To all the lads out there...

A diagnosis of testicular cancer will temporarily turn your life upside down giving rise to fear, anger, resentment and frustration. This booklet has been designed with you in mind. Hopefully it will answer many of your questions, help give you some insight into your possible treatment and provide some helpful tips on coping with the times ahead.

Always remember that there is every chance that you will be cured. It will be a long journey but with a bit of knowledge you will hopefully get through it a lot easier.
"Although rare compared to other cancers, testicular cancer most commonly affects young men between the ages of 15 and 45 with over 2,200 cases being diagnosed each year."

However if found at an early stage cure rates of approximately 98% are usually possible. Even when testicular cancer has spread to other areas in the body cure can still be achieved and the majority of men diagnosed with any stage testicular cancer will be alive 10 years after treatment has finished.

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.
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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 so 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.
Clinical diagnosis

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, the majority of men will be cured. Even if testicular cancer has spread to other areas of the body a cure can still be achieved.

Informative videos on all stages of testicular cancer treatment can be found at yourprivates.org.uk

Ultrasound scan

An ultrasound scan is extremely accurate at diagnosing testicular cancer and if cancer is suspected a referral will be made to a hospital specialist called a urologist. If there is a strong suspicion that testicular cancer is present then a decision will be made to surgically remove the affected testicle. This decision will not be taken lightly but will be in a man’s best interest. No one will want to wait around and see what happens; surgery to remove the testicle (orchidectomy) will usually be the only time that a definite cancer diagnosis can be verified or ruled out.

A number of other tests will be performed routinely:

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 effect treatment has had in reducing cancerous activity and may be repeated after orchidectomy if they were abnormal beforehand. Blood tests to measure kidney and liver function will also usually be requested.

Occasionally, if there is obvious evidence that testicular cancer is present and has spread to other areas of the body, a referral may be made to an oncologist (cancer specialist) to see if treatment such as chemotherapy should be given before surgery (orchidectomy).

Chest X-ray

This is performed to make sure that the lungs are clear 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 therefore be detected in the urine. However not all testicular cancers produce BHCG and so it is not used as a standard test. Some non regulated performance enhancing drugs can also cause a positive result.
**Computerised Tomography scan (CT)**

A CT scan is performed to check for any signs that testicular cancer has affected other areas of the body; lungs or lymph glands in the abdomen (see page 8). The scan takes a series of x-rays, which are fed into a computer to build up a three-dimensional image of the inside of the body and takes from 10 to 30 minutes to perform. A special drink or an injection of a dye into a vein which helps highlight areas of the body more clearly will usually be given. This may cause a warm sensation for a few minutes. The scan is painless, but involves lying still for 10-20 minutes.

**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 in a fluid called lymph. Lymph fluid will contain various types of cells and substances that are no longer needed. The fluid will be transported through the lymphatic drainage system and pass through small nodules or nodes that act as filters responsible for removing them. Cancerous cells which break off from an organ which has cancer can also travel along this route and become trapped at the lymph nodes where they can then accumulate and affect a new area of the body.

**Surgery (orchidectomy)**

Orchidectomy (unilateral) is the surgical removal of one testicle and is usually performed very quickly after a suspected diagnosis of testicular cancer. It is a simple procedure which may take about half an hour to perform and will be carried out under general anaesthetic. During surgery a small incision is made into the groin region on the affected side and the testicle is removed from above. The scrotum will not be cut. A prosthetic (artificial) testicle can be inserted in place of the cancerous testicle. Men may also be offered the possibility of sperm storage before surgery (see page 33).
Falsey or not?
The health care team may discuss the insertion of a false (prosthetic) ball to take the place of the old one. These 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 but some men may have problems with them in the longer term.

Once inserted the neck of the scrotum is closed with stitches to prevent the prosthesis from moving back up to the groin.

Some problems may include:
- The overall cosmetic result may vary.
- Scar tissue forming around the implant inside the scrotum can sometimes cause a thick fibrous growth of tissue which may in turn 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.
- Surgery can cause small spots of calcium in the testicle to appear usually some years following surgery. Although they are harmless they can sometimes be confused with the type of calcium deposits (microlithiasis), which in some circumstances is linked to the development of testicular cancer.
- A prosthetic testicle will not react to temperature like a normal one and will stay the same size.

Men who are unsure of whether they want an implant or not can have the procedure performed at a later date if they wish.

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 some weeks to fully disappear.
- Men can have a bath or shower; normally after 24 hours, but it is important not to rub soap on the wound area. 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. Painkillers which may have been prescribed should be taken on a regular basis, (not just when pain is felt) until comfortable. Always read the instructions to ensure they are taken correctly. 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 reviewed in an outpatient clinic or referred to an oncologist for further treatment; it may be a good idea to await for these arrangements to be made before returning to work as further time off may be needed.
Occasionally a collection of blood may form under the surgical wound (haematoma) or the wound may become infected. Men should seek medical advice in this situation.

It is important to avoid heavy lifting and or strenuous exercise for the first few weeks. Men should only start driving when they are able to do an emergency stop without hesitation.

Sexual activity can begin again after two weeks as long as it is not uncomfortable.

Men will be given a follow up appointment within a few weeks of orchidectomy to see a hospital specialist (oncologist) where the results of the operation will be discussed along with the need for any further recommended treatment.

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 taken at the same time as the orchidectomy.

Once a man has had an orchidectomy their follow up care will usually be managed by an oncologist (cancer specialist).

For more information on orchidectomy please visit www.yourprivates.org.uk.
The following websites have a great deal of information with regard to work related issues and are well worth a visit. **If men are self employed and have to stop working due to their illness they should be entitled to incapacity benefit providing they have been paying National Insurance contributions previously.**

They may also be entitled to other benefits or rebates if they are going to be out of action for some time.

**Macmillan cancer support:**
www.macmillan.org.uk or phone 0800 808 1234

**Citizens Advice Bureau:**
www.citizensadvice.org.uk or phone 0207 833 2181

**Government benefit enquiry line:**
www.direct.gov.uk or phone 800 882 200

“One thing I think men would worry about is feeling like less of a man. I would tell them that I feel no different in any way, except for the fact that I have a nice scar.”

O.B.
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, were 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% that it is cancer.”
D.F.

“I returned home in shock and immediately went on the internet doing 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.
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 **25-45**, with a peak age of **35** years old.

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 **15-35**, with a peak age of **25** years old.

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 rarer non germ cell tumours (Sertoli, Leydig) 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 testicular swelling.

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**Figure 4. Male pelvic anatomy**

**Figure 5. 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 8)

- **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. They are sometimes referred to as “secondaries”. Testicular cancer which has spread from its primary site in this way tends to be deposited in 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 1 on page 16).

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 × Normal and HCG < 5,000 and AFP < 1,000
- **S2**: LDH 1.5-10 × Normal or HCG 5,000-50,000 or AFP 1,000-10,000
- **S3**: LDH > 10 × Normal or HCG > 50,000 or AFP > 10,000
Figure 6. Diagram illustrating testicular cancer staging (TNM system)
<table>
<thead>
<tr>
<th><strong>Stage 1</strong></th>
<th><strong>Stage 2</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>This is the earliest stage of testicular cancer.</td>
<td>The cancer is contained within the testicle and has not spread to nearby lymph nodes or other organs.</td>
</tr>
<tr>
<td><strong>Stage 2</strong></td>
<td><strong>Stage 2</strong></td>
</tr>
<tr>
<td>The cancer cells have spread into nearby lymph nodes in the abdomen or pelvis.</td>
<td>Stage 2A - lymph nodes are all smaller than 2cm.</td>
</tr>
<tr>
<td>This is further split into sub stages 2A, 2B and 2C.</td>
<td>Stage 2B - lymph nodes are between 2cm and 5cm.</td>
</tr>
<tr>
<td></td>
<td>Stage 2C - at least one lymph node is bigger than 5cm.</td>
</tr>
<tr>
<td><strong>Stage 3</strong></td>
<td><strong>Stage 3</strong></td>
</tr>
<tr>
<td>This can be split into 3A, 3B and 3C.</td>
<td>Stage 3A - cancer has spread to distant lymph nodes or lungs.</td>
</tr>
<tr>
<td></td>
<td>Stage 3B - cancer has spread to nearby lymph nodes or distant lymph nodes and lungs and there is a moderately high marker level.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
</tbody>
</table>

**Record your staging:**

<table>
<thead>
<tr>
<th>Your TNM stage</th>
<th>T</th>
<th>N</th>
<th>M</th>
</tr>
</thead>
</table>

| Your stage | 1 | 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 do 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 a worthless thing to say. It’s understandable they don’t know what to say, but it is extremely difficult to hear.
S.F.
To ensure that men get the best possible treatment after an orchidectomy in line with current national and international treatment guidelines, their particular circumstances will be discussed at a specialist medical forum 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 discuss each individual medical case taking into account the results of the operation, blood tests and scan results. They will 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 and treatments.

Some hospitals will have nurses who specialise in treating testicular cancer (germ cell tumour nurse specialists) who will be able to guide men through their treatment or answer any specific questions they may have. They may also know of local support groups for testicular cancer which men may find helpful.

**Localised testicular cancer**

Early stage seminoma or non-seminoma which is confined to the testicle can usually be treated with a policy of surveillance. This means regular CT scans and blood tests will be performed to detect any recurrence. Should testicular cancer reoccur then chemotherapy will be given and men potentially cured.

However some men may find that they want to get on with their lives and not keep returning for scans as frequently as surveillance requires. In this situation a limited dose of chemotherapy can be given after surgery to reduce the risk of cancer returning.

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 the lymph nodes at the back of the abdomen which may still harbour some testicular 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. Some studies have indicated that radiotherapy may increase the chance of a second cancer occurring many years after treatment and now it tends to be used less often.

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

After treatment men will be followed up on a regular basis with visits to clinic every 6-8 weeks. These visits will gradually become less 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 of course need to regularly perform testicular self-examination of their remaining testicle.**
Non localised testicular cancer

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

Testicular cancer that has spread to the lungs, liver or brain is still testicular cancer and not a separate cancer.

Recent research has shown that the majority of men diagnosed with testicular cancer at any stage will be alive 10 years after treatment.

Chemotherapy

Chemotherapy is the use of cancer fighting drugs (cytotoxic) to attack and destroy cancer cells within the body. 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 chemotherapy can be given as a day case treatment or during a short stay in hospital. Blood tests will usually be performed prior to BEP to check that the body’s immune system is healthy enough to cope with the treatment.

A breathing test called a lung function test will be performed as one type of chemotherapy drug, bleomycin may decrease lung function. A drip (cannula) will be sited into a vein in the hand, arm or neck and the chemotherapy administered through it. Anti-sickness (antiemetic), drugs can also be given through these tubes as well.

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. The treatment regime is also known as a cycle. Each cycle of treatment is given over 3 weeks and 3 or 4 cycles of BEP chemotherapy are given depending on the extent of the disease.

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

Chemotherapy can temporarily cause infertility so men will be advised to store some sperm (see sperm banking on page 33).
<table>
<thead>
<tr>
<th><strong>One cycle 3 Day BEP</strong></th>
<th><strong>One cycle 5 Day BP</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(3-4 cycles over 2-3 months)</strong></td>
<td><strong>(3-4 cycles over 2-3 months)</strong></td>
</tr>
<tr>
<td><strong>Day 1</strong> Etoposide and Cisplatin</td>
<td><strong>Day 1</strong> Etoposide and Cisplatin</td>
</tr>
<tr>
<td><strong>Day 2</strong> Infusion of all BEP drugs</td>
<td><strong>Day 2</strong> All BEP drugs</td>
</tr>
<tr>
<td><strong>Day 3</strong> Etoposide only</td>
<td><strong>Day 3</strong> Etoposide and Cisplatin</td>
</tr>
<tr>
<td><strong>Day 8</strong> Bleomycin</td>
<td><strong>Day 4</strong> Etoposide and Cisplatin</td>
</tr>
<tr>
<td><strong>Day 15</strong> Bleomycin</td>
<td><strong>Day 5</strong> Etoposide and Cisplatin</td>
</tr>
<tr>
<td>Break</td>
<td><strong>Day 8</strong> Bleomycin</td>
</tr>
<tr>
<td></td>
<td><strong>Day 15</strong> Bleomycin</td>
</tr>
<tr>
<td></td>
<td>Break</td>
</tr>
</tbody>
</table>
Chemotherapy effects

Table 3. Potential chemotherapy side effects

<table>
<thead>
<tr>
<th>Common side effects of chemotherapy:</th>
<th>Try:</th>
<th>Avoid:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea and vomiting:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Anti sickness medication will be given on a regular basis and it is important for men to take this as otherwise they will puke!</td>
<td>• Hot and spicy foods (curry, Cajun cooking etc.)</td>
<td></td>
</tr>
<tr>
<td>• Ginger; beer, tea or biscuits (eat regularly throughout the day)</td>
<td>• Foods with high sugar content</td>
<td></td>
</tr>
<tr>
<td>• Peppermint tea, always drink slowly taking lots of sips</td>
<td>• Fatty and greasy foods (chips, burgers etc.)</td>
<td></td>
</tr>
<tr>
<td>• A small meal a few hours before chemo starts</td>
<td>• Large meals</td>
<td></td>
</tr>
<tr>
<td>Never have chemotherapy on an empty stomach</td>
<td>• Eating and drinking too fast and drinking with meals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Alcohol</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Caffeine (which is found in tea/coffee/chocolate including chocolate bars/energy drinks)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Baby food this is designed for babies and has very little nutrition for adults!</td>
<td></td>
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</tbody>
</table>

Taste: (chemo can cause a metallic taste in the mouth)

• Fresh pineapple or other sharp tasting fruit
• Boiled sweets while having treatment
• Seasoned or marinated meat with meals to add flavour
• Using herbs and spices in cooking to add stronger taste
<table>
<thead>
<tr>
<th>Common side effects of chemotherapy:</th>
<th>Try:</th>
<th>Avoid:</th>
</tr>
</thead>
</table>
| **Mouth sores or ulcers from chemotherapy:** | • Eating fresh pineapple which can help prevent and heal mouth ulcers by stimulating saliva which protects the mouth  
• Bonjela  
• A soft child’s/baby bristle toothbrush and baby/soothing (for instance) aloe vera toothpaste  
• A soft puréed or liquid diet to prevent chewing  
• Rinsing the mouth with salt water on a regular basis if tolerable up to 4-5 times a day  
• Sucking crushed ice during treatment  
• Artificial saliva which can be prescribed by a doctor  
• Vaseline for the lips | • Tomato and citrus fruit based products and tobacco  
• Oral care products that may cause a dry mouth and products that contain alcohol or peroxide  
• Hot and spicy foods (curry, Cajun etc.)  
• Nuts and seeds |
| **Tiredness:** | • Getting small restful naps  
• Meditating, which some people find beneficial  
• Sleeping tablets which can be prescribed if insomnia is becoming a big problem |
<table>
<thead>
<tr>
<th>Common side effects of chemotherapy:</th>
<th>Try:</th>
<th>Avoid:</th>
</tr>
</thead>
</table>
| **Loss of appetite:**             | • Having small frequent meals throughout the day  
                                   • Fortified soups/drinks or milk shakes | |
| **Diarrhoea:**                    | • Rice and pasta  
                                   • Potatoes with skins  
                                   • Dry crackers/biscuits  
                                   • White bread  
                                   • Bananas (a good source of potassium which is essential for the body’s metabolism). Excessive diarrhoea will deplete potassium levels | • High fibre foods (bran, fruit, nuts etc.) |
| **Hair loss:**  
This may occur 2-3 weeks after chemotherapy | • A baseball cap  
                                   • Shaving hair off when it starts to fall out | • Head cooling devices that may reduce the circulating blood supply which can reduce the effectiveness of the chemo |
| **Low immune system from chemotherapy:** | • Paying meticulous attention to hygiene. Hands must be washed after going to the toilet  
                                   • Wearing a hat in summer or strong sun and avoid sunbathing in direct sunlight which could possibly cause scaring | • Drugs/alcohol which may depress the immune system and make men feel like crap  
                                   • Travelling to foreign countries where risk of picking up illness is greater  
                                   • Vaccines. Ask an oncologist about when to travel and when to receive vaccines after treatment |
<table>
<thead>
<tr>
<th>Common side effects of chemotherapy:</th>
<th>Try:</th>
<th>Avoid:</th>
</tr>
</thead>
</table>
| Tingling in the arms and feet due to nerve damage (peripheral neuropathy) from chemotherapy: | • Keeping hands and feet warm and avoid extremes of temperature  
• 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  
• Gentle exercise | |
| Inflammation in the lungs with shortness of breath due to low circulating haemoglobin (oxygenated blood) from chemotherapy: | • To inform a doctor as a blood transfusion may be needed  
• Resting  
• To inform a doctor if there are breathing difficulties being experienced | • Taxing, strenuous tasks  
• Smoking completely! |
| Tinnitus (ringing in the ears) from chemotherapy: | • Encouraging people to speak slowly and clearly  
• Listening to gentle background music as some people think this may help  
• Telling a doctor if hearing problems are being experienced | |
### Common side effects of chemotherapy:

**Try:**

- Using an electric shaver to avoid cuts
- Non perfumed moisturizing creams
- To check with an oncologist to see how long to 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
- To 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

**Avoid:**

- Wet shaving which may break the skin
- Non perfumed soaps when having radiotherapy and have tepid baths
- Vigorous rubbing of the skin around the treated area

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**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.**

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**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 considering going back to work or for a busy lifestyle.
- It may also take family and friends time to adjust to long term changes in a man’s health so do not be surprised if they are acting a bit strange or distant.
- 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 afterwards.
If there are any signs of residual cancer following chemotherapy within the lymph nodes in the abdomen it may be suggested that men undergo the following additional treatment:

**Retroperitoneal Lymph Node Dissection (RPLND)**

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.

This operation is performed under a general anaesthetic, and can take up to 4 hours to perform. An incision (cut) is made from just below the breastbone to just below the navel (belly button). The intestines and other organs are gently lifted out of the way so that the lymph nodes at the back of the abdomen can be clearly seen. Lymph nodes on the same side as the affected testicle are first 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 damage the nerves that control the discharge of sperm through the penis (ejaculation). New surgical techniques mean that this problem can usually be avoided.

If there is a possibility that men may need this surgery, and if they are fit enough to produce sperm samples for storage before treatment starts (if not performed prior to previous chemotherapy), some of their sperm can be stored (see Testicular Cancer and Fertility on page 33).

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.
After RPLND

- Men will be given painkillers to take home. They should use them as prescribed on a regular basis (not just when they feel pain).
- Men should try to eat a high fibre diet to prevent constipation which may then aggravate any pain that they may be experiencing; they should also aim to drink 2-3 litres of fluid a day to help soften their stools. A mild laxative may be helpful.
- Men should take things easy for 2 weeks after surgery. If they live alone it may be beneficial to stay with someone who can keep an eye on 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. Men should try and walk upright without stooping.
- They should not drive for 3-4 weeks following surgery as they may not be able to stop effectively in an emergency.
- They should be able to return to work after 4 weeks but may need to be longer if they have a particularly physical job.
- They will need to obtain a sick certificate from their GP.
- Sexual intercourse should be avoided for approximately 4 weeks after surgery.

**Recurrent disease**

If testicular cancer returns in the remaining testicle then a further orchidectomy is usually warranted. This will mean that a man will become infertile and be unable to get an erection suitable for sexual intercourse due to lack of testosterone. In this situation testosterone replacement therapy will be needed (see page 37). In recent years the possibility of further chemotherapy with the addition of partial removal of the remaining testicle (partial orchidectomy) has gained more support and this may be discussed.

If men develop recurrent cancer in their lymph nodes, lungs, liver or brain further chemotherapy can be given and in some circumstances specific deposits of cancer can be removed using specialist surgery.

A combination of chemotherapy and radiotherapy can also be used to treat areas of cancer that cannot be removed by surgery.

**High dose chemotherapy with stem cell support**

This can be used to treat residual or recurrent cancer when standard chemotherapy has previously been used and allows higher doses of chemotherapy to be given. Before high-dose treatment, cells in the blood (called stem cells) are taken and stored. These stem cells can then be used to produce new healthy blood cells, to replace any that further chemotherapy may affect.

Shortly after high-dose treatment, the stem cells are returned to the body through a drip into a vein (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 allowing the body to recover from treatment.

This is often a very intensive and demanding treatment and it 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. This does not mean they are a guinea pig for some crazy experiment. 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 and improve cancer cure rates or reduce the possible side effects of treatment. An oncologist or specialist nurse may discuss these possibilities. If a man does decide to take part in a clinical trial, he is 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

**Cancer Research UK**
www.cancerhelp.cancerresearchuk.org/trials/

**Orchid**
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. It may also take their family and friends time to adjust to long term changes in their health so men should not be surprised if they are acting a bit strange or distant.

- 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 here at www.macmillan.org.uk or here at checkemlads.com
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 realizing 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.
**Fertility**

Many men worry that they may not be able to have children after they have been treated for testicular cancer. Chemotherapy can cause infertility during and for a time after treatment but this is usually temporary.

In some men who have had poor fertility prior to treatment it can occasionally improve things. In some men however it could be permanent and for this reason they will be advised to store sperm before starting chemotherapy. The rate at which the sperm count recovers varies from person to person, but it generally returns to normal within two to three years. Sperm can be frozen and stored for some time and when men want to father a child, their sperm can be thawed and used to make their partner pregnant ‘artificially’. Please see section 5 for further details on how to sperm bank.

**Sex life**

One of the commonest questions asked by men before and after treatment for testicular cancer is whether their sex life will be affected. The important thing to remember is that the removal of one testicle will not usually affect sexual performance or the ability to father children, if the other testicle is healthy and functioning normally. This is because the remaining healthy testicle will produce more testosterone and sperm to make up for the difference.

If both testicles are removed then testosterone replacement therapy will be needed (see page 37). This can be given in the form of injections or gels and should enable a man to have normal sexual intercourse.

Any course of treatment may make men too tired to be interested 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 problems. 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.

**Coping with treatment and adjusting to life after testicular cancer**

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 hit 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 more easily than a family member or friend.

**A holistic approach**

Often following treatment a holistic approach is needed. This means optimising health and wellbeing, staying healthy through exercise, diet and a positive mental outlook.

There are organisations that can help men access holistic treatments such as Penny Brohn Centres and Maggie’s Centres.

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, especially those who have had chemotherapy, treatment may reduce their testosterone levels. For more information on low testosterone levels please see page 37.

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Some men may find that when they have been given the “all clear” and there is no evidence of any further cancer they may feel that they need some counselling. The following websites have comprehensive information regarding support after cancer; [www.macmillan.org.uk](http://www.macmillan.org.uk)

Also

Find a Therapist

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

Counselling Directory

[www.counselling-directory.org.uk](http://www.counselling-directory.org.uk)

or Telephone: 0844 8030 240

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 on-line 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, perhaps in a pub where they can talk over a few pints.

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.

I got through my experience by talking to my family and friends about what I was going through. The worst thing you can do is bottle things up and not talk. To lose a big part of your masculinity is a major shock, however by being honest and talking openly about my feelings not only helped me get through it, but it also helped my family and friends come to terms with my illness. Throw in a little bit of humour as well with your mates and believe me, this is a perfect way to deal with the emotions that are associated with having cancer. I know it’s an old cliché, but laughter really is the best form of medicine.

Darren “One Ball Couchman”, survivor of 10 years.

DID YOU KNOW?

Over the course of a lifetime, the testicles may generate an average of fourteen gallons of ejaculate. Ejaculate travels at 28mph!

The average number of times a healthy male will ejaculate in a lifetime is 7,200. Of this number, approximately 2,000 times will result from masturbation.
What is sperm storage?
Storing sperm, also known as sperm banking, is the preservation of sperm by freezing. The sperm may 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 the quality of the sperm.

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.

However men in this situation should still consider storing their sperm before treatment as occasionally their sperm count may get worse after treatment.

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, 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, or in tablet form.

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

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

Q. What are Lymph Nodes?

A. The human body has a natural drainage system; the lymphatic system which is responsible for cleansing the body of unwanted substances such as bacteria and unwanted blood cells. Lymph nodes are filters situated along the lymphatic drainage system. Their job is to filter out and trap these unwanted substances. Sometimes cancer cells can travel via the lymphatic drainage system to these lymph nodes and affect other areas of the body.
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. 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 testicular cancer 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.

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 well-being

Where is testosterone made?

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.

How will men be affected by an orchidectomy?

Unilateral orchidectomy means the removal of one testicle.

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 as well as it should although this is usually not permanent.

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.

Section 5: Related issues
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 dramatically, many men will feel tired, low in mood and can sometimes 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 early 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 any symptoms that they may have.
## Types of testosterone replacement

There are several methods of testosterone replacement therapy;

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| **Gels (Testim®, Testogel®, Tostran®)** | • These are applied daily usually after a shower or bath, and men need to wait at least 5 minutes before dressing afterwards.  
• 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. |
| **Injections (Nebido®, Sustanon 250®, Virormone®)** | • 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).  
• Possible skin irritation or soreness can occur around the site of the injections.  
• Nebido tends to give very steady levels of testosterone.  
• 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. |
| **Patches (Andropatch®, Intrinsa®)**     | • Can cause skin irritation or reactions.  
• Not currently available in the UK. |
| **Capsules (Restadol®/Testocaps™)**      | • These provide much lower levels of testosterone than other preparations so may not be recommended. |
| **Mucoadhesive Buccal tablets (Striant™ SR)** | • Buccal tablets can become dislodged from the gum.  
• Not currently available in the UK. |
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 at least 3 months to obtain a steady level in the blood stream and 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 events or 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, people 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 the 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 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) other than what has been medically prescribed. Too much testosterone can cause medical problems.

Testosterone levels should be measured on a regular basis and replacement therapy adjusted to keep these normal.
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.

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.
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, packed in the scrotum or ball bag. 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 or 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 95% of testosterone, the male sex hormone and are located outside of the body in the nad sack 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 create 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 (jizz or spunk). The whole process takes about seven weeks. The leydig cells distributed throughout the testicle are the body’s main source of testosterone.

What does testosterone do?
Testosterone is essential to the development of the reproductive organs and other male characteristics such as:

- mood
- body and facial hair
- low voice
- muscle development
- the ability to have an erection
- sex drive (libido)

Without enough testosterone a man may lose his sex drive, suffer from fatigue, depression, hot flushes and osteoporosis (thinning of the bones). Keeping fit and avoiding too much fatty fried food, sugar and caffeine all of which can reduce testosterone levels, can keep testosterone healthy.
Testicle terminology you may like to use.
(Feel free to add your own)
The Testicles aka: your acorns, baby-makers, back wheels, baubles, bum balls, bum buddies, chestnuts, cods, conkers, cream crackers, doodads, figs, globes, goolies, hairy conkers, heirlooms, jingle berries, jizz diamonds, ju-ju beads, knackers, knob nuts, love apples, love nuts, love spuds, marble halls, meaty bites, nads, nobby halls, nuggets, nutmegs, nuts, plums, pounders, rocks, spunk spillers.


A man’s ability to raise and lower his testicles is called the cremasteric reflex. The cremasteric muscles often move the testicles naturally, but a male can control the movement by tensing or relaxing his stomach and using the pubococcygeus muscle.

When a man receives a blow to his testicles he usually feels pain in his gut. The nerves in the genitals are connected to nerves in the abdomen and the pain travels up them via the same pathway the testicles took when they descended into the scrotum (inguinal canal).

Testosterone friendly food:
Asparagus; Rich in vitamin E, considered to stimulate the production of testosterone.

Almonds and nuts; A source of natural fatty acids, which provide the raw material for hormonal production.

Eggs/Avocado; Source of vitamin B5 and B6 (avocado B6) which help balance hormone levels.

Brown rice, white meat (chicken), salmon, oysters, peanuts, beans and cheeses; A good source of zinc. Testosterone is dependent on zinc.

Bananas; Rich in B vitamins like riboflavin’s which are necessary for testosterone production.

Blueberries, cantaloupe, pineapple, citrus fruits, spinach, tomatoes and red peppers; These are all rich in vitamin A, essential for the normal function of the reproductive organs.

Foreign words for testicles:
Latin - testiculis
Czech - varlata
Danish - testiklerne
Iceland - eist/a
Afrikaans - testikels
Basque - barrabil
Irish - magarile
Welsh - ceilliau
Maltese - tat
Dutch - testikels
Estonian - mumandid
Finnish - kiveskia
French - testicules
German - testicles
Hungarian - golyo
Italian - coglione
Polish - jadno
Portuguese - testiculos
Romanian - testiculele
Norwegian - baller
Spanish - cojon
Swedish - testiklar
Turkish - er bezi
Signs and symptoms of testicular cancer

A lump can be felt in over 90% of cases and in approximately 80% of cases this will be painless. A cancerous testis may not feel unduly uncomfortable or painful whereas a testis inflamed by infection will.

Non-cancerous testicular conditions

Testicular cancer is usually initially identified as a lump in the testicle, but there are also a number of non-cancerous conditions of the testicles, which can affect younger men between the ages of 15-25. These may often have similar symptoms to testicular cancer and may cause worry (see below).

Epididymo-orchitis

This is inflammation of the epididymis and / or testis, which is usually due to infection. It is particularly common in young males aged 15-30 and may occur as a result of a urinary infection or sexually transmitted disease. Occasionally it can occur as a result of surgery to the urethra or prostate. Ball swelling tends to occur quite rapidly and is often described as “bloody painful”. The swelling may take some weeks to fully settle and will usually require a two week course of strong antibiotics. Supportive underwear (not boxers) may help along with regular painkillers such as paracetamol and ibuprofen.

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 8).

If a man finds a lump or abnormal swelling in their testicle(s) they should see their GP as soon as possible. If a GP cannot give a definitive diagnosis then an ultrasound of the scrotum will be requested and a referral may be made to a hospital specialist called a urologist for further assessment. Although the majority of testicular abnormalities will not be cancer, if cancer is suspected then treatment will happen usually within a two week period.

Epididymitis: means inflammation of the epididymis
Orchitis: means inflammation of the testis
Varicocele
This is a collection of dilated veins in the scrotum (think varicose veins). It often affects men between the ages of 15-25 and occurs next to and above one or both of the testicles. It involves the spermatic cord which carries sperm from the testes to the penis and which also contains blood vessels and nerves. Normally the veins in the spermatic cord are undetectable. When they become distended they have been medically described as feeling like a “bag of worms”! A varicocele can occur on one or both sides of the testicles and are usually not painful but may cause a “dragging” sensation. They may affect 15% of the male population and are associated with male infertility.

Hydrocele
The testis is surrounded by a protective tissue sac, which produces a lubricating fluid to allow a man’s baubles to move freely. Excess fluid usually drains into the veins in the scrotum. However, if this drainage route has been affected by infection or trauma, fluid may accumulate and is called a hydrocele. A hydrocele will often feel like a small fluid filled balloon and may cause a chronic ache or discomfort. It can often be surgically repaired if it becomes too problematic or too big, but is usually treated depending on whether bothersome symptoms are present.

Epididymal cysts
These are small fluid filled cysts, which may contain sperm. They are usually about the size of a pea but can be larger. They are smooth and spherical and tend to be found in the head of the epididymis and are separate from the testicle. They are not cancerous. They can be surgically removed if they become too big or painful, however removal can cause epididymal obstruction, which may then have an impact on a man’s fertility. For more information on non-cancerous conditions please see www.yourprivates.org.uk.

Testicular pain
OK we have all had it. Sometimes there is no apparent reason for it but it is pretty annoying anyway. There are several factors which can be involved including stress, wearing underwear that is too tight as well as sexual arousal with an erection but without ejaculation (also known as blue balls). If a man is very physically active there is always a chance that they may strain their lower back or groin while playing sport, which then may irritate nerves in...
Pain from blue balls will usually go after a few hours while chronic sports damage may need further input from a GP or physiotherapist.

### 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 approximately 4% of newborn baby boys may have undescended testicles). Research has shown that the risk of testicular cancer is greater in this situation. 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 in rare circumstances this can lead to some men developing 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 be more at risk of developing testicular cancer.

DID YOU KNOW?

- A man’s testicles can increase in size by up to 50% when he is aroused.
- The testes of the Right Whale are thought to be the biggest in the animal kingdom each thought to weigh around 500kg each!
Men with HIV are up to twice as likely to develop testicular cancer.

**Controversial factors**

- A sedentary (not very active) lifestyle may increase the risk. Regular exercise reduces the risk.
- Repeated trauma (rather than inevitable knocks) may increase the risk.
- Some recent research has suggested that men who smoke cannabis on a regular basis and go on to develop testicular cancer may suffer from a more aggressive type.

**Why Orchid?**

The Greeks had a word for balls. Greek civilization was the birthplace of medicine; think Hippocratic Oath. They named the male testicle Orchis - a tuber - because the male testicle has the same shape as the tuber of the orchid. The treatment for both testicular and prostate cancer can require the surgical removal of one or more testicles, an operation known as an orchidectomy. So ORCHID is a very appropriate name for the charity which aims to make life bloom, as well as save many unnecessary orchidectomy operations.

**Testicular Self Examination (TSE)**

This is the easiest way to identify any potential testicular problems. It only takes a few minutes to perform and gives men a good excuse to feel their nads (like they need one!). It's best performed monthly after taking a bath or shower when the scrotum will be warm, relaxed and pleasant to touch.

1. Check each testicle separately using one or both hands (Figure 2).
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 3).
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
Section tips

Men should:

- Perform testicular self-examination on a regular basis, at least once a month. Get to know their balls and what is normal for them (one is likely to be slightly larger or hang down slightly lower). Involve a partner to make it more enjoyable.
- Get themselves checked by a GP as soon as possible if they find an unusual lump in their testis. The likelihood is that it will not be testicular cancer (around 96% of testicular abnormalities aren’t cancer) but this still needs to be ruled out. They shouldn’t delay as in rare cases some types of testicular cancer can progress quickly.
- Spending hours on a games console or computer or lazing around all day won’t do their balls any favours. Take a regular break and try to get some fresh air and exercise.

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.
What is Orchid doing?

**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 microsite 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.

**Research**

**CarPET trial**
Orchid is currently funding a clinical trial which is comparing BEP chemotherapy with high dose carboplatin chemotherapy to treat seminoma. BEP chemotherapy may cause long term side effects which may be less with carboplatin. This study is also looking at the use of PET-CT scans to assess the response to treatment.

The main aims of this study are to:
- Learn more about the safety and side effects of high dose carboplatin.
- See how well it works to treat seminoma.
- See if using PET-CT scans can help spot an early response to carboplatin better than standard CT scans, leading to fewer men needing 4 cycles of carboplatin.

**GAMMA trial**
This is a trial looking at a combination of chemotherapy treatment for men whose testicular cancer has recurred. Men who have recurrent testicular cancer are usually treated with a combination of several types of chemotherapy actinomycin D, methotrexate, etoposide and cisplatin. Although this is a very successful treatment a number of side effects can occur: The researchers have replaced etoposide and cisplatin with drugs called paclitaxel and oxaliplatin, which are known to also work well in treating germ cell tumours.
The aim of this study is to see if this combination is more effective and has less side effects.
Men may find the following links useful:

**Orchid**
www.orchid-cancer.org.uk/
www.yourprivates.org.uk
For information on testicular cancer, individual stories and current research projects.

**Support Groups / Forums**

**Checkemlads Testicular cancer Awareness and Support Site**
www.checkemlads.com
Contact: philly@checkemlads.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 checkemlads and Orchid is not responsible for any content.

**Macmillan Cancer Support**
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
Telephone: 0141 341 5675
Email: 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
Helpline: 0845 123 23 10
(Mon to Fri, 9.30am to 5pm)
Switchboard: 01275 370 100
Email: helpline@pennybrohn.org
Provides a programme of complementary care.

**Regional Charities/Support**
**Brighton**
**Talking Testicles**
www.talkingtesticles.org.uk
Contact: Ryan Walshe
Mobile: 07886 178 069
Email: info@talkingtesticles.org.uk

**Bristol**
**It’s in the Bag**
www.uhbristol.nhs.uk/itsinthebag
Contact: 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
Email: therobincancertrust@gmail.com

**Manchester**
**The Mark Gorry Foundation**
info@themarkgorryfoundation.co.uk

**Norwich**
**It’s On The Ball**
www.itsontheball.org
Telephone: 01603 288 115
Email: info@itsontheball.org
**Nottingham**

**Ballboys**

www.ballboys.org.uk

Telephone: 08456 062 225

Lines open 9.30 - 4.30 Monday to Thursday

**Guernsey**

**Male Uprising in Guernsey**

(male cancer)

Email: trevor.kelham@me.com

Telephone: 07911 721 614

**Wales**

**Tenovus, your cancer charity**

www.tenovus.org.uk

**Scotland**

**Cahonas Scotland**

www.cahonasscotland.com

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**Important contact numbers**

**Urology Specialist Nurse contact no:**

**Urology unit/ward contact no:**

**Oncologist contact no:**

**Sperm Bank contact no:**

**Other contact:**

**Other contact:**
Resources…

For further information and support on male cancer, please visit the Orchid website at www.orchid-cancer.org.uk or yourprivates.org.uk.

Orchid has produced a series of leaflets and factsheets on specific issues relating to male cancer which can be downloaded from the website.

**Low-down**, Orchid’s newsletter features the latest news and developments in male cancer including research, treatments, new services and events.

Written and edited by:
Orchid Cancer Appeal and Orchid Editorial Board
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To be reviewed 2017

References to sources of information used in this booklet are available from Orchid.

Orchid has a **Male Cancer Helpline** manned by specialist nurses on 0808 802 0010 or email helpline@orchid-cancer.org.uk

Orchid is the UK’s leading charity dedicated to supporting men and their families who are affected by male-specific cancers:- testicular, prostate and penile.

Established in 1996 by a young testicular cancer patient and the oncologist who saved his life, Orchid works to improve the lives of people affected by male cancers through a world class research programme, educational campaigns and raising awareness and an extensive support service.

Models featured in this brochure are used for illustrative purposes only.