A patient guide to testicular cancer

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Introduction

The information contained in this leaflet has been prepared to provide general guidance to patients who have been diagnosed with testicular cancer. Although the leaflet will provide you with some of the information that applies to your individual care, it is important to remember that every case is different and this information is, therefore, not exhaustive and does not constitute medical advice.

The care and treatment that you require will be discussed with you by a member of the testicular cancer team. If you have any queries or require further details, you should contact a member of the team. The numbers can be found at the end of the leaflet.

Testicular cancer is the most common form of cancer in younger men but it remains relatively rare with approximately 2400 new cases in the United Kingdom each year.

Testicular cancer is highly curable with appropriate treatment, even when the disease has spread to other organs in the body, with an overall cure rate of approximately 98%. The following information describes testicular cancer and helps anyone with a diagnosis of this tumour to understand how and why decisions for their individual care are reached.

With this information, it is hoped you will feel that you have the resources needed to be involved in making decisions about your care.

What is testicular cancer?

The testicles are made up of groups of specialised cells and have two main functions:

- To produce sperm
- To produce the male hormone, testosterone

Testicular cancer is a disease of certain groups of these cells. The growth and repair of cells within the testicles usually occurs in an
organised and controlled manner. If for some reason this process gets out of control, the cells will continue to divide and grow, developing into a lump which is called a tumour.

Tumours can be benign or malignant. A benign tumour consists of noncancerous cells and does not spread to other parts of the body. A malignant tumour consists of cancer cells which have the ability to spread beyond the testicle, and which, if left untreated, may invade and destroy surrounding tissue.

Sometimes cells can break away from the original (primary) cancer and spread to other organs in the body via the bloodstream or lymphatic system (system of thin tubes that run throughout the body). When these cells reach a new site, they can continue to divide and form a new tumour. This is known as a secondary or metastasis.

There are two main types of testicular cancer - seminoma and non-seminomatous.

Occasionally there can be a mix of the two. Testicular cancers are also termed germ cell tumours.

Seminomas most commonly occur in men between the ages of 30 and 45 years of age, while non-seminomas usually affect younger men from 20 to 35 years.

Other rare types of testicular tumour are called ‘Leydig cell’ and ‘Sertoli cell’ tumours. Rarely a ‘lymphoma’ (a tumour developing from a certain type of blood cell) can occur in the testicle, usually in men aged 50 or over. If you have one of these types of cancer, further detailed information will be given to you by your doctor or nurse.

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

- Undescended testicles at birth, this is when a boy is not born with both testicles in the scrotum (this is called cryptorchidism and is usually corrected whilst still a child with a surgical procedure called an orchidopexy)
• Testicular cancer is far more common in the European and American population than in men of Asian or Afro-Caribbean origin

• Several links within families have been identified. The brother of a patient is 5 to 10 times more at risk of developing the disease. The risk to the son of a patient is around double. Nevertheless the absolute risks are low as the tumour is so rare

• Various theories have been suggested regarding lifestyle, environmental factors or trauma, but none of these have yet been confirmed through research.

If you are interested in more detailed information about testicular cancer, we recommend Macmillan Cancer Support booklet ‘Understanding Testicular Cancer’. To contact Macmillan Cancer Support call 0808 808 00 00 and request a copy or access their website at: http://www.macmillan.org.uk

How is a diagnosis made?

A diagnosis of testicular cancer is confirmed following surgery to remove the testicle. A specialist doctor, known as a histopathologist examines the testicular tissue under a microscope and identifies which type of testicular cancer you have. All tissue specimens are seen by two histopathologist; one at the local hospital where the operation is performed and then by a specialist histopathologist from Queen Elizabeth Hospital, Birmingham. This ensures that an accurate diagnosis is obtained and we are able to plan any treatment based on a specialist opinion.

Occasionally, when the testicle has not been removed or there is no evidence of a tumour in the testicle on an ultrasound scan, a diagnosis can be made from a blood or urine test, by looking for tumour markers (substances that are produced by the cancer). Signs and symptoms of the disease can also be found from
physical and X-ray examinations, this helps with diagnosis. More information on tumour markers is available overleaf.

Very rarely, a biopsy, where a small amount of tissue is removed from a lump that has spread from outside the testicle, may be required to confirm the diagnosis.

What happens if a diagnosis of cancer is made?

In order to advise you on the best treatment options, information will be collected on:

- Histological details of the type of tumour
- A CT scan of your chest, abdomen and pelvis
- Blood results of what are known as tumour markers

This is all part of the tumour staging process.

Following a histological diagnosis, a CT scan is performed on the chest, abdomen and pelvis to screen for any signs that the disease has spread. The scan will be examined at the local hospital where it is performed and will then be sent to QEHB to be reviewed. As testicular cancer has a predictable pattern of spreading, potentially affected areas are closely examined for signs of cancer.

As part of the diagnosis it is also important for us to have information on testicular tumour markers. Tumour markers are a group of blood tests which indicate the growth of testicular cancer cells and are important in the staging of testicular cancer. There are three separate tests:

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

AFP and HCG are produced when testicular cancer cells are growing. The LDH is used at diagnosis to suggest how far the disease has spread.
Not all germ cell cancers produce these tumour markers – approximately 70% of teratomas are ‘marker positive’ and approximately 20 - 30% of seminomas are ‘marker positive’.

These blood tests are also very important as an indicator for response to treatment and for use in follow up care after treatment. They will be checked regularly throughout any treatment and at every visit during the 5 year follow up care at Queen Elizabeth Hospital, Birmingham.

Blood tests are specific to germ cell tumours and is a not a test to detect for all types of cancers.

When a diagnosis of cancer is made, each individual case is discussed at a multi-disciplinary team (MDT) meeting. A team of experts will review your information to consider which treatment(s) may be the best option for you. Treatment can include surveillance, radiotherapy, chemotherapy and / or surgery.

It can take a little time for all the tests to be arranged and for the results to be available so it may be a few weeks before you are seen by the oncologist in their new patient clinic.

The testicular tumour unit new patient clinic

You will be seen by the oncologist within a few weeks of your surgery.

Oncology is the area of medicine which treats cancer.

You will be referred to the regional cancer centre because testicular tumours are comparatively rare. The specialist testicular tumour unit team are based at the Queen Elizabeth Hospital, Birmingham. The team consists of:

• Dr Emilio Porfiri - Consultant Medical Oncologist
• Professor Nick James – Consultant Clinical Oncologist
• Mr Prashant Patel - Consultant Urologist
• Dr Mariam Jafri - Consultant Medical
• Mr Richard Viney - Consultant Urologist
• Dr Shalini Chaudhri - Consultant Histopathologist
• Dr Peter Riley and Dr Ian McCafferty - Consultant Radiologist
• Paul Hutton – Macmillan Clinical Nurse Specialist in Testicular Cancer
• Dr Sue Avery – Senior Andrologist
• Specialist Registrar
• QEHB Psychology team

There are often other health care professionals involved in your care such as clinical psychologists, dietitians, pharmacists, social workers, and radiographers.

Occasionally, we may not have had the opportunity to have the results reviewed before your appointment, so you may be asked to return within a couple of weeks after seeing the doctor, to allow more time for the necessary reports to be gathered.

Following your first appointment you should have received information on the type of cancer you have and the appropriate treatment options, based on the information available. Other issues to be discussed with you, if appropriate, will be:

• Fertility (sperm banking) and sexuality
• Treatment side effects
• Advice, information and support on all aspects of your treatment and care

You will be given a provisional plan of when any treatment will begin.

We would expect any further treatment that you need to be commenced within 8 weeks of your initial surgery.

You will be given a telephone contact number so if you have any questions or concerns whilst at home, you are able to contact a named person within the Cancer Centre for advice and support.
Macmillan Clinical Nurse Specialist

The Macmillan Clinical Nurse Specialist (CNS) in testicular cancer is an experienced oncology nurse who works with the other members of the team to provide high quality medical and psychological care for men with testicular cancer and their families.

The CNS should be present at your first consultation at Queen Elizabeth Hospital, to clarify any information and discuss matters important to you.

It is very important that you are able to have your questions answered and concerns discussed and the CNS will make every effort to be at your side at this difficult time. If he or she is unable to be there, the named nurse for the clinic will be there to offer support and information.

You will be given a contact telephone number for the CNS so that you are able to contact them should you have any worries or need further information when at home.

The CNS will be on hand to co-ordinate any treatment and investigations throughout your treatment and follow up care and is always available should you need to get in touch. His or her responsibilities include:

- Providing informational support
- Counselling
- Ward visits during in-patient stays
- Reviews of patients receiving outpatient chemotherapy
- Organising and co-ordinating all aspects of treatment and follow up
- A point of contact for all testicular cancer patients and their families.

The clinical nurse specialists’ main responsibility is to promote a sense of well being and reduce anxiety following a diagnosis of testicular cancer and to reduce the negative affect this event
may have on you and your family. He or she is there to offer advice and support whenever you need it.

The CNS can be contacted on 0121 371 4509 (direct line with answerphone) or on 0778 993 2836.

It is important that you make a list of all medicines you are taking and bring it with you to all your follow up clinic appointments. If you have any questions at all, please ask your surgeon, oncologist or nurse. It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatients appointments.
Glossary of medical terms used in this leaflet:

**AFP (Alpha Feta Protein)** - A tumour marker

**Adjuvant** - treatment given to reduce the risk of recurrence in stage one of the disease

**Biopsy** - a procedure to remove cells for analysis to determine a diagnosis

**Chemotherapy** - the treatment of cancer with drugs

**CT scan** - Computed Tomography (CT) uses special X-ray equipment to obtain many images from different angles. Then a specially designed computer programme joins them together to show detailed pictures of the inside of the body. A CT scan can be used to detect a metastatic disease

**Cryptorchidism** - undescended testicle(s)

**GCT - Germ Cell Tumour** - the most common type of testicular cancer including teratoma and seminoma

**Histopathology** - the area of medicine which specialises in diagnosing disease by examining cells from a tumour under the microscope

**Histopathologist** - a doctor who specialises in pathology (detection of disease)

**HCG (Human Chorionic Gonadotrophin)** - a tumour marker

**LDH (Lactate Dehydrogenase)** - a tumour marker

**Leydig cell tumour** - a rare type of testicular cancer

**Lymphoma** - a type of cancer which can present in the testis, usually found in older men

**Oncology** - the treatment of cancer

**Oncologist** - a doctor specialising in the treatment of cancer

**Orchidectomy** - operation to remove the testicle

**Orchidopexy** - operation to bring the testicle down into the scrotum
**Radiotherapy** - X-ray treatment that uses high energy rays to damage or kill cancer cells

**Sertoli cell cancer** - a rare type of testicular tumour

**Seminoma** - a type of testicular tumour

**Testosterone** - male hormone produced by the testicles

**Tumour marker** - a substance found in the blood which can indicate the presence of cancer and can be used to monitor response to treatment and detect relapse
About this information

This guide is provided for general information only and is not a substitute for professional medical advice. Every effort is taken to ensure that this information is accurate and consistent with current knowledge and practice at the time of publication. We are constantly striving to improve the quality of our information.

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The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.

Oncology

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