

“Although rare compared to other cancers, testicular cancer most commonly affects young men between the ages of 15 and 45. Over 2,400 cases of testicular cancer will be diagnosed each year.”

The information in this booklet is for men and their families who have been affected by a diagnosis of testicular cancer and outlines the types of treatment and issues which will be involved from the point of diagnosis onwards.

**[www.orchid-cancer.org.uk](http://www.orchid-cancer.org.uk)**



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# Section 1: Diagnosis

“ I first found a small pea-sized lump on my left testicle in October 1999 but out of ignorance/embarrassment I ignored it. It wasn't till June 2000 I found it started to hurt and the lump was a lot bigger. I went and told my mum, then saw the doctors who sent me to the hospital. ”  
M.W.

“ I noticed a small lump on one testicle. I was checking myself in the bath at the time. I went straight to my GP who thought it was a vein. The lump grew considerably, it was surrounding nearly half of my testicle, so I went back. He then sent me straight to the hospital. ”  
O.B.

“ I was in the shower after football training, washing myself, when I discovered a hard lump on my left testicle. It felt quite large (a bit bigger than a pea) and I knew that wasn't usually there. I phoned the GP the next day to get an appointment to get it checked out. ”  
R.H.

“ I felt a small lump on the top of my left testicle. I also, from time to time, had a dull achy pain coming from the left testicle. The thought of 'Oh God, what if it's cancer' shot through my mind but I thought, 'I'm young, fit and healthy, I wouldn't have cancer'. Wrong. I left it longer and longer, hoping and expecting it to go away. However, in November 2009, with the lump slightly larger and showing no signs of disappearing, I decided to see the doctor. ”  
C.P.

# Diagnosis: Tests

One of the most important things for men to remember after a diagnosis of testicular cancer is that although treatment will happen quickly and it will take some time to adjust to normal life afterwards testicular cancer is very treatable and nearly all men will be cured.

Informative videos on all stages of testicular cancer treatment can be found at [yourprivates.org.uk](http://yourprivates.org.uk)

## Ultrasound scan

An ultrasound scan is extremely accurate at diagnosing testicular cancer. If there is a strong suspicion that testicular cancer is present men will be referred to a hospital specialist called a urologist who will arrange for several other tests to be performed.

## Blood tests

Some testicular cancers produce chemicals, which are released into the bloodstream. These chemicals, called tumour markers, are alpha-fetoprotein (AFP), beta human chorionic gonadotrophin (BHCG) and lactate dehydrogenase (LDH). They may be abnormal in the presence of particular types of testicular cancer. For instance, AFP and HCG can be raised in the presence of a particular type of testicular cancer called non seminoma.

They can also be used to measure the effectiveness of treatment and may be repeated after initial treatment if they were abnormal beforehand.

Occasionally, if there is evidence that testicular cancer has spread to other areas of the body, a referral may be made to an oncologist

(cancer specialist) to see if chemotherapy should be given before any other type of treatment.

## Chest X-ray

This is performed to make sure that the lungs are healthy and functioning normally.

## Pregnancy test

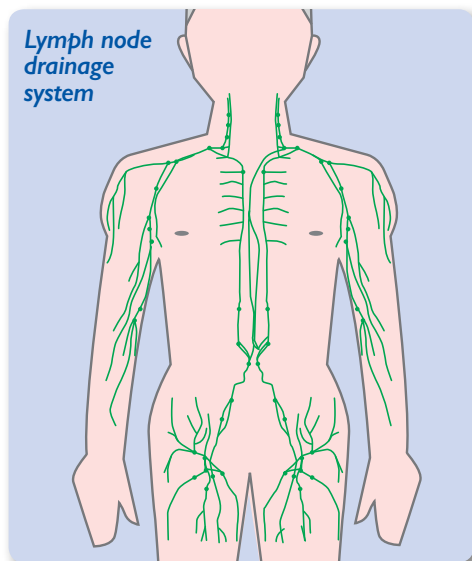
BHCG is produced in the blood during pregnancy and in the presence of certain types of testicular cancer. Large amounts of BHCG can be detected in the urine and potentially identified by a pregnancy test. However not all testicular cancers produce BHCG and so should never be used as a definitive test for testicular cancer. Some performance enhancing drugs can also cause a false positive urine test.

## Computerised Tomography scan (CT)

A CT scan is performed to check for any signs that testicular cancer may have spread to other areas of the body such as lymph glands in the abdomen (see diagram on page 7). The scan takes a series of x-rays, which are fed into

a computer to build up a three-dimensional image of the body and takes from 10 to 30 minutes to perform. An injection of dye may be given before the scan to help identify specific areas of the body and this may cause a warm sensation for a few minutes. The scan is painless, but involves lying still while it is being performed.

### What are Lymph Nodes?

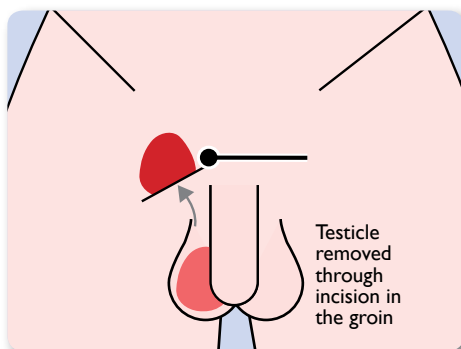


The human body is covered by a special type of drainage system called the lymphatic drainage system. This system is responsible for transporting excess fluid from the organs and tissues of the body as a fluid called lymph. Lymph fluid will contain various types of cells and substances that are no longer needed. These will be transported along the lymphatic system and pass through small nodules or nodes that act as filters responsible for removing them. Cancerous cells can also travel in this way and can sometimes spread to other areas of the body.

## Surgery (orchidectomy)

If testicular cancer is identified then the standard procedure will be to surgically remove the affected testicle. This is the most effective way to remove the cancer and identify it.

Orchidectomy (unilateral) is the surgical removal of one testicle. It is a simple procedure which may take about half an hour to perform and will be carried out under general anaesthetic. A small incision is made into the groin region on the affected side and the testicle is examined and removed from above (see diagram below). The scrotum will not be cut. A prosthetic (artificial) testicle can be inserted at the time of surgery. Men may also be advised on sperm storage prior to surgery (see page 29).



### Falsey or not?

Prosthetic testicles are silicone implants that can be inflated with salt water. They come in various sizes and can give a very good cosmetic result which may be of great psychological value. They can sometimes cause minor problems in some men in the longer term. The specialist team will usually

discuss the insertion of a prosthetic testicle before orchidectomy. This procedure can be performed at a later date if men are not sure that they want one at the time of surgery.

Once inserted, the neck of the scrotum is closed with stitches to prevent the prosthesis from moving out of position.

### Some problems may include:

- ▶ Scar tissue forming around the implant inside the scrotum can sometimes cause a thick fibrous growth of tissue which can sometimes cause discomfort or give rise to worry that cancer has returned.
- ▶ Rupture of the implant can rarely occur due to vigorous activities such as contact sport, cycling or physical contact including sexual intercourse.
- ▶ Sometimes the implant may move out of its original position.
- ▶ A prosthetic testicle will not react to temperature like a normal one and will stay the same size.

### After surgery

- ▶ There will be a dressing covering the incision site on the groin. This can usually be removed 24 hours after the operation. The stitches (sutures) in the wound will usually be dissolvable but may take a few weeks to fully disappear.
- ▶ Men can have a bath or shower, normally after 24 hours, but it is important to avoid any substances (such as perfumed toiletries) around the wound site for a

few days as they may cause irritation or inflammation and delay healing. The wound should be dried by gently patting it with a clean towel/gauze pad.

- ▶ The groin and scrotal area can feel bruised and swollen after the operation. It is advisable to wear close fitting underwear, such as briefs, 'Y' fronts or a scrotal support rather than boxer shorts. This will help the bruising settle. Prescribed painkillers should be taken on a regular basis (not just when pain is felt). Often simple paracetamol combined with an anti-inflammatory medication (such as ibuprofen) are effective at reducing discomfort.
- ▶ Although this is a minor operation, it is important to take things easy for the first week. Men should be able to return to work within a few weeks. However, if they are going to be seen by the specialist team to discuss the results of their operation it might be a good idea to wait for the outcome in case further time off is needed.
- ▶ Occasionally a collection site of blood may form under the wound (haematoma) or the wound may become infected. This may cause swelling, inflammation or discomfort and men should seek medical advice if this occurs.
- ▶ It is important to avoid heavy lifting and/or strenuous exercise for the first few weeks. Men should only start driving when they feel able to perform an emergency stop without hesitation.
- ▶ Sexual activity can begin again after two weeks providing it feels comfortable to do so.

All men with testicular cancer will see an oncologist after orchidectomy to discuss the results of their surgery and to decide whether any further treatment is needed.

About 5% of men with testicular cancer may also have pre-cancerous or cancerous cells

in the opposite testicle. If this is suspected a biopsy of the opposite (contralateral) testicle may be performed at the same time as the orchidectomy.

For more information on orchidectomy please visit [www.yourprivates.org.uk](http://www.yourprivates.org.uk).



## Section tips:

- ▶ Men who are diagnosed with testicular cancer will usually be given the details of a urology specialist nurse or “key worker” who will act as their point of contact during and after treatment and who can provide them with relevant information and advice. Men should make sure that they have these details as the specialist nurse will be an important source of help and contact.
- ▶ Once a diagnosis of testicular cancer is suspected things will begin to move very quickly. Surgery will be booked and scans arranged urgently, usually within a two week period. Men should plan ahead and involve all of their family so that they can help out with any arrangements that need to be made while they are having treatment (childcare, work etc.).
- ▶ Men will need to take time off work during and after treatment. It is advisable to keep any correspondence/letters and contact details of the health professionals involved or procedures performed as proof of treatment. If men have access to an Occupational Health Team at their place of work it is a good idea to explain the current situation and possible further treatment which might be needed.
- ▶ Although the hospital where a man has been treated can issue a sick certificate to cover the surgery they will not be able to provide a long term sick certificate. This will need to be obtained from a G.P.

The following websites have a great deal of information with regard to work related issues:

**Macmillan cancer support:** [www.macmillan.org.uk](http://www.macmillan.org.uk)  
or phone **0800 808 0000**

**Citizens Advice Bureau:** [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**Government benefit enquiry line:** [www.direct.gov.uk](http://www.direct.gov.uk)

## Section 2: Testicular cancer

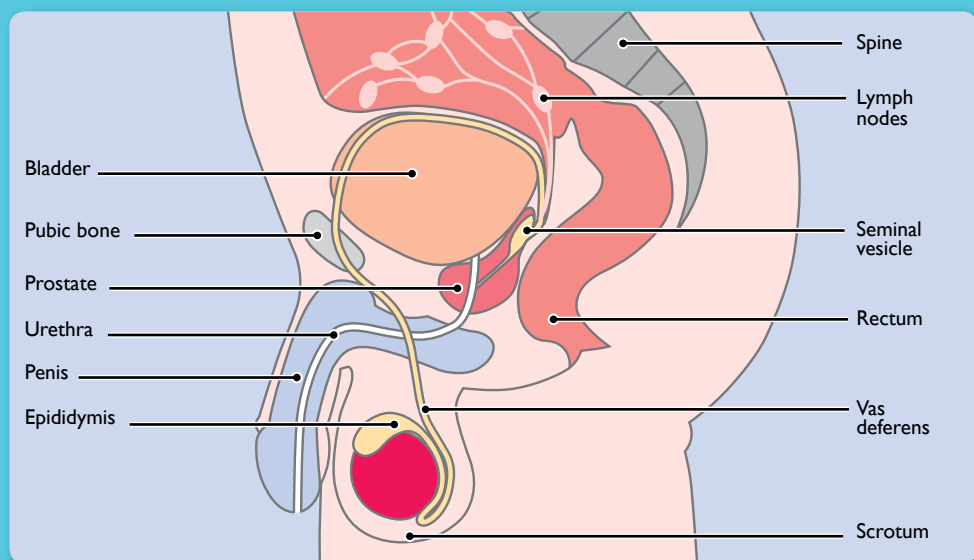
““ Shocked!!

*After denial and anger I realised the only way I was going to beat this was to try and be positive. ””*  
E.D.

““ After the ultrasound scan, I had several blood tests and then went to the consultant's room, where the consultant said that I was going to have an operation to remove the testicle which was swollen as they highly suspected that I had testicular cancer. I can still remember that point so clearly. He mentioned a fair number of different points but I was taken back completely by the word cancer. How was that possible 2 days after my 29th birthday? I had just moved away from my hometown, moved to a new job and moved in with someone and now felt a very long way from Paul's normal world. In fact, I struggled to ask any questions although I had many. I was shocked and really angry, why all this now? ””  
P.W.

““ I was in shock but at the ultrasound I had a feeling there was an issue as the radiologist was very quiet. The consultant explained the picture to me but everything seemed a bit muffled. The nurse was nice and explained that this is very treatable. In the consultant's report he put that it is 80-90% likely that it is cancer. ””  
D.F.

““ I returned home in shock and immediately went on the internet to do research. I kept it quiet, not telling anyone. The next day I phoned my dad to let him know. Hardest phone call I've ever made. It was during this phone call that I thought 'these things happen' and decided there was no point getting myself worried about it, I just needed to get on with it. With the week in France gone by with the odd ache and pain, no one other than my parents suspected a thing. Unlike everyone else who returned home, I stayed at my student accommodation for the weekend, telling people I could only be collected on Monday as my parents were busy. My dad came up on the Sunday night to take me to the hospital the next day. We had dinner then went to bed. ””  
C.P.



*Male pelvic anatomy*

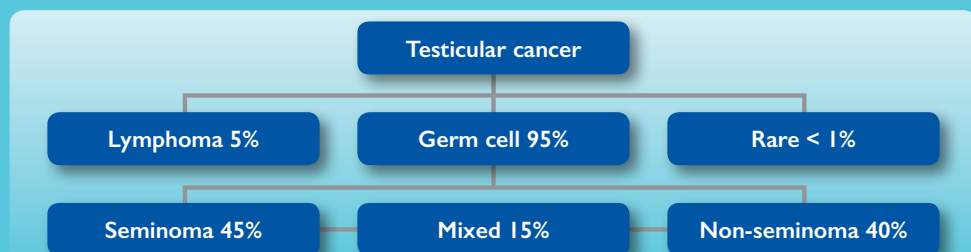
## Types of testicular cancer

The most common type of testicular cancer is called **seminoma**, a slow progressing type of cancer that does not usually spread to other areas of the body. This type of cancer is more common in men between the ages of **30-45**.

A slightly rarer type of testicular cancer is called a **non-seminomatous germ cell tumour (NSGCT)**. It used to be called a **teratoma**. **This tends to affect men between the ages of 20-35.**

Both of these tumours are also known as **germ cell tumours**. About 95% of testicular cancers will be germ cell cancers. Germ in this term means “seed” and refers to the sperm-making process. Other tumours (mixed cell tumours) may contain elements of both types of the above.

Other non germ cell tumours (Sertoli, Leydig) are extremely rare and account for only a small percentage of testicular cancers. In addition, 4% of men with lymphoma (a type of blood cancer) may also have similar symptoms to testicular cancer such as swelling in the scrotum.



*Summary of the incidence of testicular tumors*

# Classifying testicular cancer

Once a testicle has been removed it will be analysed by a medical scientist who will be able to identify the type of testicular cancer that is present.

There are two common ways of classifying testicular cancer and whether it has affected other areas in the body. The first is called the **TNM** system and is a universal method used for most cancers where:

## **T** stands for tumour size (given a value of 1-4 indicating how big it is)

- TIS** (testicular carcinoma insitu). Cancer cells are within the testes but they have not invaded the surrounding testicular tissue
- T1** Tumour confined to testicle and epididymis
- T2** Tumour has begun to infiltrate the blood vessels or lymph nodes close to the testicle
- T3** Tumour has grown as far as the spermatic cord and possibly blood vessels and lymph nodes
- T4** Tumour has invaded the scrotum

## **N** stands for affected (positive) lymph nodes (see page 7)

- N0** lymph nodes do not contain cancer cells
- N1** lymph nodes are smaller than 2cm wide
- N2** At least one lymph node is larger than 2cm but smaller than 5cm wide
- N3** At least one affected lymph node is bigger than 5cm

## **M** stands for metastases

Metastases are deposits of cancer which form as a result of the primary cancer travelling to other organs in the body or bones. Testicular cancer which has spread from its primary site in this way may affect the lungs, liver or brain.

- M0** There is no evidence that the cancer has spread to other organs
- M1a** The cancer has spread to the lungs or distant lymph nodes furthest away from the testicle
- M1b** Organs such as the liver or brain have been affected

A further way of categorising testicular cancer is to split it into 3 stages (see table on page 14).

The results of tumour markers can also be added to either of these systems to predict possible treatment success. This is denoted as **S** where **S** stands for **Serum markers**.

- ▶ **SX**: Tumour marker studies not available or not performed
- ▶ **S0**: Tumour marker levels within normal limits
- ▶ **S1**: LDH < 1.5 X Normal and HCG < 5,000 and AFP < 1,000
- ▶ **S2**: LDH 1.5-10 X Normal or HCG 5,000-50,000 or AFP 1,000-10,000
- ▶ **S3**: LDH > 10 X Normal or HCG > 50,000 or AFP > 10,000

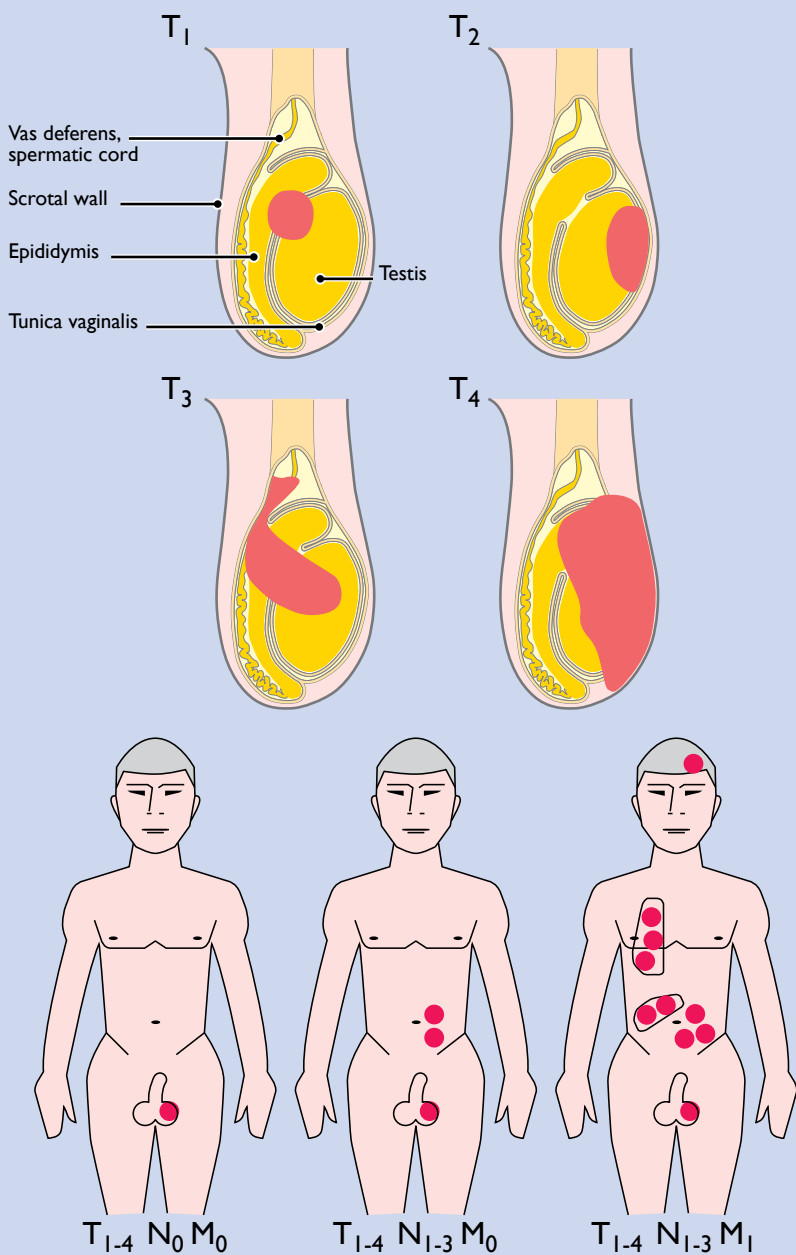


Diagram illustrating testicular cancer staging (TNM system)

**Testicular staging non TNM**

<b>Stage 1</b> This is the earliest stage of testicular cancer.	<ul style="list-style-type: none"><li>• The cancer is contained within the testicle and has not spread to nearby lymph nodes or other organs</li></ul>
<b>Stage 2</b> The cancer cells have spread into nearby lymph nodes in the abdomen or pelvis. This is further split into sub stages 2A, 2B and 2C.	<ul style="list-style-type: none"><li>• Stage 2A - lymph nodes are all smaller than 2cm</li><li>• Stage 2B - lymph nodes are between 2cm and 5cm</li><li>• Stage 2C - at least one lymph node is bigger than 5cm</li></ul>
<b>Stage 3</b> This can be split into 3A, 3B and 3C.	<ul style="list-style-type: none"><li>• Stage 3A - cancer has spread to distant lymph nodes or lungs</li><li>• Stage 3B - cancer has spread to nearby lymph nodes or distant lymph nodes and lungs and there is a moderately high marker level</li><li>• Stage 3C - can be the same as stage 3B but men have a very high marker level or their cancer has spread to another body organ, such as the liver or brain</li></ul>


The current staging of testicular cancer has recently been reviewed internationally and minor changes to the above are likely to be made over the next few years.

Record your staging:

Your TNM stage    T       N       M

Your stage    I    2a   b   c    3a   b   c

## Section 3: Post-surgical treatment



*“ Chemo was more of an annoyance than anything as it used to make me feel tired. I am an active person and sitting around doing nothing is something I hate, so this part of the cancer journey was the worst. I knew I was going to lose my hair so that was no shock but if anything my confidence was knocked because I had lost weight as well so I used to refer to myself as an alien. ”*  
R.H.

*“ Having my body changed and feeling sick all of the time from the chemo; you feel alone and it seems like you are ill all the time. It's difficult when people tell you 'you'll be ok' as they can't quantify it and feels like a worthless thing to say. It's understandable they don't know what to say, but it is extremely difficult to hear. ”*  
S.F.

# After surgery: Localised testicular cancer

To ensure that men get the best possible treatment after orchidectomy, their particular 'case' will be reviewed at a meeting called a

## **Multi-Disciplinary Team meeting (MDT).**

### **The MDT Process**

An MDT will consist of a group of medical experts including urologists, oncologists, radiologists (x-ray specialists) and other healthcare professionals. They will review each individual case taking into account the results of the orchidectomy, blood tests and scan results, then come up with a consensus opinion as to what, if any, further treatment is needed. Any decision made by this team will reflect their experience in dealing with similar cases and will be based on the latest medical research treatments, national and international guidelines.

Early stage seminoma or non-seminoma confined to the testicle can usually be treated with a policy of surveillance. This means that regular CT scans and blood tests will need to be performed. Should cancer come back, chemotherapy will be given to cure it.

Some men may not want to keep returning for scans as frequently as surveillance requires. An alternative is to have a limited dose of chemotherapy to reduce the risk of any cancer recurring.

Men may feel tired and suffer some minor side effects for a few weeks after this type of chemotherapy.

Radiotherapy can be used to treat lymph nodes at the back of the abdomen which may still contain cancer in cases of seminoma. This treatment will usually involve around 21 days of treatment every day, 5 days a week for around 10 minutes a day. It is not used for non-seminoma.

Both chemotherapy and radiotherapy (for seminoma) are as successful as each other in curing early stage testicular cancer.

After treatment, men will be reviewed on a regular basis with visits to clinic every 6-8 weeks. These visits will gradually reduce but men will still need to be monitored for around 5 years.

Most testicular cancer that reoccurs does so within 2 years of treatment. Only 5% reoccur after this.

**Men will need to regularly perform testicular self-examination of their remaining testicle.**

# After surgery: Non-localised testicular cancer

Testicular cancer may spread to lymph nodes in the abdomen or other areas of the body such as the lungs, and in any of these situations, a course of chemotherapy will be recommended.

Testicular cancer that has spread to other parts of the body is still testicular cancer and not a separate cancer.

## Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells. The chemotherapy used to treat testicular cancer is administered directly into the bloodstream where it then circulates around the body and is known as systemic treatment.

The drugs most commonly used to treat testicular cancer are Cisplatin, Etoposide and Bleomycin. A combination of all three is a treatment known as BEP. BEP can be given as

a day case treatment or during a short stay in hospital.

Before chemotherapy, a breathing test called a lung function test will be performed as one type of chemotherapy (bleomycin) may affect lung function. A drip will be sited into a vein, usually in the arm and chemotherapy will be given.

BEP chemotherapy can be given in different ways and the exact duration of treatment will be decided by an oncologist. It can be given as a regime over three days or five days on an inpatient or outpatient basis. This pattern of treatment is also known as a cycle. Each cycle of treatment is given over 3 weeks and 3 or 4 cycles of BEP may be given.

Men who have high tumour markers or more widespread disease may be offered different doses of chemotherapy.

### BEP chemotherapy regime

One cycle 3 Day BEP (3-4 cycles over 2-3 months)	One cycle 5 Day BP (3-4 cycles over 2-3 months)
Day 1 Etoposide and Cisplatin	Day 1 Etoposide and Cisplatin
Day 2 Infusion of all BEP drugs	Day 2 All BEP drugs
Day 3 Etoposide only	Day 3 Etoposide and Cisplatin
Day 8 Bleomycin	Day 4 Etoposide and Cisplatin
Day 15 Bleomycin	Day 5 Etoposide and Cisplatin
Break	Day 8 Bleomycin
	Day 15 Bleomycin
	Break

# Chemotherapy effects

## Potential chemotherapy side effects

Common side effects of chemotherapy:	Try:	Avoid:
<b>Nausea and vomiting:</b>	<ul style="list-style-type: none"> <li>• Anti-sickness medication can be given on a regular basis</li> <li>• Ginger beer, ginger tea or ginger biscuits (eat regularly throughout the day)</li> <li>• Peppermint tea, always drink slowly taking lots of sips</li> <li>• A small meal a few hours before chemo starts</li> </ul> <p><b>Never have chemotherapy on an empty stomach</b></p>	<ul style="list-style-type: none"> <li>• Hot and spicy foods</li> <li>• Foods with high sugar content</li> <li>• Fatty and greasy foods (chips, burgers etc.)</li> <li>• Large meals</li> <li>• Eating and drinking too fast and drinking with meals</li> <li>• Alcohol</li> <li>• Caffeine (which is found in tea/coffee/chocolate including chocolate bars/energy drinks)</li> <li>• Baby food this is designed for babies and has very little nutrition for adults</li> </ul>
<b>Taste:</b> (chemo can cause a metallic taste in the mouth)	<ul style="list-style-type: none"> <li>• Fresh pineapple or other sharp-tasting fruit</li> <li>• Boiled sweets while having treatment</li> <li>• Seasoned or marinated food with meals to add flavour</li> <li>• Using herbs and spices in cooking to add stronger taste</li> </ul>	

Common side effects of chemotherapy:	Try:	Avoid:
<b>Mouth sores or ulcers from chemotherapy:</b>	<ul style="list-style-type: none"> <li>• Eating fresh pineapple can help prevent and heal mouth ulcers by stimulating saliva which protects the mouth</li> <li>• Bonjela</li> <li>• A soft child's/baby bristle toothbrush and baby/soothing (for instance) aloe vera toothpaste</li> <li>• A soft puréed or liquid diet to prevent chewing</li> <li>• Rinsing the mouth with salt water on a regular basis if tolerable up to 4-5 times a day</li> <li>• Sucking crushed ice during treatment</li> <li>• Vaseline for the lips</li> </ul>	<ul style="list-style-type: none"> <li>• Tomato and citrus fruit based products and tobacco</li> <li>• Oral care products that may cause a dry mouth and products that contain alcohol or peroxide</li> <li>• Hot and spicy food</li> <li>• Nuts and seeds</li> </ul>
<b>Tiredness:</b>	<ul style="list-style-type: none"> <li>• Getting small restful naps</li> <li>• Sleeping tablets which can be prescribed if insomnia is becoming a big problem</li> </ul>	

Common side effects of chemotherapy:	Try:	Avoid:
<b>Loss of appetite:</b>	<ul style="list-style-type: none"> <li>• Having small frequent meals throughout the day</li> <li>• Fortified soups/drinks or milk shakes</li> </ul>	
<b>Diarrhoea:</b>	<ul style="list-style-type: none"> <li>• Rice and pasta</li> <li>• Dry crackers/biscuits</li> <li>• White bread</li> <li>• Bananas (a good source of potassium which is essential for the body's metabolism). Excessive diarrhoea will deplete potassium levels</li> </ul>	<ul style="list-style-type: none"> <li>• High fibre foods (bran, fruit, nuts etc.)</li> </ul>
<b>Hair loss:</b> This may occur 2-3 weeks after chemotherapy	<ul style="list-style-type: none"> <li>• A baseball cap</li> <li>• Shaving hair off when it starts to fall out</li> </ul>	<ul style="list-style-type: none"> <li>• Head cooling devices that may reduce the circulating blood supply and reduce the effectiveness of the chemo</li> </ul>
<b>Low immune system</b>	<ul style="list-style-type: none"> <li>• Paying meticulous attention to hygiene. Hands must be washed after going to the toilet</li> <li>• Wearing a hat in summer or strong sun and avoid sunbathing in direct sunlight which could possibly cause scarring</li> </ul>	<ul style="list-style-type: none"> <li>• Drugs/alcohol which may depress the immune system and make men feel bad</li> <li>• Travelling to foreign countries where risk of picking up illness is greater</li> <li>• Vaccines. Ask the specialist team if precautions need to be taken when receiving any vaccinations e.g. when travelling abroad</li> </ul>

Common side effects of chemotherapy:	Try:	Avoid:
Tingling in the arms and feet due to nerve damage (peripheral neuropathy) from chemotherapy:	<ul style="list-style-type: none"> <li>• Keeping hands and feet warm and avoid extremes of temperature</li> <li>• To make sure that care is taken when preparing food (use gloves) or when running hot water (test with the elbow) as there may be a risk of burning</li> <li>• Gentle exercise</li> </ul>	
Inflammation in the lungs with shortness of breath due to low circulating heamoglobin (oxygenated blood) from chemotherapy:	<ul style="list-style-type: none"> <li>• A blood transfusion may be needed</li> <li>• Resting</li> </ul>	<ul style="list-style-type: none"> <li>• Taxing, strenuous tasks</li> <li>• Smoking</li> </ul>
Tinnitus (ringing in the ears) from chemotherapy:	<ul style="list-style-type: none"> <li>• Encouraging people to speak slowly and clearly</li> <li>• Listening to gentle background music as some people think this may help</li> </ul>	

Common side effects of chemotherapy:	Try:	Avoid:
<b>Skin changes:</b>	<ul style="list-style-type: none"> <li>• Using an electric shaver to avoid cuts</li> <li>• Non-perfumed moisturising creams</li> <li>• Avoid prolonged exposure to the sun as chemo can make skin more sensitive. It is essential that at least factor 15 sun screen is used when sunbathing</li> <li>• Allow 6 weeks after radiotherapy treatment before exposure to the sun. It may also be best to cover the treated area for up to a year</li> </ul>	<ul style="list-style-type: none"> <li>• Wet shaving which may break the skin</li> <li>• Non-perfumed soaps when having radiotherapy and have tepid baths</li> <li>• Vigorous rubbing of the skin around the treated area</li> </ul>

Semen (the fluid that contains sperm) may contain some residual chemotherapy following treatment and if sexual intercourse is planned within 48 hours of finishing treatment it is advisable to use a condom.



### Tips:

- ▶ The effects of chemotherapy may take some time to subside after treatment. This can take a few months to a year or more. Men may feel tired or exhausted for a few months afterwards and should take this into account when considering going back to work or for a busy lifestyle.
- ▶ Although there is no definite evidence that radiotherapy or chemotherapy can affect children that are fathered after treatment it is usually advisable for men to use a condom for 6-12 months following chemotherapy treatment.

Following chemotherapy a further CT scan will be performed to see how successful treatment has been. If treatment has been effective then men will be reviewed by the specialist team on a regular basis with blood tests and further scans.

# After chemotherapy (if disease is still present)

If there are any signs of residual cancer following chemotherapy affecting lymph nodes in the abdomen it may be suggested that men undergo the following additional treatment:

## Retroperitoneal Lymph Node Dissection (RPLND)

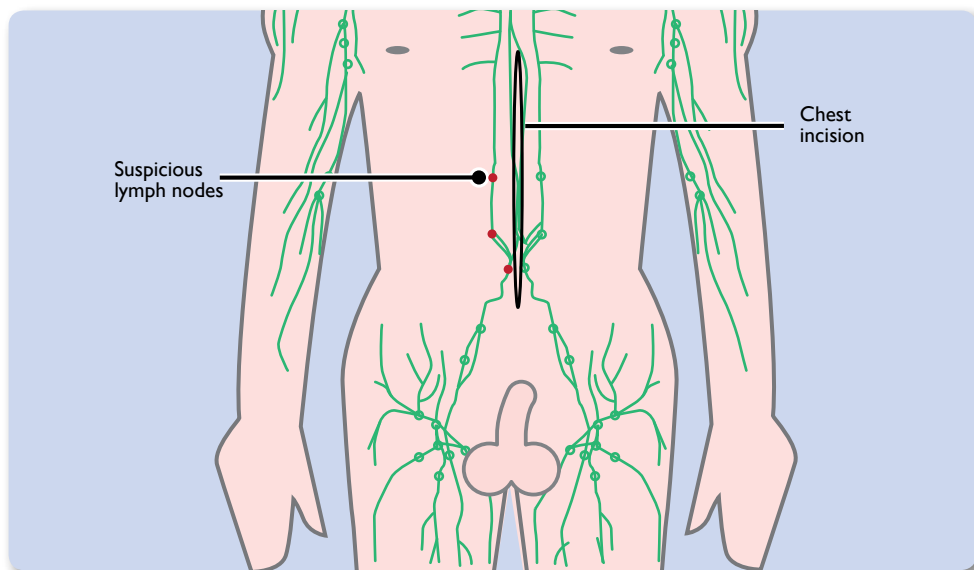
This operation is performed under a general anaesthetic, and can take up to 4 hours. An incision (cut) is made from just below the breastbone to just below the navel (belly button). Lymph nodes on the same side as the affected testicle are removed followed by any others that look suspicious of containing cancerous cells.

Retroperitoneal Lymph Node Dissection can affect a man's fertility, as the operation can sometimes damage the nerves that control the discharge of sperm through the penis (ejaculation).

Although this further surgery may make it more difficult for men to father a child, it should have no physical effect on a man's ability to get an erection.

Retroperitoneal Lymph Node Dissection is not usually performed for seminoma unless lymph nodes are over 3cm in size.

Hospital stay is usually 7-10 days.



## After RPLND: Tips

- ▶ Painkillers should be used as prescribed on a regular basis (not just when pain is felt).
- ▶ Try to eat a high fibre diet to prevent constipation which may aggravate pain. Aim to drink 2-3 litres of fluid a day to help soften stools. A mild laxative may be helpful.
- ▶ Take things easy for 2 weeks after surgery. If men live alone it may be beneficial to stay with someone who can support them as they may tire easily.
- ▶ Heavy lifting and vigorous exercise should be avoided for at least 6 weeks to allow the abdominal muscles to heal. Try and walk upright without stooping.
- ▶ Do not drive for 3-4 weeks until able to stop effectively in an emergency.
- ▶ It should be possible to return to work after 4 weeks but may need to be longer if it is a particularly physical job.
- ▶ A sick certificate from a GP will need to be obtained.
- ▶ Sexual intercourse should be avoided for approximately 4 weeks after surgery.

## Recurrent disease

Recurrent testicular cancer tends to affect lymph nodes rather than the remaining testicle. In this situation further chemotherapy will be given with a good chance of cure. If cancer develops in the remaining testicle it is usually classed as a new cancer. In this situation a further orchidectomy will usually be performed. This will mean that men will not be able to have an erection or sexual intercourse without the use of testosterone replacement therapy (see page 33). Rarely, if the cancer is at an early stage and is only affecting a small area of the testicle then a partial orchidectomy may be performed, although this is not standard treatment.

Surgery can also sometimes be used to remove isolated areas of cancer elsewhere in the body.

### High dose chemotherapy with stem cell support

This can be used to treat residual or recurrent cancer when standard chemotherapy has not been successful and allows higher doses of chemotherapy to be given. Before high-dose treatment, cells in the blood (called stem cells) are removed and stored.

Shortly after the chemotherapy is given, the stem cells are returned to the body through a drip (like a blood transfusion). They make their way back to the bone marrow (where blood cells are made) and start to produce healthy cells again.

This is often a very intensive and demanding treatment and will mean staying in hospital for a few weeks.

# Clinical trials

If men are having chemotherapy, they may be offered the chance to participate in a clinical trial. Clinical trials are aimed at improving treatment outcomes for cancer. Most of the time they will be using one or more traditionally effective treatments such as chemotherapy in conjunction with each other to try to improve and reduce the possible side effects of treatment. An oncologist or specialist nurse may discuss these possibilities. If men decide to take part in a clinical trial, they are free to opt-out at any time.

**For further information on clinical trials that are being used to treat testicular cancer please visit:**



## NHS

[www.nhs.uk/Conditions/Cancer-of-the-testicle/Pages/clinical-trial.aspx](http://www.nhs.uk/Conditions/Cancer-of-the-testicle/Pages/clinical-trial.aspx)

## Cancer Research UK

<http://www.cancerresearchuk.org/about-cancer/testicular-cancer/research-clinical-trials/research>

## Orchid


[www.yourprivates.org.uk](http://www.yourprivates.org.uk)



## Section tips:

- ▶ The effects of chemotherapy may take some time to subside after treatment. This can take a few months to a year or more. Men may feel tired or exhausted and should take this into account when they are considering going back to work or for a busy lifestyle as they may not be able to function as well as before treatment.
- ▶ Although there is no definite evidence that radiotherapy or chemotherapy can affect children that are fathered after treatment it is usually advisable to use contraception for 6 -12 months afterwards.
- ▶ Adjusting to life after treatment for testicular cancer can be difficult. There will be a number of physical and psychological factors that men will need to come to terms with and obtain help. A good start for information on these issues can be found at [www.macmillan.org.uk](http://www.macmillan.org.uk)

## Section 4: Sex, life and the universe



“ Message to partners: I think you have the hardest job of all. Men are strange to get your head around! You'll help us most by listening and being around during the major treatment stages. ”  
B.T.

“ I was scared to death. I thought I was going to be a freak and never get a girlfriend. I decided to take one step at a time and not look too far ahead. This helped me to not worry about future events that were not within my control. Plan on what you are going to do after finishing treatment, treatment is hard but it can be made all the easier if you feel you have something to look forward to after treatment. ”  
P.W.

“ Do it together - or, at least, do it the way that will work for you. Every cancer is different so don't go looking on the internet too much and only speak with fellow sufferers if you think it will be a good thing for you. Stay strong, be positive and be true to yourself. Don't worry about the days when you are low and be honest about how you feel. ”  
P.M.

“ I'd like to say that I'm now travelling the world in sandals preaching to everyone how my life has changed after cancer, but in reality, it only changed it for a couple of months and then you always seem to get back in the same routine you had previously. Now over 7 months later, it's beginning to take a more prominent role in my life as I am now realising how lucky I am to be a survivor when so many don't manage that. I only wish that I was a radically different person now, to who I was before my diagnosis, and I do feel guilty that I don't feel that it happened that way for me like it does for so many others affected. Maybe I just haven't really come to terms with it yet and just need to talk to someone professional about why I feel like that, because I've never really had the opportunity to delve into it with someone that way. Or maybe it's just my way of coping with it. ”  
M.H.

# Sex

One of the most common questions asked by men after treatment for testicular cancer is whether their sex life will be affected. The removal of one testicle will not usually affect sexual performance or the ability to father children, providing the other testicle is healthy and functioning normally. This is because the remaining healthy testicle will produce enough testosterone and sperm to compensate.

If both testicles are removed **then testosterone replacement therapy will be needed** (see page 33). This can be given in the form of injections or gels and should enable a man to have normal sexual intercourse.

Cancer treatment may make men lose interest in sex. This is called loss of libido and is common to many illnesses, not just cancer. It is worrying, but it is usually a temporary side effect and once treatment is over and the body begins to return to normal, libido will usually also return.

Sexual problems are very personal and very important, and talking about them can be a great help. Although this can sometimes be difficult, once men have summoned up the courage to talk openly to their partners, many of them find that their fears of rejection are unfounded. Sexual relationships are built on many things including love, trust and common experiences. Men may even find a new closeness after talking through a problem with their partner. Some hospitals have specialist counsellors (psychosexual counsellors) who are trained to help people with sexual concerns. If men are worried about this they

should ask their doctor or nurse specialist for further information.

**One common fear is that cancer cells can be passed on to a partner during sex. This is not true. Cancer is not infectious and it is perfectly safe to have sexual intercourse.**

## Fertility

Many men worry that they may not be able to have children after they have been treated for testicular cancer. Chemotherapy can cause temporary infertility after treatment but this is usually temporary (see page 32).

## Coping

Most people feel overwhelmed when they are told they have cancer even if the chance of cure is very high. Many different emotions can arise which can cause confusion and frequent changes of mood. Men may experience feelings such as fear, resentment and anger.

**This does not mean, however, that they are not coping with the illness.**

For many men treatment for testicular cancer happens very quickly. Some may be just finishing college or university, starting out in life with a new job, partner or young family.

During treatment their everyday life will be put on hold and it is not until treatment has finished and they are not attending a hospital regularly that the full realisation of what they have been through may affect them.

## Psychological support

Some men will find that having family and friends who understand what they have been through will be enough to help them get back to normal life. Others may find that they may benefit from talking to someone through counselling. There is nothing to be ashamed of in undergoing counselling and often men will find that they can talk to a stranger more easily about aspects of their life, fears and anxieties than a family member or friend.

Orchid currently offers a Telephone Counselling Service for men who have been affected by testicular cancer. Please email **nurse@orchid-cancer.org.uk** for more details or phone **0808 802 0010**.

## A holistic approach

This means adapting lifestyle to optimise recovery and well-being by staying healthy through exercise, diet and a positive mental outlook.

Many hospitals are working with charities and local services to provide this type of support and there may be “workshops” or meetings that men may be able to attend. They should ask their specialist nurse about these services.

Talking to other men who have been through similar treatment is also extremely beneficial either face to face or via online forums.

## Low testosterone

In some men, treatment with chemotherapy may reduce their testosterone levels. For more information on low testosterone levels please see page 33.

For comprehensive information regarding support after cancer see:

[www.macmillan.org.uk](http://www.macmillan.org.uk)

For video clips of men discussing various issues in relation to testicular cancer, treatment and follow up: [www.yourprivates.org.uk](http://www.yourprivates.org.uk) and [www.healthtalkonline.org/cancer/Testicular\\_Cancer](http://www.healthtalkonline.org/cancer/Testicular_Cancer)

## Support groups

Many men find a lot of support from online testicular cancer forums (see end of booklet), where they can discuss common feelings and treatments. It is often one of the best ways to express their feelings and learn that they are not alone.

Some men may also wish to form a meeting group where they can talk.

Orchid is always interested in hearing about testicular cancer support groups.

Please email **nurse@orchid-org.uk** with details of a support group that may be able to offer advice.

# Section 5: Related issues

## Testicular cancer treatment and fertility

### What is sperm storage?

Storing sperm, also known as sperm banking, is the preservation of sperm by freezing. The sperm can then be used at a later date for artificial insemination or other assisted reproduction techniques such as in vitro fertilisation (IVF). This is when an egg is surgically removed from a woman's ovaries and fertilised with sperm in a laboratory. The fertilised egg, which is called an embryo, is then returned to the woman's womb to grow and develop.

### Why consider sperm banking?

Sometimes treatment for testicular cancer with a combination of surgery (unilateral orchidectomy) and chemotherapy may lead to temporary or rarely, permanent infertility and therefore sperm storage should be discussed before treatment.

Even if a man does not plan to start a family, sperm banking is worth considering in case he changes his mind in the future.

### Where can a sperm bank or clinic be found?

The specialist healthcare team will be able to advise men if the hospital where they are being treated has sperm banking facilities. They can also provide them with information on a local fertility centre where they may be offered the opportunity to bank sperm. Sperm can be stored for 10 years initially but

this period can be extended if fertility remains impaired after this time.

### Visiting the sperm bank or clinic

When a man first visits the clinic, the specialist healthcare team will discuss the process of sperm banking and answer any questions and concerns that he or his partner may have.

Men will be asked to provide a sperm sample, through masturbation, to the clinic which will be frozen and stored. When a man is ready to have a child the semen can be thawed and used to artificially inseminate their partner. Prior to sperm banking men will also be asked to have some blood tests to check for antibodies to the infectious viruses HIV, Hepatitis B and Hepatitis C. This is standard practice, and confirmation that they have not been exposed to these viruses will be needed before their sperm can be frozen. Having any of the above viruses does not exclude them from storing sperm but further advice will need to be given.

To provide a sample men may be required to make several visits to a clinic. It is advisable to abstain from ejaculating three days before sperm storage to ensure the best amount and quality of sperm is obtained.

In some circumstances it is possible to ejaculate into a condom at home, providing the sample can be taken to the sperm bank within an hour. The condom will be provided by the sperm bank and will not contain lubrication or spermicide.

Not everyone is suitable for sperm banking and a low sperm count, poor sperm quality, and the freezing and thawing process can all affect its quality.

**Q.** What is a normal sperm count?

**A.** On average men produce 1.5 - 5 mls of ejaculate which may contain between 20 - 150 million sperm per millilitre and approximately 60% of this sperm should appear normal.

Some men with testicular cancer have a low sperm count before they start treatment and sometimes in these men, successful treatment for testicular cancer can cause their sperm count to return to a more normal level.

For men who are unable to store sperm it can in some instances be extracted from the testicles using Testicular Sperm Extraction (TESE); a surgical technique which involves removing small pieces of testicular tissue under a general anaesthetic and checking for the presence of sperm. If sperm is present and is successfully retrieved, it can be used to fertilise an egg outside of the uterus (IVF). In some instances the sperm removal can be performed at the time of orchidectomy. However this type of procedure does require a lot of preparation to ensure that the sperm is collected and prepared properly and will need to be discussed with the specialist healthcare team before an orchidectomy is performed.

**Only one healthy sperm is needed to father a child.**

## What tests and consents are involved in banking sperm?

There are a number of tests and consent forms that men will need to complete including:

- ▶ If a man is under the age of 16 he will need his parent or guardian's permission to have his sperm treated and stored.
- ▶ Blood will be screened for HIV, hepatitis B and hepatitis C.
- ▶ Men will need to confirm what they would like done with their sperm in the event of their death.

**Q.** Following cancer treatment, what happens if tests show that a man is fertile?

**A.** They will need to discuss the results with their specialist healthcare team. They may wish to have the stored sperm destroyed. If a man's sperm count is still low, his sperm can be stored on an ongoing basis if desired.

## What costs are involved in storing sperm?

Currently, the NHS will pay for the costs of the initial consultations, blood tests and storage of sperm and most centres will have cover to store sperm for up to 3 years. Funding for further treatment is under review and men should discuss this with their specialist healthcare team as it can be more expensive to store the sperm longer term.

**Q.** What happens to a man's stored sperm if he moves away from the area where he was originally treated?

**A.** He must ensure the clinic and his GP are provided with his new address details as they will need to contact him in the future. He does not need to move his stored sperm. However, should he need to use it he can contact the facility where the sperm is stored and arrangements can be made to access it.

Sperm will be destroyed if no longer required for use after 10 years.

Treatment for testicular cancer will vary according to the type and stage of a man's cancer. Every case will vary but the vast majority of men will be able to father a child.

## Treatment options

**What are they and how will they affect a man's fertility?**

### Orchidectomy

Removing the affected testicle(s) and tumour by surgery is the standard treatment for testicular cancer. Having one testicle removed (unilateral orchidectomy) should not affect sexual performance and will not normally affect a man's fertility. However, a man may be advised to perform sperm banking prior to an orchidectomy in certain circumstances if it is likely that further treatment with chemotherapy may be needed afterwards or there is a possibility that the other testicle might be producing a low level of sperm. A rarer option is surgery called a partial orchidectomy where just the tumour is removed, from the testicle although this is not considered standard treatment.

Providing the cancer has not spread beyond the testicle, further treatment may not be needed and men may choose to attend a strict regime of follow up care; regular blood tests, scans and hospital appointments. This is known as surveillance. Should cancer reoccur treatment with chemotherapy can be given and this will usually cure most men.

### Chemotherapy

Chemotherapy treatments are drugs used to kill cancer cells or stop them multiplying and this type of treatment can be given through a plastic tube or cannula (drip) into the bloodstream.

A small dose of chemotherapy can be given after orchidectomy to reduce the risk of any cancer returning if the cancer was confined to the testicle.

A longer course of chemotherapy is given for more widespread disease which may have affected other areas of the body such as lymph nodes.

**Q.** What are Lymph Nodes?

**A.** The human body is covered by a special type of drainage system called the lymphatic drainage system. This system is responsible for transporting excess fluid from the organs and tissues of the body as a fluid called lymph. Lymph fluid will contain various types of cells and substances that are no longer needed. These will be transported along the lymphatic system and pass through small nodules or nodes that act as filters responsible for removing them. Cancerous cells can also travel in this way and can sometimes spread to other areas of the body (see diagram page 7).

There are some possible side effects associated with chemotherapy treatment, including lowering the number of sperm that the body produces. This may cause temporary infertility during and after treatment and, in rare cases, permanently. Men who are having chemotherapy in either of these situations will therefore be advised to store sperm.

The effect of chemotherapy on sperm is uncertain and there is no evidence that chemotherapy given to a man can harm any children born subsequently. However, most specialist healthcare teams would advise men not to father a child for about a year after treatment.

It is not known how much chemotherapy may be present in the semen during treatment and there is a risk that partners may be exposed to chemotherapy during sexual intercourse. A condom is therefore recommended or if this is not possible men may need to avoid sex while receiving chemotherapy.

## Radiotherapy

Radiotherapy uses high energy beams of radiation to destroy cancer cells and has been used in the past to minimise the risk of seminoma returning by treating lymph nodes situated in the back of the abdomen. This type of treatment is used less today and research has shown that both radiotherapy and a single dose of chemotherapy are as effective as each other at reducing the risk of early stage seminoma recurring.

Radiotherapy can also sometimes be given following chemotherapy in men who have more advanced disease and who are unable to have further treatment surgery such as

RPLND (Retroperitoneal Lymph Node Dissection) explained below.

Radiotherapy will not normally affect a man's fertility but storing sperm may still be recommended.

## Retroperitoneal Lymph Node Dissection

Retroperitoneal Lymph Node Dissection (RPLND) is an operation which is performed to remove lymph nodes from the abdomen following chemotherapy (see page 23).

This procedure can sometimes damage the nerves that control ejaculation which may leave men unable to ejaculate normally. The sperm will not be released by the penis but will flow back into the bladder via the urethra, or water pipe (retrograde ejaculation) making them infertile. In these cases men should consider storing their sperm before surgery, if this has not already been performed.

In some instances however, it is possible to retrieve sperm from a urine sample which can then be subsequently used.

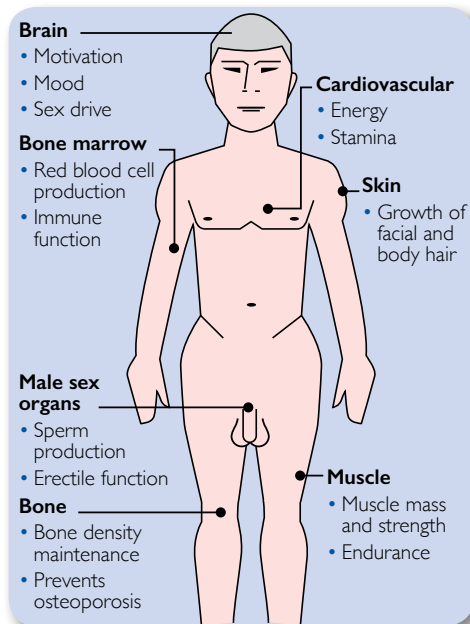


# Testosterone replacement therapy for men following testicular cancer treatment

Testosterone is the male sex hormone. It is responsible for male sexual characteristics such as:

- ▶ deep voice
- ▶ muscle tone
- ▶ bone strength
- ▶ hair pattern and balding
- ▶ sex drive
- ▶ achieving and maintaining erections
- ▶ general sense of male wellbeing

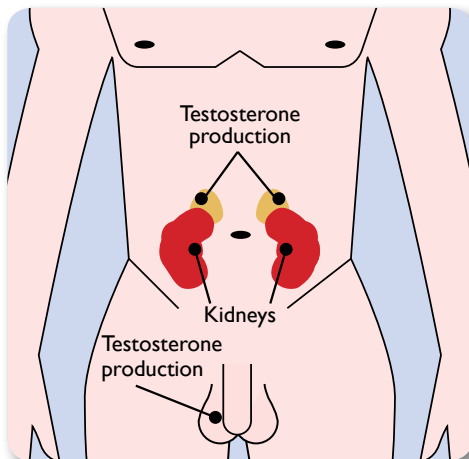
## How will men be affected by an orchidectomy?



90% of testosterone is made in the Leydig cells which line the testicles and produce sperm. A small amount is also produced in

the adrenal glands which are situated at the top of the kidneys.

## Where is testosterone made?



Having an orchidectomy should not affect the overall circulating testosterone level in the body as the remaining testicle, providing it is healthy and has not had any previous abnormalities, should be able to produce enough testosterone to make up for both. However, in some men such as those who have had or are having chemotherapy, the remaining testicle may not function normally for a while afterwards.

Bilateral orchidectomy means the removal of both testicles.

After bilateral orchidectomy, the body will not be able to produce sperm and only very low levels of testosterone will be made from the adrenal glands.

In this situation testosterone will fall to a minimal level and men will need to start testosterone replacement therapy.

### **How will men know if their testosterone is low?**

If testosterone levels fall below normal, many men will feel tired, low in mood and can develop hot flushes. Weight gain and a loss of muscle strength can also occur. These 'symptoms' can often be quite vague and difficult to recognise.

More specifically low testosterone levels may stop men from getting erections (for instance in the morning) or erections not strong enough for masturbation or sexual intercourse.

If testosterone levels are very low for a prolonged time, breast swelling (gynaecomastia), thinning of the bones (osteoporosis) and an increase in cardiovascular disease can also occur.

### **How else could men be affected by their treatment?**

Because treatment for testicular cancer is intense and occurs in a fairly short space of time, men not only have to recover from the physical and mental strain of their illness but may find themselves struggling with the symptoms of low testosterone as well.

Although low mood and sometimes depression can occur after testicular cancer treatment, men should consider asking their specialist team or GP to check them for possible testosterone deficiency.

A simple way of identifying potentially low testosterone levels is to have a blood test performed which can measure the level of testosterone that the body is producing.

### **The blood test to measure testosterone levels**

It is important that this particular blood test is performed in the morning. Men can eat and drink normally. Testosterone levels are at their highest in the morning, and this is when the test will be more accurate. The results should only take a few days to be fully processed in most areas.

### **What is the normal level?**

A normal level of testosterone is usually considered to be between approximately 9 - 30 nmol/L (nanomoles per litre).

A level below 8 nmol/L is considered to be low and the blood test should be repeated. If it is low on 2 occasions taken at the right time of the day, then men will usually benefit from starting testosterone replacement therapy.

Men who think that they may have a low testosterone level should speak to their specialist hospital team who can arrange for them to be assessed for this problem. If low testosterone is diagnosed they may be referred to a hormone specialist (endocrinologist).

Borderline levels are between 9 - 12 nmol/L and will often be monitored. Treatment is not usually started in this range as it does not tend to make a difference to how most men feel.

However, if men do have borderline levels it may still be possible to try testosterone replacement therapy for an initial period (for instance for 6 months) to see if it improves symptoms.

## Types of testosterone replacement

There are several methods of testosterone replacement therapy;

Type	Tips
<b>Gels (Testim®, Testogel®, Tostran®)</b> These are gels that are applied in a thin layer to a clean, dry and healthy area of the skin such as the shoulders, chest or back, usually on a daily basis.	<ul style="list-style-type: none"><li>• These are applied daily usually after a shower or bath, and men need to wait at least 5 minutes before dressing afterwards.</li><li>• It is very important that men wash their hands before and after use to avoid any transfer to their wife or partner; or if someone else applies it for them, they need to wear gloves to stop testosterone being absorbed into their body.</li></ul>
<b>Injections (Nebido®, Sustanon 250®, Virormone®)</b> Sustanon or Virormone are given as an injection into the muscle of the buttocks (or thickest part of the leg) every 2 or 3 weeks. Nebido is an injection which will release testosterone into the body over a certain length of time and is called a depot injection. It is given deep into the muscle of the buttocks every 10 - 14 weeks. The injection is more oily and a little deeper so can be more uncomfortable. Testosterone injections are usually given by GP practice nurses.	<ul style="list-style-type: none"><li>• The injections themselves can be uncomfortable and the vial should always be warmed up for a few minutes before the injection is given (see instructions on packaging).</li><li>• Possible skin irritation or soreness can occur around the site of the injections.</li><li>• Nebido tends to give very steady levels of testosterone.</li><li>• Other testosterone injections lead to a rapid rise for the first week as the testosterone kicks in, then the levels usually fall off and men may feel it wear off completely before the next injection is due.</li></ul>
<b>Patches (Andropatch®, Intrinsa®)</b> These are patches that can be applied to clean dry skin like a nicotine patch.	<ul style="list-style-type: none"><li>• Can cause skin irritation or reactions.</li><li>• <b>Not currently available in the UK.</b></li></ul>
<b>Capsules (Restadol®/Testocaps™)</b> Three or four capsules are usually taken daily for the first 2 - 3 weeks, reduced to 1 - 3 capsules daily. They should be taken with a meal and swallowed not chewed.	<ul style="list-style-type: none"><li>• These provide much lower levels of testosterone than other preparations so may not be recommended.</li></ul>
<b>Mucoadhesive Buccal tablets (Striant™ SR)</b> These are tablets that are placed on the gum above the front teeth and dissolve gradually.	<ul style="list-style-type: none"><li>• Buccal tablets can become dislodged from the gum.</li><li>• <b>Not currently available in the UK.</b></li></ul>

## How do men know if the treatment is working?

If men start any of these treatments their testosterone levels will have to be checked on a regular basis to ensure a normal level is achieved. Most men start to feel better within a few weeks of treatment, but it may take up to 3 months or more to feel the full effects.

If testosterone replacement therapy does improve a man's symptoms following treatment for testicular cancer then it can be continued indefinitely. In some men who have had a unilateral orchidectomy, testosterone levels may eventually return to normal and testosterone replacement therapy can be discontinued.

Some men may also find that it will take a little while to find the best treatment for them and may need to try different types of replacement therapy.

## Are there any side effects?

Although testosterone is commonly thought to cause aggression and hostility, it is actually responsible for helping the body adapt to challenging and stressful situations. However like all medications testosterone replacement therapy may cause some side effects and it is important to read the information supplied with any medication.

Common side effects are oily skin and spots. Less often, men may complain of headaches, nausea, excess sweating, tiredness and mood changes. Long term, testosterone levels will need to be monitored to make sure they stay within the normal range, and check that testosterone has not affected their liver; blood count (circulating blood level) or prostate gland.

**Men should not stop testosterone treatment without consulting their GP or specialist team.**

## Testosterone and the prostate gland

The prostate gland is located just below the bladder. It is only found in men and is responsible for helping to produce the fluid found in semen. The gland is tiny at birth, but grows in size after puberty due to rising levels of testosterone.

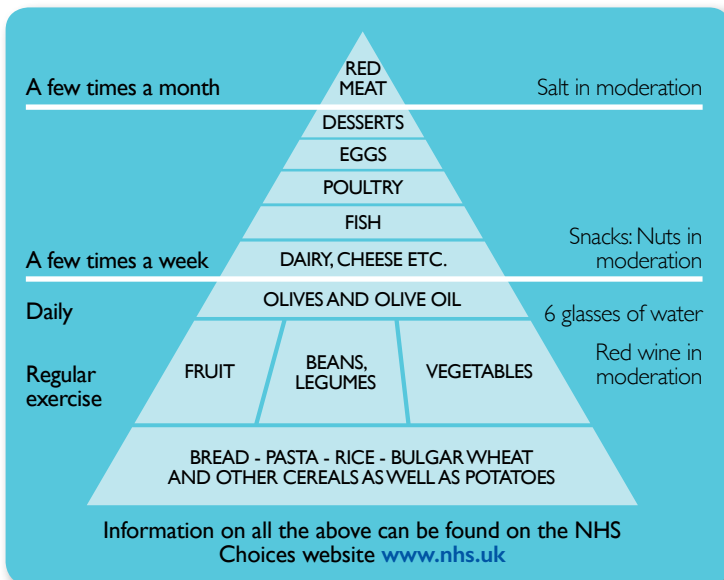
Testosterone stimulates prostate growth and can cause prostate enlargement. Although testosterone does not cause prostate cancer, it can cause active disease to progress, so treatment is not started in people who are being treated for this disease. People at high risk of prostate cancer; or with a high prostate blood test (prostate specific antigen or PSA) may need to see a urologist to decide whether testosterone will be safe for them. Monitoring with PSA blood tests and an examination of the prostate is also necessary for everyone over 40 who commences testosterone replacement treatment.

**It is extremely important that men do not take supplements of testosterone (such as those used in weight training, body building or available online) in addition to that already prescribed. Too much testosterone can cause medical problems.**

## Tips:

- ▶ Physical exercise is very good for improving energy levels; reducing anxiety and low moods as well as promoting feelings of general well-being. A few seconds sprinting can increase testosterone levels and graduated exercise such as brisk walking or supervised cardiovascular training may also help.
- ▶ Sleep - a good night's sleep can help increase testosterone levels naturally.
- ▶ Avoid stressful situations. Practice relaxation techniques such as deep breathing or other natural ways to reduce your stress levels. Stress will lower testosterone levels.
- ▶ Avoid excessive alcohol intake. Alcohol can lower testosterone levels.
- ▶ Try and eat a healthy mixed diet and keep to a healthy weight. Being overweight leads to a fall in testosterone.

A good all round diet for health is the Mediterranean diet (below)



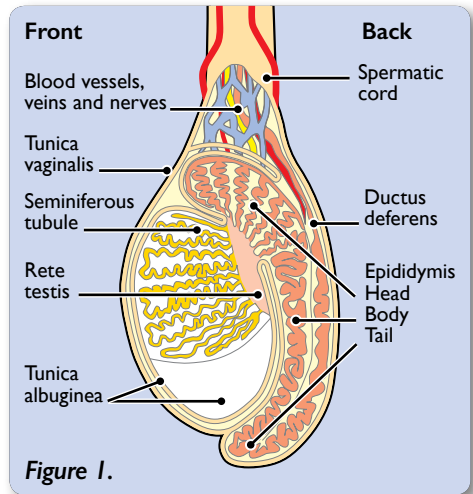
Several foods which contain minerals that are thought to be important for normal testicular health include:

- ▶ Asparagus.
- ▶ Almonds and nuts.
- ▶ Eggs and avocado.
- ▶ Brown rice, white meat (chicken), salmon, oysters, peanuts, beans and cheeses.
- ▶ Bananas.
- ▶ Blueberries, cantaloupe, pineapple, citrus fruits, spinach, cabbages, tomatoes and red peppers.

## Section 6: The basics

The testicles are two small oval shaped organs (which can also be called testes or gonads). They are the male sex glands and hang down majestically behind the penis in the scrotum. It's quite normal for one testicle to be slightly larger than the other, although the size and shape of each should be roughly the same. It is also normal for one to hang down lower. Testicles start growing around the age of 11-12 and by early adulthood may reach about 2 inches long (5cm), nearly one inch in breadth (2.5cm), and 1.2 inches (2.7cm) in height, weighing in at around 10-14 grams. They produce sperm and approximately 90% of testosterone, the male sex hormone and are located outside of the body in the scrotum because sperm develop best at a temperature several degrees cooler than the normal internal body temperature, at around 34.7° Celsius (94.6° Fahrenheit).

The cells inside the seminiferous tubules (see **Figure 1.**) are called germ cells and produce sperm. The sperm move into the epididymis where they mature. They get stored there for a few weeks until they eventually move up the vas deferens to combine with fluids from the prostate and seminal vesicles to form what men normally think of as semen. The whole process takes about seven weeks. The leydig cells distributed throughout the testicle are the body's main source of testosterone.



### Signs and symptoms of testicular cancer

A lump can be felt in over 90% of cases **directly attached to the testicle** and in around 80% of cases this will be painless. A cancerous testis may not feel unduly uncomfortable or painful whereas a testis inflamed by infection will.

#### Other symptoms may include:

- ▶ Dragging sensation, pain/discomfort.
- ▶ Recent history of scrotal trauma 10%, leading to examination and discovery of a lump.
- ▶ Breast swelling or tenderness (called gynaecomastia). This is rare but may be caused by hormones, which are produced by some types of testicular cancer.
- ▶ Back pain caused by enlarged lymph nodes in the back (see page 7).

# Possible risk factors for testicular cancer

Unlike many cancers, there are few known strong risk factors for testicular cancer; and we cannot currently predict who is likely to get the disease (unlike the link between lung cancer and smoking). While most of these cancers occur in unsuspecting individuals, some risk factors can be traced in a minority of cases. These include:

- ▶ A previous history of testicular cancer.
- ▶ Men born with an undescended testicle (cryptorchidism) where the testicle fails to descend into the scrotum. (Even though the testicles hang in the scrotum they develop in the abdomen. Directly prior to or after birth they descend into the scrotum. However, a small percentage of newborn baby boys may have undescended testicles). Although minor surgery can be performed during childhood to correct this condition the risk still remains higher. Some previous research has suggested that approximately 10% of men diagnosed with testicular cancer will have had a history of this condition.
- ▶ Pre-cancerous cells found inside the testicle also known as intratubular germ cell neoplasia (IGCN). This may be found incidentally during other investigations such as investigations into male infertility. If the cells are left there is a 50% chance that they will develop into testicular cancer within five years.
- ▶ A man's risk of developing testicular cancer is increased roughly by 9 times if their brother and 4 times if their father had it.

- ▶ There is some evidence that seems to indicate that men who are taller than average may be at a slightly increased risk of testicular cancer.
- ▶ Twins have an increased risk of testicular cancer; especially if identical. But as testicular cancer is rare the risk is still low.
- ▶ A build up of calcium in the testicles called microlithiasis. Some research has suggested that where there are other risk factors in rare circumstances it may lead to the development of testicular cancer.
- ▶ Caucasian men have a higher risk of testicular cancer than men from other ethnic groups.
- ▶ A small percentage of men who suffer from infertility or poorly functioning testicles appear to slightly be more at risk of developing testicular cancer.
- ▶ Men with HIV are up to twice as likely to develop testicular cancer.

## Controversial factors

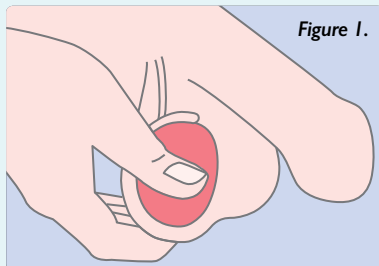
- ▶ A sedentary (not very active) life style may increase the risk.
- ▶ Repeated trauma (rather than inevitable knocks) may increase the risk.
- ▶ Some recent research has suggested that the chronic long term use of cannabis may increase the risk of developing testicular cancer and possibly a more aggressive type.

# Testicular Self-Examination (TSE)

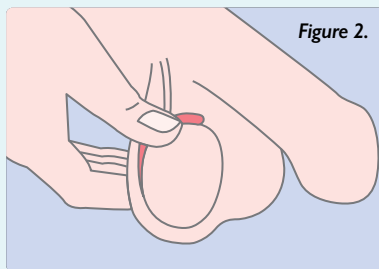
This is the easiest way to identify any potential testicular problems. It only takes a few minutes and is best performed monthly after taking a bath or shower when the scrotum will be warm and relaxed.

1. Check each testicle separately using one or both hands (Figure. 1).
2. Roll each testicle between the thumb and fingers to check that the surface is free of lumps or bumps. Do not squeeze!
3. Men should get to know their balls; their size, texture, anatomy, magnificence. Identify the epididymis or sperm collecting tube, often mistaken for an abnormality that runs behind each testicle (Figure. 2).
4. Encourage a partner to have a go as they may be more likely to identify a problem in the future and get a man to do something about it.

For video advice on testicular self-examination visit:  
**[www.yourprivates.org.uk](http://www.yourprivates.org.uk)**



**Figure 1.**



**Figure 2.**

## Orchid's key developments

Orchid is dedicated to raising awareness of testicular cancer as well as funding research into its treatment. Key developments from this funded research have been:

- ▶ The launch of the Orchid Tissue Bank. This is an internationally renowned tissue bank for cancer research analysis. The Orchid Tissue Bank has the largest collection of penile cancers in a tissue array in Europe; indeed, it has probably the largest testicular tissue bank in the world, and is custodian of the largest series of untreated prostate cancers.
- ▶ The introduction of the single shot carboplatin regime following surgery, instead of the more toxic radiotherapy, as the standard treatment for early stage testicular tumours.
- ▶ The discovery of reduced incidence of second tumours combined with earlier diagnosis, leading to our campaign to remove just the tumour (lumpectomy), rather than the whole testicle (orchidectomy), for a better quality of life for patients, including the possibility of 'natural' fatherhood.
- ▶ New highly successful treatments for men with aggressive testicular cancers.

# How is Orchid helping?

## Awareness

Orchid has a proactive education programme delivering awareness sessions to schools, businesses and the community and around 120 awareness events or talks are currently provided by the Orchid team each year. Orchid has produced a very popular informative Z-card combining a mixture of humour and testicular health and cancer awareness facts.

## Education

Orchid provides publications for anyone who has been affected by testicular cancer including a comprehensive information booklet, plus factsheets on testicular cancer and fertility as well as testosterone replacement therapy.

Orchid has also created a one stop micro-site [yourprivates.org.uk](http://yourprivates.org.uk) which contains downloadable information as well as a number of informative video clips where healthcare professionals and testicular cancer survivors discuss a number of issues.

It also includes a downloadable school resource pack which is PSHE approved and can be used to teach children about testicular health and cancer awareness.

## Support

Orchid provides a National Male Cancer Telephone Helpline for anyone worried or affected by male cancer. This is a free service and is staffed by Orchid Male Cancer Information Nurse Specialists.

Orchid is also piloting a telephone testicular cancer counselling service for men who have been affected by testicular cancer. For more details please phone **0808 802 0010**.



# Men may find the following links useful:

## **Orchid**

[www.orchid-cancer.org.uk/](http://www.orchid-cancer.org.uk/)

[www.yourprivates.org.uk](http://www.yourprivates.org.uk)

For information on testicular cancer, individual stories and current research projects.

## **Support Groups / Forums**

### **Checkmlads Testicular cancer**

#### **Awareness and Support Site**

[www.checkmlads.com](http://www.checkmlads.com)

Contact: [philly@checkmlads.com](mailto:philly@checkmlads.com)

A website with a large Facebook forum with many men sharing their experience and providing helpful tips on how to cope with treatment.

This forum is regulated by checkmlads and Orchid is not responsible for any content.

### **Macmillan Cancer Support**

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Telephone: 020 7840 7840

Fax: 020 7840 7841

Questions/helpline: 0808 808 00 00

A huge source of information for anyone who has been affected by cancer including support services.

### **Maggie's Cancer Caring Centres**

[www.maggiescentres.org](http://www.maggiescentres.org)

Telephone: 0141 341 5675

Email: [enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

Help centres, run by professionals, who can discuss any aspect of cancer. Also run support groups and weekly sessions in relaxation, stress management, nutrition and health.

### **Penny Brohn Cancer Care**

[www.pennybrohncancercare.org](http://www.pennybrohncancercare.org)

Helpline: 0845 123 23 10

(Mon to Fri, 9.30am to 5pm)

Switchboard: 01275 370 100

Email: [helpline@pennybrohn.org](mailto:helpline@pennybrohn.org)

Provides a programme of complementary care.

## **Regional Charities/Support**

### **Bristol**

#### **It's in the Bag**

[www.itsinthebag](http://www.itsinthebag)

Contact: [hello@itsinthebag.org.uk](mailto:hello@itsinthebag.org.uk)

Telephone: Sue Brand 0117 342 3472

or Mobile: Pete Styles 0777 171 0733

### **Colchester**

#### **The Robin Cancer Trust**

[www.therobincancertrust.org](http://www.therobincancertrust.org)

Email: [therobincancertrust@gmail.com](mailto:therobincancertrust@gmail.com)

### **Norwich**

#### **It's On The Ball**

[www.itsontheball.org](http://www.itsontheball.org)

Telephone: 01603 288 115

Email: [info@itsontheball.org](mailto:info@itsontheball.org)

### **Guernsey**

#### **Male Uprising in Guernsey (male cancer)**

Email: [trevor.kelham@me.com](mailto:trevor.kelham@me.com)

Telephone: 07911 721 614

### **Wales**

#### **Tenovus, your cancer charity**

[www.tenovus.org.uk](http://www.tenovus.org.uk)

### **Scotland**

#### **Cahonas Scotland**

[www.cahonasscotland.com](http://www.cahonasscotland.com)