

The Beatson
West of Scotland Cancer Centre
Pan Glasgow Urology / Oncology



Patient Information

Testicular Germ Cell Cancer Explained

The Beatson
West of Scotland Cancer Centre
1053 Great Western Road,
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Introduction

The information contained in this leaflet has been prepared to provide you with some general guidance when you have a suspected diagnosis of testicular germ cell cancer. This guidance may apply to your individual circumstances. However it is important to remember that your Medical and Nursing team who are looking after you will explain individual details with you personally.

What is testicular germ cell cancer?

The testicles are made up of groups of specialised cells which have 2 main functions:

1. Sperm production.
2. Male hormone production – Testosterone.

Testicular germ cell cancer although relatively rare, is the most common form of cancer in young men. In Scotland approximately 200 new cases of testicular germ cell cancer are diagnosed each year.

Testicular germ cell cancer is a highly treatable and curable cancer, with potential cure rates of approximately 95%. High cure rates for testicular cancer can be achieved with appropriate treatment, even when the cancer has spread outside the testicle to other areas of the body.

Testicular germ cell cancer is a disease of cells within the testicle. The growth and repair of cells within the testicles usually happens in a controlled and organised manner. In testicular cancer this process becomes out of control and cells continue to grow and divide, developing into a lump which is called a tumour.

Cancerous tumours can be benign or malignant. A benign tumour consists of cells which cannot spread to other parts of the body. However a malignant tumour consists of cancerous cells which have the ability to spread to other parts of the body.

Testicular germ cell cancer cells can move from the testicle (primary site of origin) and travel to other organs in the body such as lymph nodes in the abdomen or lungs via the blood stream or lymphatic system. When this happens the cells continue to divide and grow to form a new tumour. This is known as metastasis or secondary cancer.

There are 2 main types of testicular germ cell cancer: Seminoma and Non-Seminoma. In some men with testicular cancer there can be a mixture of both types. Testicular Cancer is also known as germ cell cancer. Seminomas most commonly occurs in men aged 25-55, while non seminomas usually affect younger men aged 15-35 years.

Other rare types of testicular tumours include "Leydig Cell" or "Sertoli Cell" tumours and "Lymphoma" (a tumour developing in the lymphatic cells). If you have one of these rare types of testicular cancer, your Consultant or Specialist Nurse will give you individual information regarding further treatment options.

What causes testicular germ cell cancer?

The cause of testicular germ cell cancer has not been identified but is associated with the following risk factors:

- Undescended Testicles - Before birth testicles move from the abdomen to the scrotum. However if this process does not happen naturally before birth (maldecent), an

operation during childhood called an orchidopexy is performed to correct this.

- Caucasian Ethnicity - Testicular cancer is more common in European and American white men than Asian or afro-Caribbean men.
- Hereditary - Links within families are being researched to look for a possible genetic component. However it is rare for testicular cancer to affect more than 1 member of the family.
- Lifestyle / Environmental Factors – various theories have been suggested including sedentary lifestyles (low levels of physical activity), infections, trauma, although none of these theories have been confirmed through research.

If you are interested in more detailed information on testicular cancer, you can discuss this with your health care professional or there is further written information freely available to you. Macmillan Cancer Support has produced a booklet 'Understanding Testicular Cancer'. To obtain a free copy of this you can drop into our Information Centre on Level 1 of the cancer centre or you can call Macmillan Cancer Support on 020-7840-7840/ 0808 808 00 00 (Mon-Fri 9am-8pm) or access their website at <http://www.macmillan.org.uk>.

How is testicular cancer diagnosed?

Most cases of testicular cancer are diagnosed on the basis of classical symptoms such as a testicular lump, pain or swelling. You will be examined by a doctor who is a urologist surgeon and have a testicular ultrasound scan. On some occasions when there is no evidence of a tumour on ultrasound scan, a diagnosis can be confirmed based on blood tests which check

for tumour markers, and / or signs and symptoms of testicular germ cell cancer which has spread. Signs of testicular germ cell cancer which has spread can include persistent back or abdominal pain, altered bowel habits, shortness of breath with or without a cough. If your doctor suspects you have testicular germ cell cancer which has spread you may also be asked to attend for a chest x-ray.

If you are suspected as having testicular cancer – What happens?

When you have a suspected diagnosis of testicular germ cell cancer, you will have surgery to remove your testicle called an orchidectomy. Your surgeon will offer the insertion of a testicular prosthesis which is an 'artificial' testicle that will give you the appearance of a testicle. This can be done during this procedure, however we will discuss this with you before the surgery.

A diagnosis of testicular germ cell cancer is confirmed when the cells from the removed testicle (orchidectomy) are examined under a microscope. This is done by a Doctor called a histopathologist, who will produce a 'pathology report' identifying which type of testicular cancer you have. In the West of Scotland all testicular specimens should be analysed by 2 histopathologists, one at your local hospital where your surgery is performed, and then by a histopathologist in Glasgow who specialises in testicular cancer diagnosis. The pathologist can tell not only which type of testicular cancer you have but also if any cancer cells are seen in the blood or lymph vessels which were removed with the testicle at the time of your operation. This ensures that an accurate diagnosis is made and provides important information which helps in recommending any necessary further treatment you may need.

Following on from your surgery you will have further investigations and tests. This includes blood tests to check for tumour markers and a CT scan to check for cancer which may have spread. These tests help confirm your diagnosis and staging of your cancer. This information is important in determining if further treatment is needed following surgery. Please remember, even if your testicular germ cell cancer has spread it is still a highly treatable and potentially curable cancer.

Understanding tumour markers

Tumour markers can be produced by certain types of testicular germ cell cancer cells, but it's important to note that not all testicular germ cell cancers produce them. 50% of non seminoma types produce tumour markers, and 15-40% of seminoma types produce tumour markers. These tumour markers can be detected by blood tests.

There are 3 types of tumour markers we check in testicular cancer:

- AFP- Alpha Fetoprotein
- HCG – Human Chorionic Gonadotrophin
- LDH – Lactate Dehydrogenase

Checking your blood for tumour marker level is important in diagnosis and staging. After surgery to remove your testicle you will have regular blood tests to check for tumour markers. It is also important to monitor if your markers start to go down or increase after surgery as this can indicate if you will need further treatment after surgery.

Checking your blood for tumour markers is useful in monitoring your response during further treatment if required. You will also have tumour marker blood tests taken throughout 'follow up' care. This helps to detect early signs of possible recurrence after your primary treatment. Please remember we will discuss your personal markers in detail with you at all the different stages.

CT scan and staging of testicular cancer

Testicular germ cell cancer has a predictable pattern of spreading if it moves outside the testicle. This is secondary or metastatic testicular cancer. Common areas of spread are lymph nodes in the abdomen (tummy), and/or chest, and the lungs. For this reason you will have a CT scan, which is a detailed x-ray examination of your chest, abdomen and pelvis. This scan is usually done in your local hospital within around 3 weeks of your operation to remove your testicle.

What happens next?

It can take a little time for the results of your tests to become available. Your Urologist (Surgeon) will request your case is reviewed at the West of Scotland, regional urology-oncology multi-disciplinary meeting (MDT). This is a weekly meeting of a team of experts including urologists, oncologists, radiologists, pathologist, and nurse specialists who review your test results and consider and agree which treatment(s) options would be best for you.

Further treatment options

Further treatment options can be surveillance, chemotherapy, and/ or radiotherapy. Following your case review at the MDT you will be referred to an Oncologist. This is a doctor who specialises in the treatment of cancer.

Your Oncologist will send out an appointment for you to come to the out patient clinic at the Beatson West of Scotland Cancer Centre or in certain cases follow up may be done at other urology - oncology clinics at your district general hospitals. Consultants from the Beatson West of Scotland Cancer Centre visit some local hospitals across the West of Scotland. Your doctor will advise if you will be referred to the Beatson or if you will be referred to your local hospital.

Oncology out patient clinic - 1st visit

At your first visit to The Beatson West of Scotland Cancer Centre you will be seen by your Oncologist who will discuss your test results and explain your treatment option(s). These options as previously mentioned can be surveillance, chemotherapy, and/ or radiotherapy. You will have an opportunity to discuss your management, and receive verbal and written information relating to your proposed treatment plan. Other issues which may be discussed include treatment advice, possible side effects explained, fertility advice, and employment advice.

You will also have blood tests taken which includes a routine HIV blood test for all patients with a confirmed seminoma type of testicular cancer. You will be examined by the doctor; and you may also be seen by the testicular cancer clinical nurse specialist.

The Testicular Germ Cell Cancer Team at the Beatson consists of –

- Consultant Medical Oncologist – Jeff White
- Consultant Medical Oncologist – Ashita Waterston
- Germ Cell Cancer Nurse Specialist – Nicola Thomson
- Teenage and Young Adult Nurse Specialist – Julie Cain
- Specialist Registrar Doctor
- Secretary – Kate Houston

At your first visit we will let you know when you will return to the out-patient clinic, or be admitted to the cancer centre to start treatment. We will also give you the telephone numbers of your nurse specialist who you can contact for advice and support throughout your care.

Testicular germ cell cancer treatment options

In many cases of testicular germ cell cancer no further treatment is required following surgery to remove the testicle. Your oncologist will advise you of the risk of your cancer coming back, and whether this risk is high or low. This advice will be based on the pathology report and monitoring of your blood tests for tumour markers.

What is Surveillance ?

Surveillance is an observation treatment strategy recommended in men who have a low risk of their cancer coming back (stage 1 low risk testicular germ cell cancer). Surveillance consists of regular attendance at the out patient

clinic for examination, blood tests, chest x-ray, and review. You will attend the clinic at the Beatson Cancer Centre, or an oncology clinic at your local hospital. This simply depends if your Oncology Consultant from the Beatson has a clinic at your local hospital.

What happens if I need Chemotherapy?

Chemotherapy is treatment with cytotoxic (toxic to cells) drugs which are given to kill cancer cells. Chemotherapy treatment is given at The Beatson West of Scotland Cancer Centre. Chemotherapy drugs are given directly into your vein via a cannula (needle) in your arm connected to an intravenous infusion (drip). If you need chemotherapy we will explain which type and how much chemotherapy you require when you meet your Oncology Doctor.

Chemotherapy nurses specifically trained in giving chemotherapy will give your treatment. Chemotherapy is given as a course of treatment called a treatment cycle. You will have your treatment plan confirmed, and your doctor / nurse specialist will inform you of the possible side effects of your treatment, and how to look after yourself during chemotherapy.

Fertility information and sperm storage

When you have a testicle removed men understandably often ask if this will affect their future fertility (ability to have children). In most cases, the remaining testicle produces sperm which maintains your ability to have children in the future. However if you require further treatment with chemotherapy, this can affect sperm production during your treatment and for 6 to 12 months afterwards. If your Doctor thinks that your

fertility may be affected by the treatment you require, they will discuss the option of sperm storage.

To sperm store it is a legal requirement that you have blood tests to check for viruses including Hepatitis, and HIV. After receiving your viral blood test results you will be given an out patient appointment to attend a specialist fertility unit. You will be seen by a Doctor called an Embryologist who specialises in fertility treatment. It is this Doctor who will explain sperm storage options and invite you to consent to this if you want to sperm store. You can have further information about fertility options from your Oncologist, Urologist or Specialist Nurse, so please do ask if you have further questions.

What happens if I have Radiotherapy?

Radiotherapy is the use of high energy x-rays (radiation) to kill cancer cells. . Your first visit to the radiotherapy department is for the planning of your treatment. To accurately plan the area your doctor wants to treat we will use a 'Planning' CT scanner which gives us a 3 dimensional image of the area to receive radiotherapy. A doctor (Clinical Oncologist) specialising in radiotherapy treatment will then prescribe a radiotherapy treatment plan for you, and we then compute the best way to deliver your treatment. Radiotherapy planning and treatment delivery is done by radiographers. We give your treatment on a machine called a linear accelerator. A course of radiotherapy treatment may last 2-4 weeks, where treatment is given once per day (called a fraction of treatment). Radiotherapy treatment is normally given Monday to Friday This will be explained by your doctor and radiographers at your planning visit and again on your first day of treatment. Each daily treatment takes around 10 minutes, but most of this time is spent with your radiographers positioning you in the same way as your planning visit and setting the linear accelerator to your

individual treatment plan to ensure your treatment is delivered accurately. Radiotherapy treatment itself takes only a few moments. When the radiographers leave the room to switch the machine on they monitor you closely on closed circuit TV. You do have to lie still during treatment but you can breathe normally. You will not feel anything during treatment and will feel no different afterwards. Your radiographers will explain all of your treatment, its possible side effects and how to look after yourself during radiotherapy.

Information for men who are unwell at time of diagnosis

Some men, who have a suspected diagnosis of testicular germ cell cancer, can be unwell for a variety of reasons. It can be due to the cancer having spread to other organs, or having very high blood test levels of tumour markers, or from pressure preventing your kidneys from working properly. In this situation you may need to be transferred to The Beatson West of Scotland Cancer Centre to start treatment as early as possible. Your Doctor will discuss this with you and arrange for you to be admitted to The Beatson cancer centre.

When you are admitted to the cancer centre you will be seen by an Oncologist Doctor who will explain your diagnosis in more detail and discuss the treatment you require. This is usually chemotherapy and before beginning treatment you will need some further tests. This may include more scans such as CT scan or MRI scan, blood tests, breathing tests and hearing tests. These tests are to assist your doctor in completing your 'staging investigations'. All of these confirm the extent of your cancer, and baseline tests prior to chemotherapy.

Summary

When there is a suspected diagnosis of testicular germ cell cancer, this can be a very worrying time for you and your family. It is normal to feel a whole range of emotions during this time. It is important to be aware that testicular germ cell cancer is a very treatable and potentially curable cancer. During your cancer experience you will meet with many members of the team who are specialised in treating this type of cancer. Your cancer care team are aware of how you may be feeling and reacting to your situation, and will aim to deliver a treatment plan which is specific to your individual needs.

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Leaflet QA approved L.Webster

Information sources:

The above author and checking group

Scottish Intercollegiate Guidelines Network-

SIGN 124 Management of adult testicular germ cell tumours

www.sign.ac.uk/guidelines/publications/index.html

www.macmillan.org.uk

www.cancerresearchuk.org

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