal or if you have a problem or concern you may wish to discuss.

If you have any symptoms or concerns you can telephone a member of the team to discuss these. If necessary we will arrange an urgent clinic appointment, usually within a week, to be seen.
Symptoms to watch for

If you experience any of the following persistent symptoms you should contact us:

- Testicular swelling or pain
- Shortness of breath
- Cough
- Lower back pain
- Unexplained weight loss
- Abdominal pain or swelling
- Headache
- Unexplained fatigue

Contact details

If you have any of the above symptoms or concerns related to your condition please contact your Clinical Nurse Specialist (CNS):

Carolyn Gosney CNS     Tel: 0113 206 7676
Tuesday morning, Wednesday all day, Friday morning.
Email: carolyn.gosney@leedsth.nhs.uk

Victoria Washington CNS
Monday, Tuesday, Thursday, Friday - afternoons.
All day Wednesday
Email: victoria.washington@nhs.net

You can also contact Dr Stark’s secretary

Tel: 0113 206 8266 Monday to Friday - office hours
Follow-up investigations

It is important that you have your tests done as set out in your schedule. You should have blood tests and chest x-rays as close to the date given as possible. CT scans are booked appointments. If you cannot make the date given please let us know well in advance, so that we may be able to change it to a more convenient time.

It may be possible to have blood tests at your local hospital or GP surgery, but you will need to have x-rays and CT scans at a hospital. In most hospitals you do not need an appointment for blood tests or x-rays, but at many GP surgeries it is necessary to book an appointment for a blood test.

We will review the results of your tests and scans and send the results to you by post. We will also send a copy to your GP. If any of the tests are abnormal we will contact you to discuss any further action needed. We may need to arrange a clinic appointment or repeat blood tests.

You will be given blood and x-ray forms for your first schedule follow-up 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 as per schedule. CT scan appointments will be sent directly by post by the radiology department in St James’s.

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

Blood tests - tumour markers
- **AFP**: Alpha Fetoprotein
- **HCG**: Human Chorionic Gonadotrophin
- **LDH**: Lactate Dehydrogenase
Tumour markers can show us if there is active testicular cancer or not. They are proteins that are normally present in small amounts in the blood and can be produced by testicular cancer. If your tumour markers are persistently raised, it may suggest 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 these blood tests are more useful in some people’s cancer than others.

Radiology tests

**Chest x-ray**
Testicular cancer can spread to the lungs, a chest x-ray is a simple test that can help detect this. A low dose of radiation is used to look for any abnormalities.

**CT scan**
A CT scan is another type of x-ray that allows us to see what is happening inside your body. It shows more detail than a normal x-ray and so it uses a higher level of radiation. 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 keep the number of scans to a minimum.

**Testicular self examination**
Men who have had testicular cancer have an increased risk of developing a new cancer in the other testicle compared to men who have never had testicular cancer. It is therefore important to check your remaining testis on a regular basis. We suggest you put time aside to do that once a month, after a bath or shower. More frequent examination is not advised, as changes may happen slowly so you may not notice them. There is a leaflet with more specific advice if you need.
If you feel a new lump or notice any change in size or texture you should contact us as soon as possible.

**Sexual function**
Removal of one testicle should not affect sexual function. Usually the healthy testicle that remains will produce more testosterone and sperm to compensate for the testicle that has been removed. Sexual problems do sometimes occur in men with testicular cancer.

**You may experience:**
- Loss of interest in sex
- Inability to have an erection
- Inability to keep an erection during sex or intimacy
- Ejaculation without producing semen

In many cases problems come from the emotional reaction to the diagnosis of cancer, or concern about the appearance of your body after surgery. These reactions often resolve in time. If the appearance of your testicles affects you an artificial testicle (known as prosthesis) may be fitted. These may improve your confidence. They are usually not put in at the time the testis is removed, but some months later. One side-effect is that they can be uncomfortable. You may ask for the prosthesis to be removed if this becomes a problem for you.

If you have ongoing problems it is important to let us know so that we can assess you to see if the cause is likely to be physical or emotional. If appropriate you can be referred to a counsellor.
Low fertility 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 before your cancer or because of the result of chemotherapy or radiotherapy treatment. Because of the risk of infertility, sperm storage is offered before you start chemotherapy or radiotherapy.

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 can happen in rare cases due to nerve damage following abdominal surgery to remove any remaining masses after completing chemotherapy. The operation doesn’t stop you getting an erection but your orgasm will feel different because it’s dry.

Occasionally sexual problems may occur as a result of treatment or because the remaining testicle is not producing enough testosterone.

**The remaining testis is not making enough hormones**
Most men will have no problems with the remaining testis after diagnosis, however, sometimes it does not work as well as it should. This is often because the testis has not been entirely healthy for many years before the cancer developed.

_Hypogonadism is when the testicle produces less testosterone than normal and can lead to a combination of any of these symptoms:_
- Loss of interest in sex
- Unexplained tiredness
- Weight gain

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• Decreased beard and body hair
• Tender nipples
• Development of breasts
• Mood changes
• Hot flushes/sweats

Long term, low testosterone can be bad for your heart. Testosterone levels can be measured by a blood test and hormone replacement can be given if required.

Long term side-effects and late effects of treatment

Most men with testicular cancer will be cured by removal of the affected testicle, but some will need extra treatment with chemotherapy or radiotherapy or sometimes both. Surgery may be needed in some cases following chemotherapy to remove remaining masses.

Some side-effects that develop during treatment may take a long time to improve or may become permanent. Other effects can develop many years after treatment has finished. You may not experience any after effects at all.

Other possible long-term effects of chemotherapy treatment can include:

• Changes in the feeling in your hands and feet (peripheral neuropathy)
• Hearing loss or ringing in the ears (tinnitus)
• Lung problems

These changes are usually temporary but may take up to 12 months or more to resolve. Occasionally they are permanent. Some men who have had chemotherapy find that when
their hands are cold their fingers become white or blue 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.

**Possible even longer term late effects of chemotherapy can include:**

- A greater likelihood of becoming overweight
- Raised blood pressure
- Raised cholesterol
- High blood sugar levels, or sometimes diabetes.

These may lead to an increased risk of heart disease. Taking regular exercise, eating healthily, watching your weight and stopping smoking are important ways you can help yourself.

If you and we know about your long term effects we can assess them and offer treatments in many, but not every case.

**Long term effects of radiotherapy on the abdomen**

A small number of patients with testicular cancer have radiotherapy to their abdomen. All cancer treatments can have long term side-effects but from radiotherapy they are generally limited to the area that has been treated. They are often due to damage to blood vessels and connective tissue cells.

These changes can gradually appear over a long time, sometimes several years. If you had radiotherapy in the past and are worried about side-effects, ask to go back to your radiotherapy department and talk to the doctor.
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 chemotherapy we recommend that you wait for 6-12 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 is important to carry on using a reliable form of contraception.

Returning to work or college

Some people choose to return to work during treatment. We don’t advise that, but some people greatly prefer that as long as their work place is aware and sympathetic. If you are a student then try talk to your personal tutor about any worries you might have on your return. If you are going back to work, it may help to have a meeting with your employer. If you are still having some side-effects from the treatment, discuss any reasonable changes that can be made to help you get back to work, this could be a staged return.

You may want to ask for time or training to catch up with any changes you may have missed when you were off sick.
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, harassment and victimisation and unfair dismissal.

**Money matters**

A cancer diagnosis can have an effect on your income, 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. Ask your CNS to refer you to Macmillan or a social worker.

The Department for Work and Pensions provides information about benefits that you may be entitled to.

**Insurance**

After having a diagnosis of cancer, it can be more difficult to get life insurance, travel insurance and a mortgage. For life insurance it may be helpful to contact an independent financial advisor. For travel insurance ask your CNS who may have a list of insurers that you may find useful.
Useful organisations and contact numbers

Leeds Cancer Support
Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

We can be found in the information lounges in Bexley Wing and also in the purpose built Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre
The centre is on the St James’s Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can just drop in for a coffee and a chat anytime.

Information Lounge Level 1 Outpatients Department

Open from 10.00am - 4.00pm. Tel: (0113) 206 8816

Information Lounge Level -2 Radiotherapy Department

Open from 8.30am - 6.00pm Tel: (0113) 206 7603

Sir Robert Ogden Macmillan Centre

Open from 10.00am - 4.00pm. Tel: (0113 206 6498)

All the above services can be emailed on: leedsth-tr.Cancersupport@nhs.net
Cancer Research UK
Information about treatments, research and clinical trials.

www.cancerresearch.org.uk   Helpline: 0808 800 4040

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.

www.orchid-cancer.org.uk   Tel: 0808 802 0010

Relate
Advice, relationship counselling, sex therapy and support.

www.relate.org.uk