

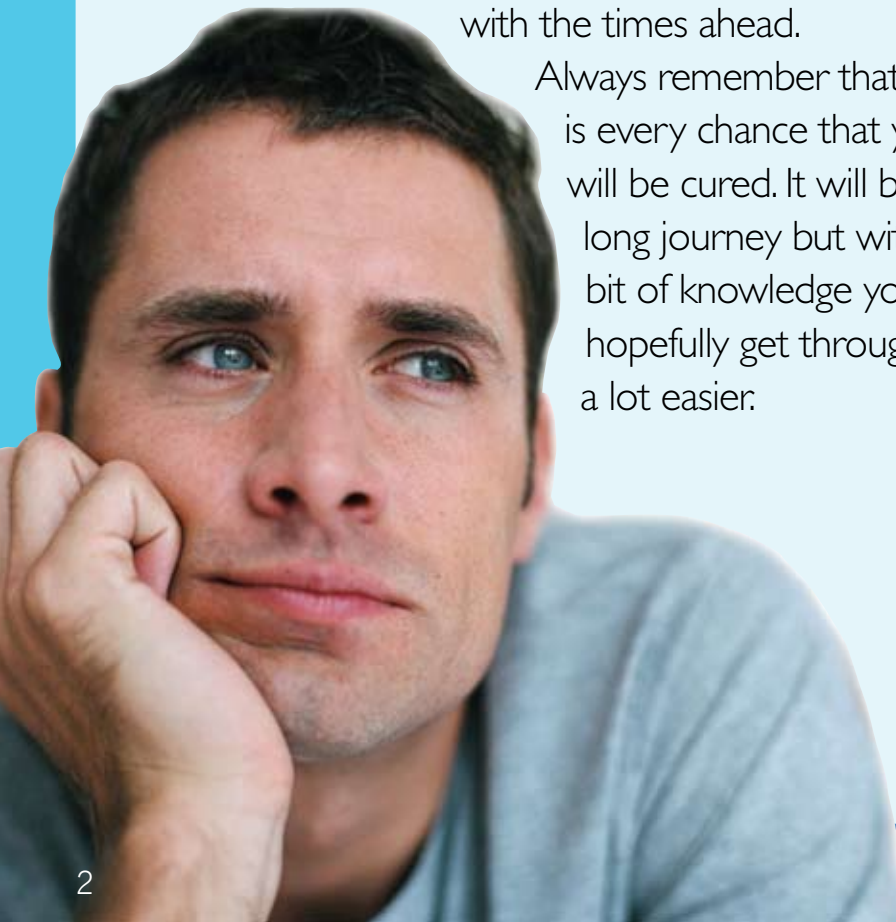
Testicular Cancer

Everything you need to know

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 still rare compared to other cancers, testicular cancer is the most common cancer in younger men aged between 15 and 45 with approximately 2,000 cases being diagnosed each year.”

However if found at an early stage cure rates of 98% are usually possible. Even when testicular cancer has spread to other areas in the body cure can still be achieved.

This booklet is aimed at increasing men's awareness of testicular health in general as well as providing support for men who have been diagnosed and are being treated for testicular cancer:

www.orchid-cancer.org.uk

ORCHID 
FIGHTING MALE CANCER

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Section 1: The basics

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.

Scrotum aka: ball bag, bag-of-tricks, ball-basket, ball-sack, daddy-bag, happy-sack, sack-o'-nuts, sleeping-bag, sperm-sack, tadpole-carrier, tool-bag, winky-bag.

DID YOU KNOW?

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 actually 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 excruciating 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).

The testicles

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. For most men, the left testicle hangs lower – but in some men, it is not abnormal for the right one to be lower. Your 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 your sperm and approximately 95% of your testosterone, the male sex hormone and are located outside of the body in your nad sack because sperm develop best at a temperature several degrees cooler than normal internal body temperature, at around 34.7° Celsius (94.6° Fahrenheit).

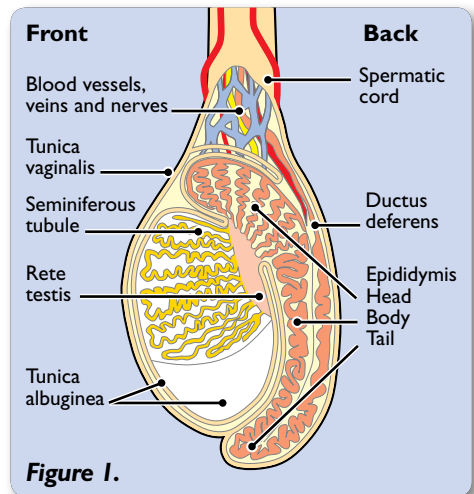
The cells inside the seminiferous tubules (see **Figure 1.**) are called germ cells and create sperm. The sperm move into the epididymis where they mature. They get stored there for a few weeks until they eventually move up the vas deferens to combine with fluids from the prostate and seminal vesicles to form what you 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:

- ▶ **body and facial hair**
- ▶ **low voice**
- ▶ **muscle development**
- ▶ **the ability to have an erection (hard-on, stiffy)**
- ▶ **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 your testosterone healthy. Some men will also undergo a change called andropause, the male equivalent of menopause as they get older (usually over the age of 40), when their testosterone levels may fall naturally also producing these effects.



Non-cancerous testicular conditions

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.

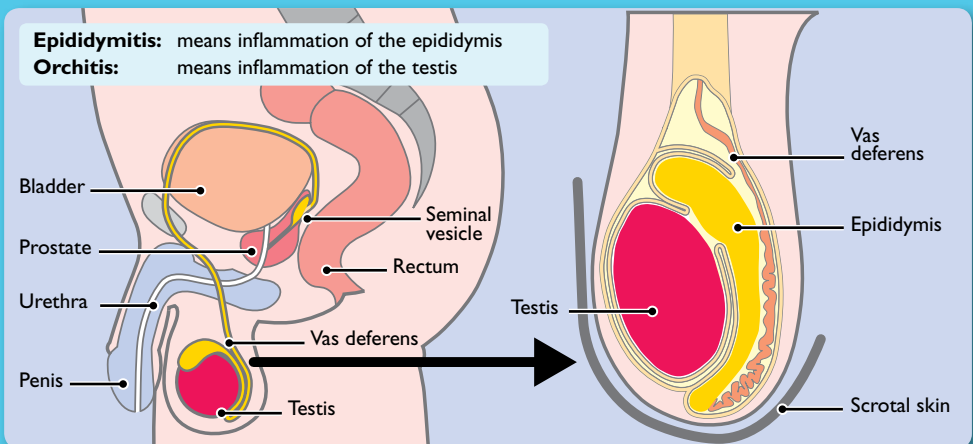
Blueberries, cantaloupe, pineapple, citrus fruits, spinach, tomatoes and red peppers;

These are all rich in vitamin A, essential for the normal function of the reproductive organs.

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. If the symptoms have not settled after a few weeks you will need to see your GP for further advice.



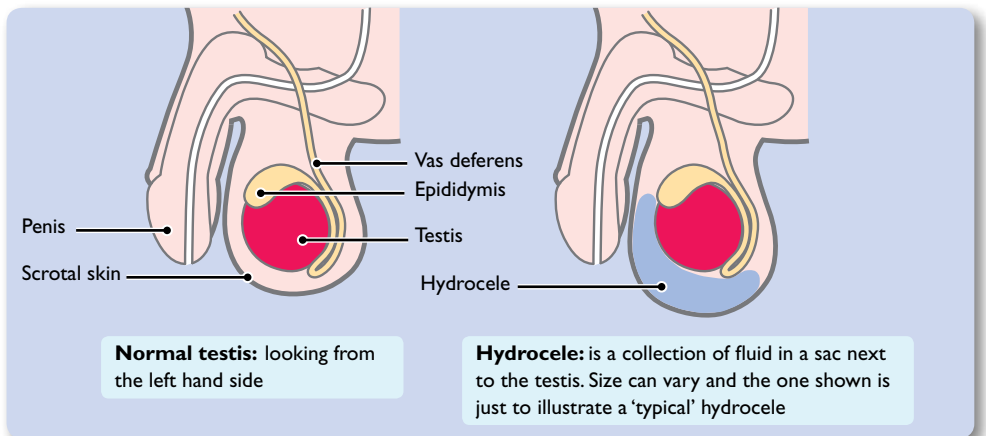
For more information visit: <http://www.patient.co.uk/health/Epididymo-orchitis.htm>

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 usually occurs on the left side of the testes due to blood supply near the left kidney but can affect both. Varicoceles can vary in size 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 your 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.



For more information visit: <http://www.patient.co.uk/health/Hydrocele.htm>

Epididymal cysts

These are small fluid filled cysts, which may contain semen. They are usually about the size of a pea but can be larger. They usually develop in adults around the age of 40 and may take many years to form. They are smooth and spherical and tend to be found in the head of the epididymis. They are benign. 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.

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 you are very physically active there is always a chance that you may strain your lower back or groin while playing sport, which then may irritate nerves in your lower body and cause testicular discomfort. Likewise dodgy or damaged hips can cause pelvic and groin pain.

Pain from blue balls will usually go after a few hours while chronic sports damage may need further input from your GP or physiotherapist.

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!

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:

- ▶ 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 nad sack. However approximately 30% of premature and 4% of on-time newborns may have undescended testicles). Research has shown the risk of testicular cancer increases dramatically if this is not corrected by the age by puberty.
- ▶ Pre cancerous cells found inside the testicle also known as carcinoma in situ (CIS). They may be found when a man has a testicular biopsy for instance during investigations into infertility. Also referred to as intratubular germ cell neoplasia (IGCN). If the cells are left there is a 50% chance that they will develop into testicular cancer within 5 years.
- ▶ A brother/father with testicular cancer.
- ▶ A previous history of testicular cancer.
- ▶ A sedentary (not very active) life style increases the risk. Regular exercise reduces the risk.



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.

- ▶ Mumps (a rare complication called mumps orchitis) may cause an increased risk.
- ▶ Repeated trauma (rather than inevitable knocks) increases risk.
- ▶ A recent study has shown a correlation between smoking marijuana and an increased risk of aggressive testicular cancer!
- ▶ Caucasian men have a higher risk of testicular cancer than men from other ethnic groups.
- ▶ Men with HIV are up to twice as likely to develop testicular cancer.

Other possible factors

- ▶ There is some evidence that seems to indicate that men who are taller than average have an increased risk of testicular cancer and men who are shorter than average have a reduced risk.
- ▶ 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 studies have shown that up to 40% of men with this condition may go on to develop testicular cancer. However men with a smaller than average testicle (less than 12mls) or who have had a history of undescended testicle or who are less than 31 years old are more at risk.

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 - hoden

Hungarian - golyo

Italian - coglione

Polish - jadro

Portugese - testiculos

Romanian - testiculele

Norwegian - baller

Spanish - cojon

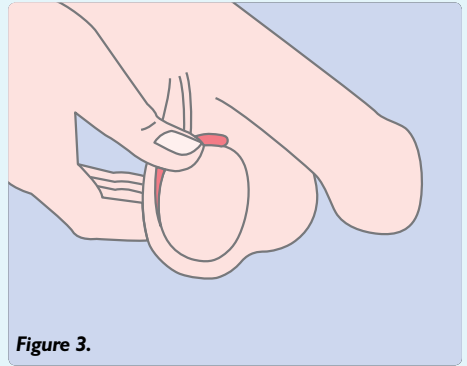
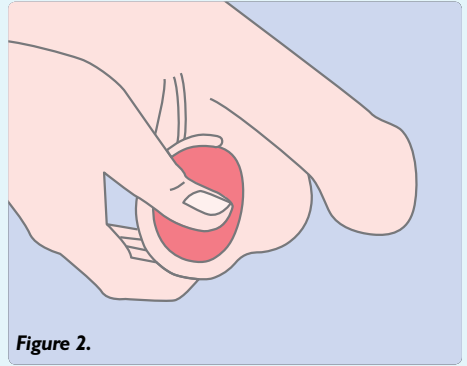
Swedish - testiklar

Turkish - er bezi

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 you a good excuse for feeling your nads (like you need one!). It's best performed monthly after you have had a bath or shower when your scrotum will be warm, relaxed and pleasant to touch.

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



For video advice on testicular self examination visit:

<http://www.orchid-cancer.org.uk/451/Check-em-Out> or

<http://www.channel4embarrassingillnesses.com/>

[video/how-to-check-yourself/how-to-check-your-testicles/](http://www.channel4embarrassingillnesses.com/video/how-to-check-yourself/how-to-check-your-testicles/)

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Section tips:

- ▶ Perform testicular self-examination on a regular basis, at least once a month. Get to know your balls, involve your partner to make it more enjoyable. Tell your mates to do the same but probably not with your partner.
- ▶ If you find an unusual lump in your testis get it checked by your GP. The likelihood will be that it will not be testicular cancer but testicular cancer still needs to be ruled out. Do not delay as in rare circumstances some types of testicular cancer can progress quickly.
- ▶ If you spend hours on your games console or computer, take a regular break and try to get some fresh air and exercise. Lazing around on your balls all day will not do them any favours. Get up, do something and keep those love spuds healthy!

Section 2: 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.

Diagnosing testicular cancer

Testicular cancer is the most common malignancy in men aged between 15-35 years with just over approximately 2,000 new cases a year: **It is becoming more common in Caucasian males.**

Signs and Symptoms

A lump can be felt in 97% of cases and in approximately 86% of cases this will be painless. A malignant testis may not feel unduly uncomfortable or painful whereas a testis inflamed by infection will usually be very tender and painful.

- ▶ Pain 31%.
- ▶ Dragging sensation 29%.
- ▶ Recent history of 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.
- ▶ Enlarged lymph nodes (see page 23) in the back.

If you find an abnormal swelling in your testicle it is advisable to see your GP for further advice or examination. If he is unsure of the exact cause of the testicular swelling he will usually recommend an ultrasound scan of your scrotum and abdomen and refer you to a urologist for assessment. The ultrasound scan and referral will usually be made on an urgent basis meaning that you will be seen by a urologist possibly within a few days and no more than a few weeks. It does not necessarily mean that testicular cancer is present.

Referral/Consultation

Once you have had your ultrasound scan you will be reviewed by a urologist who will be able to interpret the results. If there is any doubt as to the diagnosis a further more detailed ultrasound scan may be requested. Sometimes if there is a strong suspicion that testicular cancer is present but no definitive proof, a decision may be made to surgically remove the affected testicle. This decision will not be taken lightly but will be in your 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.

Further tests

If testicular cancer is identified or suspected, your doctor will want you to have some further tests to see if there has been any potential spread of the cancer to other parts of the body. These tests may include some or all of the following:

Blood tests

Some testicular cancers produce chemicals, which are released into the bloodstream. The three main chemicals, called tumour markers, are alpha-fetoprotein (AFP), beta human chorionic gonadotrophin (BHCG) and lactate dehydrogenase (LDH). They are sometimes found to 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 of your treatment and may be repeated after orchidectomy at 48-96 hours if they were abnormal before

your operation. Blood tests to measure your kidney and liver function will also usually be requested.

Occasionally if the specific blood tests for testicular cancer are very raised or abnormal or there is obvious evidence that testicular cancer is present or has spread to other areas in your body, a referral may be made to an oncologist (cancer specialist) to see if chemotherapy should be given prior to any surgery.

Chest X-ray – This can identify any cancer which may have already spread to the lungs.

Pregnancy test!

Yes believe it or not this is sometimes used to detect testicular cancer: A pregnancy test works by identifying BHCG.

Scans

Computerised Tomography (CT)

A CT scan is performed to check for any signs that the cancer has spread to your lungs or to the lymph glands in your abdomen. The CT scan takes a series of x-rays, which are fed into a computer to build up a three-dimensional picture of the inside of the body. The scan takes from 10 to 30 minutes. You may be given a drink or injection of a dye that allows particular areas to be seen more clearly. For a few minutes, this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it is important to let your doctor know beforehand. You will probably be able to go home as soon as the scan is over. The scan is painless, but it will mean lying still for 10-20 minutes. Any scans you may need will be requested on a very urgent basis and will usually be performed within a few weeks of request.

Positron Emission Tomography (PET)

A Positron Emission Tomography scan (PET scan) can be used to find whether testicular cancer has spread beyond the testes, or to examine any lumps that remain after treatment to see whether they are scar tissue, or whether cancer cells are still present. They are not always necessary, but you can discuss with your doctor whether one would be useful in your case. A PET scan uses low-dose radioactive sugar to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken. Areas of cancer are usually more active than surrounding tissue and show up on the scan. It is not usually used on a routine basis but may be performed after initial treatment.

Magnetic Resonance Imaging (MRI)

This test may be used after chemotherapy if further detail of your disease is needed. It is able to build up cross-sectional pictures of your body. Some people are given an injection of dye into a vein in the arm to improve the image. During the scan you will be asked to lie very still on a couch inside a long chamber for up to an hour. This can be unpleasant if you don't like enclosed spaces; if so, it may help to mention this to the radiographer. The MRI scanning process is also very noisy, but you will be given earplugs. You can usually take someone with you into the room to keep you company.

The chamber is a very powerful magnet, so before entering the room you should remove any metal belongings. People who have cardiac monitors, pacemakers or metal surgical clips cannot have an MRI scan because of the magnetic fields.

Surgery (orchidectomy)

Orchidectomy is the removal of a 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 or so to perform and will usually be performed as a day case procedure under **general anaesthetic**. During this surgery a small incision is made into your groin region on the affected side and the testicle is removed from above. **Your scrotum will not be cut**. Prior to your surgery your doctor may ask you if you wish to have a prosthetic (artificial) testicle in place of the removed testicle. However some men may develop minor problems in the long term (see below). You may be offered the possibility of sperm storage before surgery (see reference section).

Falsey or not?

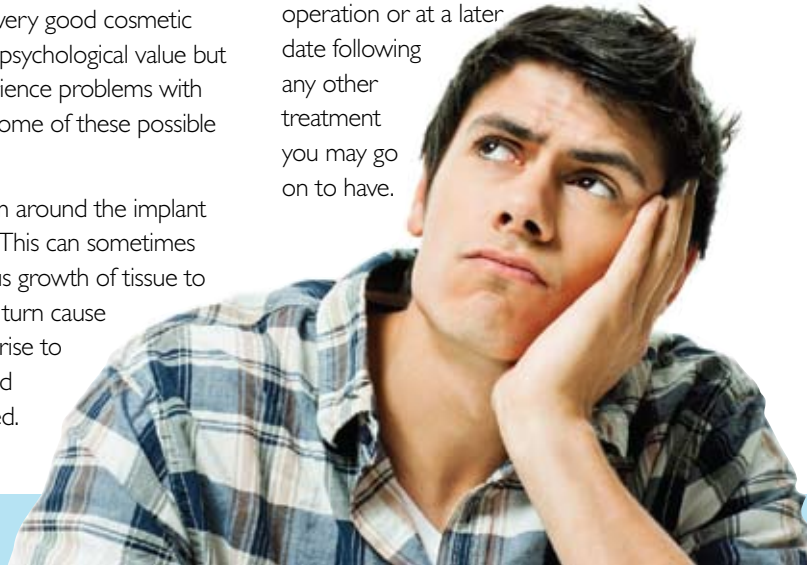
Your doctor may discuss the insertion of a false (prosthetic) ball to take the place of your old one. These are silicone implants that can be inflated with salt water. They come in various sizes and can make you feel whole again. They can give a very good cosmetic result and be of great psychological value but some men may experience problems with them at a later date. Some of these possible problems include:

- ▶ Scar tissue can form around the implant inside the scrotum. This can sometimes cause a thick fibrous growth of tissue to form which may in turn cause discomfort or give rise to worry that a second cancer has appeared.

- ▶ Rupture of the implant can rarely occur due to vigorous activities such as contact sport, cycling or physical contact including sex.
- ▶ 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), seen in testicular cancer.
- ▶ A prosthetic testicle will not react to temperature as a normal one would do and will therefore stay the same size.

If you are unsure of whether you want an implant or not, the procedure can always be performed at a later date.

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 your operation or at a later date following any other treatment you may go on to have.



After Surgery

- ▶ You will have a dressing covering the incision site on your groin. This can usually be removed at about 24 hours after the operation. The stitches (sutures) you will have in your wound will usually be dissolvable but may take some weeks to fully dissolve.
- ▶ You can have a bath or shower, normally after 24 hours, but it is important not to rub soap on the wound area. Dry the wound area by gently patting it with a clean towel/gauze pad afterwards.
- ▶ Your groin and scrotal area can feel bruised and swollen after the operation. It is advisable to wear close fitting underwear, such as briefs or 'Y' fronts or a scrotal support rather than boxer shorts while you recover. This will help the bruising settle. Take any painkillers you have been prescribed on a regular basis, (not just when you get pain) for the first 48 hours or until you feel comfortable. Always read the instructions to ensure you administer them 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. You should be able to return to work within a few weeks. However if you are being reviewed in an outpatient clinic or referred to an oncologist for further treatment; it may be a good idea to await these arrangements before returning to work as you may need to take further time off.
- ▶ Occasionally a collection of blood may form under the surgical wound (haematoma) or your wound may become infected. If you think that this is the case it is sometimes useful to phone the unit that performed your operation or contact your GP.
- ▶ It is important to avoid heavy lifting and or strenuous exercise for the first few weeks. Only start driving when you are able to do an emergency stop without hesitation.
- ▶ You may begin your normal sexual activity again two weeks after your operation, as long as you feel comfortable. Having an orchidectomy should not affect your ability to have an erection, but the psychological stress associated with a potential diagnosis of a cancer may affect your performance.
- ▶ You should be given a follow up appointment within a few weeks of your operation for the tissue results of your operation, blood and scan results. At this time any further recommended treatment will usually be discussed.

Section tips:

- ▶ If you are diagnosed or suspected of having testicular cancer you will usually be given the details of a urology specialist nurse or “Key worker” who will act as your point of contact during and after your treatment as well as provide you with relevant information and advice. Make sure you have these details as the specialist nurse will usually have access to other medical professionals who may be involved in your care and may be able to liaise with them if you are having problems. They may also be involved in planning your future care or treatment.
- ▶ Once a diagnosis of testicular cancer is suspected things will begin to move very fast for you, surgery will be booked and scans arranged usually within a two-week period. **Plan ahead.** Try and involve all of your family. Let them know what is happening so that they can help with any arrangements that need to be made while you are having treatment (childcare, work etc.).
- ▶ While you are being treated and afterwards, you will need to take some time off work. **Keep any correspondence/ letters and contact details of the health professionals you meet or procedures that you undergo as proof of your treatment in case your employer wants evidence. It may also be a good idea to talk to your human resources department** and inform them of your current situation and the fact that you are likely to need some time off. Think about working from home if possible. Although the hospital where you have been treated can issue you with a sick certificate to cover your stay in hospital they will not provide you with a long term sick certificate. You will have to get one from your G.P.

The following websites have a great deal of information with regard to work related issues and are well worth a visit if you think you may get problems. **If you are self employed and have to stop working due to your illness you should be entitled to incapacity benefit providing you have been paying National Insurance contributions previously.** You may also be entitled to other benefits or rebates if you are going to be out of action for some time.

Macmillan cancer support:

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Financialissues/Financialissues.aspx> or phone **0800 808 1234**

Citizens Advice Bureau:

www.citizensadvice.org.uk or phone **0207 833 2181**

Government benefit enquiry line:

http://www.direct.gov.uk/en/D11/Directories/DG_1001165
or phone **0800 882 200**

““ The surgery was on the 19th of August and it's now the 21st. The first night was bad but I think that was probably the anaesthetics. My groin is very tight in my bikini line and the cut is just below my belt line on the fat pad above the penis. My girlfriend being a nurse changed the dressing and was very pleased with the cut as it was very neat and clean. When she removed the dressing a lot of belly hairs were coming off but I could not feel a thing as the wound area was still numb. I can walk around today but cannot fully extend yet as my groin is very tight and painful. The numbness is starting to wear off and the wound is starting to itch a bit. I am sleeping on the sofa at the moment to make it easier to go to the toilet and just in case I get knocked in my wound or groin while we are asleep. Still not tried stairs yet or showered. Going to try stairs later today and shower tomorrow morning. I had to explain to my 2 year old daughter to be careful as she does like to use me as a human bouncy castle! ””
D.F.

““ 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.

Useful telephone numbers:

Section 3: 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% 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.

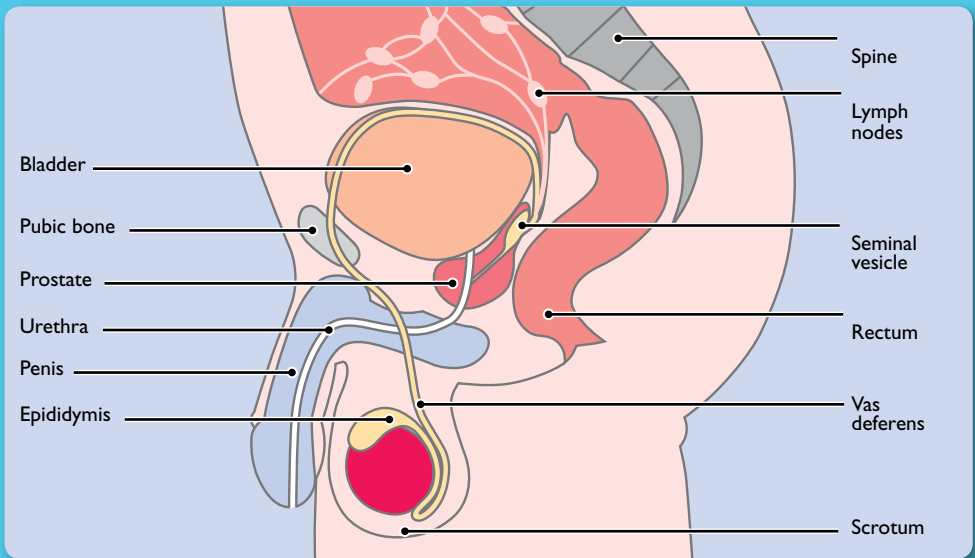


Figure 4. Male pelvic anatomy

Types of testicular cancer

The most common type of testicular cancer is called a **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 **25-55**, with a peak age of **35** years old.

A 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, usually over the age of 50 years may also have similar symptoms to testicular cancer with testicular swelling.

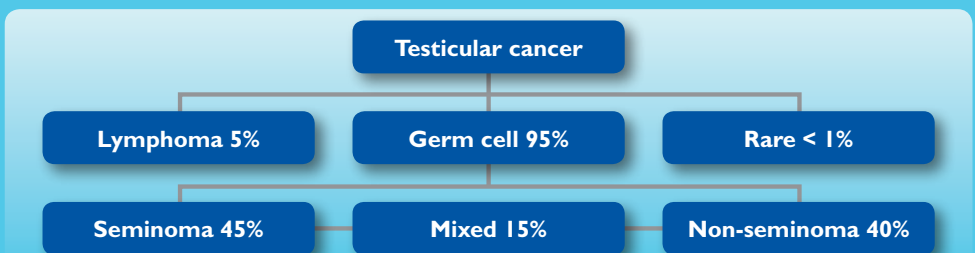


Figure 5. Summary of the incidence of testicular tumors

Classifying testicular cancer

Once your testicle has been analysed by a histo-pathologist (tissue specialist), it will be possible 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 in situ). 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

Lymph nodes are part of the body's natural drainage system and are essential for a healthy immune system. They act as filters, which eliminate waste products from the body. These waste products travel along the lymphatic drainage system where they collect at the lymph nodes. If one lymph node does not manage to filter out these substances they will travel to the next lymph node. Cancer is able to travel through the lymphatic system in the same way and become deposited in other areas of the body, (see Fig.4). The lymph nodes usually affected by testicular cancer are called the para-aortic nodes.

- 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 25).

The results of your 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

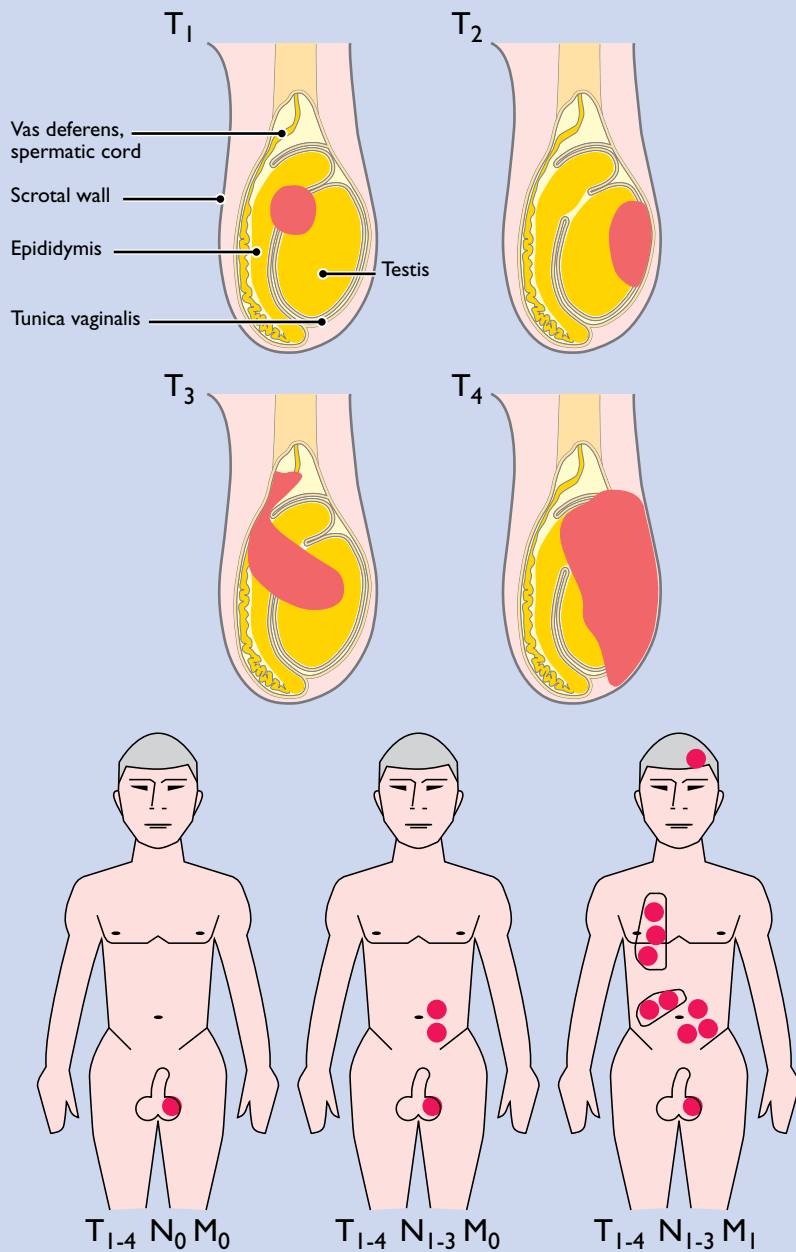


Figure 6. Diagram illustrating testicular cancer staging (TNM system)

Table 1. Testicular staging non TNM

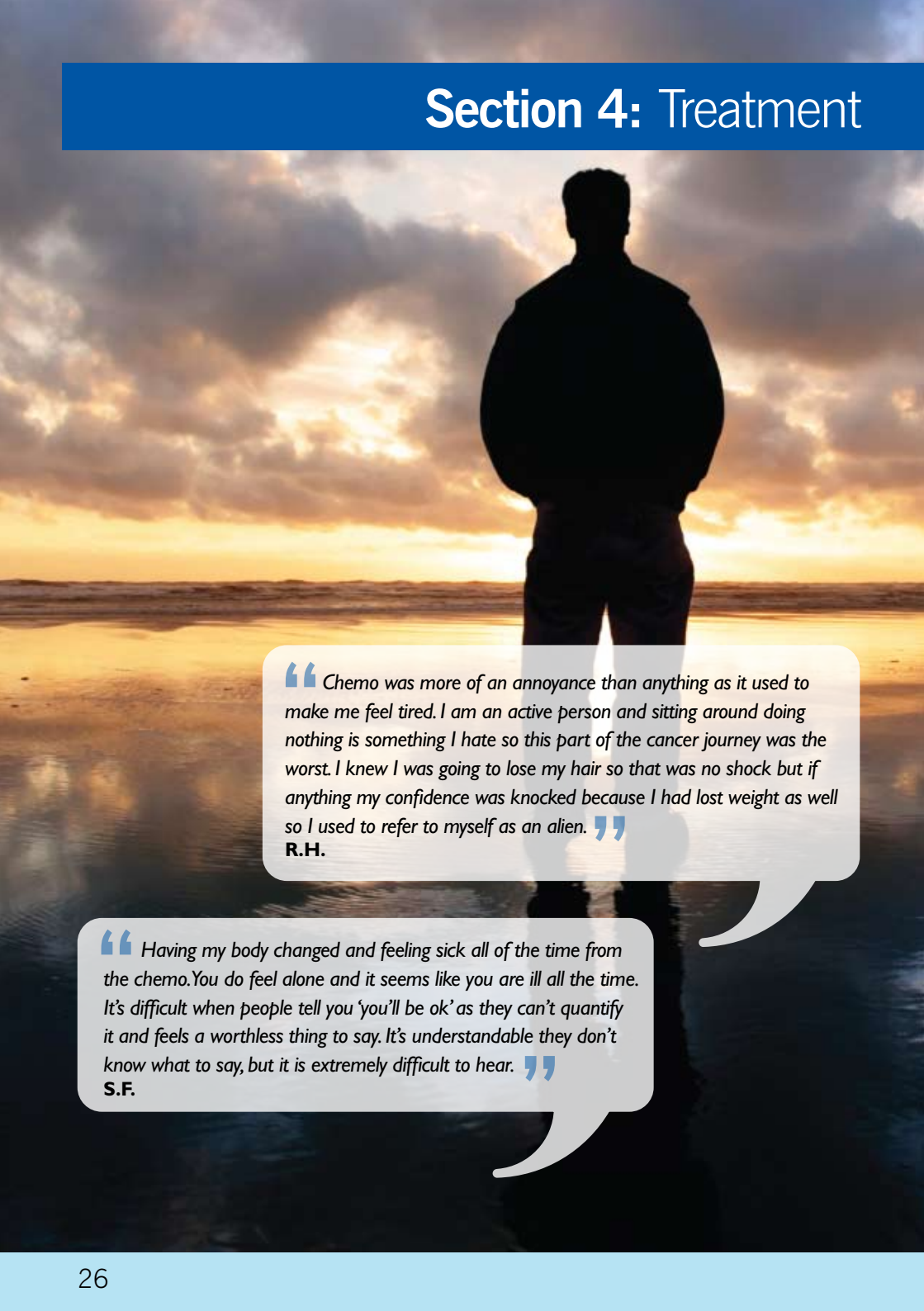
Stage 1 This is the earliest stage of testicular cancer.	<ul style="list-style-type: none">• The cancer is contained within the testicle and has not spread to nearby lymph nodes or other organs.
Stage 2 The cancer cells have spread into nearby lymph nodes in the abdomen or pelvis. This is further split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

Record your staging:

Your TNM stage T N M

Your stage I 2a b c 3a b c

Section 4: Treatment

A silhouette of a person standing on a beach, looking out at the ocean during a sunset. The sky is filled with dramatic, golden clouds, and the sun is low on the horizon, creating a warm, glowing light. The person's shadow is cast on the wet sand in front of them.

“ 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.

Treatment options

Treatment options may vary slightly around the country; however the following information should be relevant to most situations.

Once you have had an orchidectomy your follow up care will usually be carried out by an oncologist who will specialise in deciding whether any further treatment is needed. However, if you had advanced disease to begin with and had to have treatment such as chemotherapy first; you may be referred to a urologist afterwards for an orchidectomy.

To ensure that you get the best possible treatment in line with current national and international cancer guidelines your 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, histopathologists, radiologists (X-ray specialists) and other healthcare professionals. They will discuss your particular medical case taking into account the results of your operation and cancer findings along with your blood tests and scan results. They will then come up with a consensus opinion as to what if any, further treatment is needed. This will then be explained to you when you attend a follow up clinic appointment. Any decision made will reflect their experience in dealing with similar cases to yours and will be based on the latest medical research and techniques. The recommendation or outcome of the meeting

will be in your best interest. However you can ask for a second opinion if you wish or refuse the recommended treatment plan.

Stage I seminoma (early stage)

Options for seminoma disease may involve surveillance or single dose chemotherapy. Surveillance involves strict follow up appointments along with routine X-rays, scans and blood tests. For some men this is difficult due to work or other commitments and if there is a possibility that they will not be able to follow the regime, a single dose of chemotherapy may be recommended instead to prevent the risk of any future recurrence of the cancer. This will usually involve one dose of chemotherapy (Carboplatin) lasting 1.5 hours administered through a drip. It will be performed as a day case procedure. Although you may suffer some side effects for up to 7-10 days after treatment it is very successful in minimizing the chance of your cancer returning.

A third option is radiotherapy which can be used to treat the lymph nodes in your back which may still harbour some disease. This treatment usually involves around 21 days of treatment with up to 10 minutes of radiotherapy each day. Side effects vary from person to person but, for many, its success rate at reducing recurrence still outweighs its effect on a patient's lifestyle. Some studies however suggest that there is a risk of developing a secondary cancer as a result of treatment later on in life.

Both radiotherapy and chemotherapy have the same chance of preventing your cancer coming back.

If your cancer is found to be at an early stage, but you have had a history of undescended testicle or are under the age of 31 or have a smaller than usual testicle, the risk of getting testicular cancer in your other testicle is slightly higher. In this situation it may be recommended that you have chemotherapy to significantly reduce the risk of recurrence.

Stage I non seminoma

Non seminoma cancers can be divided into high or low risk groups depending on whether the cancer was totally confined to the testicle (low risk), or whether there is any evidence that the cancer has infiltrated the local blood supply around the affected area (high risk). For low risk cases surveillance may still be an option although you can opt for additional chemotherapy if you wish. If you fall into the high risk category then further treatment with chemotherapy will usually be recommended.

After your treatment has been completed, your oncologist will want you to have regular check-ups which will include blood tests, scans and x-rays. These will continue for several years. A typical programme of follow up may be similar to the following regime:

Year 1

Monthly to 6 weekly clinic visits with blood tumour markers and chest X-ray, with an abdominal CT scans at 6 and 12 months.

Year 2

Monthly clinic visits with markers and chest X-ray with a CT scan at 24 months.

Year 3, 4 and 5

3-monthly clinic visit with chest X-ray and markers.

Annually, with a chest X-ray and serum markers for up to 10 years.

If you have any problems, or notice any new symptoms in between these times, you should let your specialist know as soon as possible. Any recurrence of testicular cancer will usually occur within 2 years of treatment. **Only about 5% of relapses will occur after this.**

You should continue to perform Testicular Self Examination of your healthy testicle.

Cancer which is not confined to the testicle or has spread (metastasized)

Testicular cancer tends to spread to the lymph nodes in the abdomen and to the lungs. Over 80% of men who find themselves in this situation are treated successfully with chemotherapy. Other more serious organs, to which the cancer can spread, include the liver and brain. Even so, over 50% of these patients are treated effectively with chemotherapy.

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

Chemotherapy for non localized/high risk disease

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. They work by disrupting the growth of cancer cells as they circulate in the blood and can reach cancer cells all over the body. 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 outpatient treatment, day patient or during a short stay in hospital. Blood tests will usually need to be performed prior to BEP to check that your immune system is healthy enough to cope with the treatment.

Older men or those with medical problems such as breathing difficulties may be offered slightly different treatment regimes.

A drip will be sited into a vein in your hand, arm or neck and the chemotherapy administered through it. Anti-sickness (anti-emetic), drugs can be given to you through these tubes as well.

BEP chemotherapy can be given in different ways and the exact duration of your treatment will be decided by your 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 and will run over three weeks.

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

Table 2. 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 Infusion of all BEP drugs	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 9 Bleomycin	Day 4 Etoposide and Cisplatin
Day 16 Bleomycin,	Day 5 Etoposide and Cisplatin
Break	Day 9 Bleomycin
	Day 16 Bleomycin
	Break

Chemotherapy effects

While the chemotherapy drugs are acting on the cancer cells in your body, they may also temporarily reduce the number of normal cells in your blood. When these cells are in short supply, you may be more likely to get an infection and to tire easily. It is important to let your cancer specialist team know straight away if you feel unwell or develop a temperature at any time during your treatment.

During chemotherapy your blood will be tested regularly to make sure your white blood cells, responsible for fighting infection, and your kidneys are functioning correctly. If necessary, you will be given antibiotics to treat any infection.

Before chemotherapy you will also need to have **a hearing test (audiogram)** as chemotherapy can affect your hearing as well as **a breathing test** as some chemotherapy can sometimes affect your lungs. **You will also be advised to bank sperm.**

Below are some of the common and less common side effects associated with chemotherapy along with some tips that people have found useful on how to manage the symptoms. Some of this advice can also be used if you are having radiotherapy.

(Please use the space provided on page 37 to write down any of your own helpful tips)

Table 3. Potential chemotherapy side effects

Common side effects of chemotherapy:	Try:	Avoid:
<p>Nausea and vomiting:</p>	<ul style="list-style-type: none"> • Anti sickness medication will be given on a regular basis and it is important to take this as otherwise you will puke! • Ginger! ; beer, tea or biscuits (eat regularly throughout the day) • Peppermint tea, always drink slowly taking lots of sips • A small meal a few hours before your chemo starts <p>Never have chemotherapy on an empty stomach</p>	<ul style="list-style-type: none"> • Hot and spicy foods (curry, Cajun cooking etc.) • Foods with high sugar content • Fatty and greasy foods (chips, burgers etc.) • Large meals • Eating and drinking too fast and drinking with meals • Alcohol • Caffeine (which is found in tea/coffee/chocolate including chocolate bars/energy drinks) • Baby food this is designed for babies and has very little nutrition for adults!

Common side effects of chemotherapy:	Try:	Avoid:
<p>Taste: (chemo can cause a metallic taste in your mouth)</p>	<ul style="list-style-type: none"> • Fresh pineapple or other sharp tasting fruit • Boiled sweets while having treatment • Seasoned or marinated meat for your meals to add flavour • Use herbs and spices in your cooking to add stronger taste 	
<p>Mouth sores or ulcers from chemotherapy:</p>	<ul style="list-style-type: none"> • Fresh pineapple can help prevent and heal mouth ulcers by stimulating saliva which protects your mouth • Bonjela • Soft childs/baby bristle toothbrush and baby/soothing (for instance) aloe vera toothpaste • Soft puréed or liquid diet to prevent chewing • Rinse your mouth with salt water on a regular basis if you can tolerate it up to 4-5 times a day • Try sucking crushed ice during treatment • Artificial saliva which can be prescribed by your doctor • Vaseline for your lips 	<ul style="list-style-type: none"> • Avoid tomato and citrus fruit based products and tobacco • Avoid 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

Common side effects of chemotherapy:	Try:	Avoid:
Tiredness:	<ul style="list-style-type: none"> • If you cannot sleep to your normal pattern, try and get small restful naps, not too many however as you may not sleep in the night • Some people find benefit in meditating • Sleeping tablets can be prescribed if insomnia it is becoming a big problem 	
Loss of appetite:	<ul style="list-style-type: none"> • Try small frequent meals throughout the day • Try fortified soups/drinks or milk shakes of your favourite combinations 	
Diarrhoea:	<ul style="list-style-type: none"> • Rice and pasta • Potatoes with skins • Dry crackers/biscuits • White bread • Bananas (a good source of potassium which is essential for your body's metabolism). Excessive diarrhoea will deplete potassium levels 	<ul style="list-style-type: none"> • High fibre foods (bran, fruit, nuts etc.)
Hair loss: This may occur 2-3 weeks after chemotherapy	<ul style="list-style-type: none"> • Baseball cap • Shave your hair off when it starts to fall out (you will look hard if nothing else) • Elvis wig (and glasses)! 	<ul style="list-style-type: none"> • Head cooling devices may reduce the circulating blood supply which can reduce the effectiveness of the chemo

Common side effects of chemotherapy:	Try:	Avoid:
Low immune system from chemotherapy:	<ul style="list-style-type: none"> • Pay meticulous attention to your hygiene. Wash your hands after peeing and pooing! 	<ul style="list-style-type: none"> • Drugs/alcohol which may depress your immune system and make you feel like crap. Smoking cannabis can also affect your tumour markers giving a false representation of disease • Travelling to foreign countries where risk of picking up illness is greater • Vaccines. Ask your oncologist when you will be able to travel and receive vaccines after treatment
Tingling in your arms and feet due to nerve damage (peripheral neuropathy) from chemotherapy:	<ul style="list-style-type: none"> • Keep your hands and feet warm and avoid extremes of temperature • Make sure you take care when preparing food (use gloves) or when running hot water (test with your elbow) as you may risk burning yourself • Gentle exercise 	
Inflammation in the lungs with shortness of breath due to low circulating heamoglobin (oxygenated blood) from chemotherapy:	<ul style="list-style-type: none"> • You may need a blood transfusion • Rest • Tell your doctor if you are experiencing breathing difficulty 	<ul style="list-style-type: none"> • Avoid taxing, strenuous tasks (washing up ironing, shopping etc.) • Do not smoke!

Common side effects of chemotherapy:	Try:	Avoid:
Tinnitus (ringing in the ears) from chemotherapy:	<ul style="list-style-type: none"> • Encourage people to speak slowly and clearly to you • Some people find that listening to gentle background music may help • Tell your doctor if you are experiencing hearing problems 	
Skin changes:	<ul style="list-style-type: none"> • Electric shave to avoid cuts • Non perfumed moisturizing creams • Chemo can make your skin more sensitive to sunlight, check with your oncologist to see how long you should avoid prolonged exposure for and make sure you are using at least factor 15 if sunbathing • Allow 6 weeks after radiotherapy treatment before exposure to the sun it may be best to cover the treated area for up to a year 	<ul style="list-style-type: none"> • Wet shaving which may break your skin • For radiotherapy it is useful to avoid non perfumed soaps and have tepid baths. Avoid vigorous rubbing of the skin around the treated area

Semen (sperm) may contain some residual chemotherapy following treatment and if you plan to have sexual intercourse within 48 hours of finishing your chemotherapy it is advisable to use a condom.

After chemotherapy

If there are any signs of residual cancer following your treatment such as enlarged lymph nodes it may be suggested that you undergo the following additional treatments:

Retroperitoneal Lymph Node Dissection (RPLND)

Surgery (see below) to remove lymph nodes at the back of the abdomen may be offered. This is usually performed if there are still significant lymph nodes left following adjuvant chemotherapy or radiotherapy. This operation is called a 'Retroperitoneal Lymph Node Dissection'. It 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 your breastbone to just below your navel (belly button). Your 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 your affected testicle are first removed followed by any others that look suspicious of containing cancerous cells.

A newer keyhole technique can be used, but national guidelines suggest that this only be performed by experienced surgeons.

Retroperitoneal Lymph node Dissection can affect your 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 but your surgeon will be able to advise if it is likely to happen to you.

If there is a possibility that you may need such surgery, and if you are fit enough to produce sperm samples for storage before treatment starts, some of your sperm can be stored. Although this further surgery may make it more difficult for you to father a child, it will have no physical effect on your ability to get an erection or have an orgasm (see reference section for sperm banking).

After RPLND

- ▶ You will be given painkillers to take home. Use them as prescribed and try to eat a high fibre diet to prevent them from causing constipation which may then aggravate your pain. You should aim to drink 2-3 litres of fluid a day to help soften your stools. A mild laxative may be suggested.
- ▶ Take things easy for 2 weeks after surgery. If you live alone it may be beneficial to stay with someone who can keep an eye on you as you will tire easily. Heavy lifting and vigorous exercise should be avoided for at least 6-weeks to allow your abdominal muscles to heal. Try and walk upright without stooping.
- ▶ You should not drive for 3-4 weeks following surgery as you may not be able to stop effectively in an emergency.
- ▶ You should be able to return to work after 4-weeks but this may need to be longer if you have a particularly physical job. You will need to obtain a sick certificate from your GP.
- ▶ Sexual intercourse should be avoided for approximately 4-weeks after surgery.

Further surgery

Rarely a man may be found to have further recurrent testicular cancer in their remaining testicle. This has traditionally warranted removal of the testicle. This means that a man will become infertile and have difficulty in getting an erection. In this situation testosterone replacement therapy will need to be given. In recent years the possibility of further chemotherapy with the addition of partial removal of the remaining testicle (lumpectomy) has gained more support and if you find yourself in this situation it may be worth discussing this possibility with your oncologist.

Occasionally if you have a secondary cancer in your lungs, liver or brain it may be possible to have it removed by further specialist surgery. However this surgery will only be performed by very experienced surgeons and you may need to be referred to a specialist centre to have it performed.

High dose chemotherapy with stem cell support

If you have already had chemotherapy in the past this further treatment may be recommended. This treatment allows you to have much higher doses of chemotherapy than usual to try to destroy all the testicular cancer cells. Before high-dose treatment, cells in your blood (called stem cells) are taken from you and stored. These stem cells help

you to produce new blood cells, to replace the ones that the high-dose chemotherapy damages.

Shortly after high-dose treatment, your stem cells are given back to you 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 blood cells again.

This is a very intensive and demanding treatment and it will mean staying in hospital for several weeks. You'll need a lot of nursing and medical care until you've recovered and your blood cells are improving.

Clinical trials

If you are having chemotherapy, you may be offered the chance to participate in a clinical trial. This does not mean you 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 such as chemotherapy. Your oncologist or specialist nurse will discuss these possibilities with you. If you decide to take part in a clinical trial you 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

<http://www.nhs.uk/Conditions/Cancer-of-the-testicle/Pages/clinical-trial.aspx>

Cancer Research UK

<http://cancerhelp.cancerresearchuk.org/trials/>



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. You may feel tired or exhausted. Take this into account when you are considering going back to work or for a busy lifestyle as you may not be able to function as well as before treatment. Refer to the previously included websites for information on financial support etc. It may also take your family and friends time to adjust to long term changes in your 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 you 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 you will need to come to terms with and obtain help. A good start for information on these issues can be found here <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Livingwithandaftercancer.aspx>

For cultural and spiritual support the following websites may be of use

http://www.muslimhealthnetwork.org/kb_cancer.shtml

<http://www.cancerblackcare.org.uk/>

Your own tips:

Section 5: 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 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.

Effect on sex and fertility

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, chemotherapy can occasionally improve their fertility. For some men however it could be permanent and for this reason, it is usually advisable to store sperm before starting chemotherapy treatment. 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 by a sperm bank. Then, when you want to father a child, your sperm can be thawed and used to make your partner pregnant 'artificially'. **Please see reference section 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 affect your sexual performance or your ability to father children, if the other testicle is healthy. This is because the remaining healthy testicle will produce more testosterone and sperm to make up for the removal of the affected testicle.

If both testicles are removed due to the cancer then **you will need to have testosterone replacement therapy**. This can be given in the form of injections or gels. This should enable you to experience normal sexual intercourse.

The effect of chemotherapy on semen (the liquid that contains the sperm) and sperm is uncertain. Because of this, it is advisable to use a condom throughout treatment (this protects your partner and avoids any stinging sensations that your partner may feel from your treatment). Although there is no evidence that chemotherapy can harm children fathered after the treatment has finished, doctors usually advise that you avoid having a child for about a year.

Radiotherapy does not normally cause sterility. However, a small dose of radiation does reach the remaining testicle. There is no evidence that this radiotherapy has any effect on children fathered after the treatment, but men are usually advised to use contraceptives for 6-12 months after treatment has ended.

Any course of treatment may make you 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 remember that it is a temporary side effect and once treatment is over and your body begins to return to normal, your libido will 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 they have summoned up the courage to talk openly to their partners, many men find that their fears of rejection are unfounded. Sexual relationships are built on many things including love, trust and common experiences. You may even find a new closeness after talking through a problem with your partner. In some cases, your doctor, nurse, close friend or relative may also be able to offer help and advice. Some hospitals have specialist counsellors (psychosexual counsellors) who are trained to help people with sexual problems. If you are worried about this ask your doctor or nurse specialist for further information.

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

Your feelings

Most people feel overwhelmed when they are told they have cancer; even if the chance of cure is very high. Many different emotions arise, which can cause confusion and frequent changes of mood. You might not experience all of the feelings that are associated with being diagnosed with testicular cancer; such as fear, resentment, anger but they may occur.

This does not mean, however, that you are not coping with your illness.

Reactions differ from one person to another - there is no right or wrong way to feel. These emotions are part of the process that many people go through in trying to come to terms with their illness. Partners, family members and friends often experience similar feelings and frequently need as much support and guidance in coping with their own feelings too.

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;
<http://www.macmillan.org.uk/Home.aspx>

Also

Find a Therapist

<http://www.cpdirectory.com/cgi-bin/index.pl>

Counselling Directory

<http://www.counselling-directory.org.uk/distress-psychosexual.html>

or Telephone: **0844 8030 240**

DO NOT BOTTLE THINGS UP AND TRY TO BE A HERO.

TALK TO YOUR FAMILY OR PARTNER! GET YOUR FEELINGS OUT IN THE OPEN; YOU WILL FEEL A LOT BETTER.

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 and one of our aims in the future will be to provide a countrywide directory for men who may wish to meet or be made aware of a nearby support group.

Please phone **0203 465 5766** or email **nurse@orchid-org.uk** if you know of a support group.

Please also email any tips that helped you through your treatment.

“ 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.

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.

Sperm storage

What is sperm storage?

Storing your sperm, also known as sperm banking, is the preservation of your sperm by freezing. The sperm may be used in the future for artificial insemination or other assisted reproduction techniques.

Why consider sperm banking?

There are a number of reasons why you may wish to consider storing your sperm. Certain treatments may lower the number of sperm your body produces which in turn can lead to infertility. This may be temporary and will recover following treatment. Sometimes the treatment may lead to permanent infertility. In some cases the tumour bearing testicle may be able to produce sperm whilst the healthy one may be non-functioning. If there is any doubt, sperm storage should be discussed before surgery begins. Sometimes the cancer may return to the healthy testicle and if removed you will not be able to father a child.

Even if you don't plan to start a family, sperm banking is worth considering in case you change your mind in the future.

Where can you find a sperm bank or clinic?

Your specialist healthcare team will be able to advise you if the hospital where you are being treated has sperm banking facilities. They can also provide you with information on your local fertility centre where you may be offered the opportunity to bank your sperm.

Visiting the sperm bank or clinic

You should not ejaculate for at least 72 hours prior to your visit. Sometimes you can masturbate into a special non spermicidal condom at home but the sample needs to be brought for storage within an hour.

When you first visit the clinic, the consultant or specialist healthcare team will discuss the process and answer any questions and concerns you may have. You may wish to take someone with you at this stage or to keep notes of the meeting.

You will be asked to provide a sperm sample, through masturbation. You will be given privacy and your partner may accompany you if you wish. The clinics will then freeze and store the sperm. When you are ready to have a child the semen is thawed and then used to artificially inseminate your partner.

To provide a sample may require several visits to a clinic. Understandably, some men may find the situation stressful or embarrassing and may not be able to produce a sperm sample through masturbation. Some men may have a low sperm count and will need to visit the clinic at a later stage when the treatment has finished and the count is improved.

Not everyone is suitable for sperm banking and a low sperm count, poor sperm quality, and the freezing and thawing process can all affect your ability to father a child. If your cancer has spread and you need to begin your chemotherapy right away, your doctor may advise against sperm banking because it could delay the start of your cancer treatment. Don't worry if you are unable to bank any sperm. There are many new techniques and procedures in development.

What tests and consents are involved?

- ▶ If you are under 16 you will need your parent or guardian's permission to have your sperm treated and stored.
- ▶ Your blood will be screened for HIV, hepatitis B and hepatitis C. This is usually arranged by your specialist healthcare team. If the blood tests are positive you will still be able to sperm bank, but the samples will be stored separately.
- ▶ You will need to confirm what you would like done with your sperm in the event of your death.

Currently, the NHS will pay for the costs of the initial consultations, blood tests and sperm storage for the first year. However there may be slight variations across the country with regard to this service so please check with your oncologist or specialist nurse.



Thoughts:

Important contact numbers

Urology Specialist Nurse contact no:

Urology unit/ward contact no:

Oncologist contact no:

Sperm Bank contact no:

Other contact:

Other contact:

Useful links

You may find the following links useful:

www.orchid-cancer.org.uk/

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

Support Groups / Forums

Testicular Cancer Resource Centre: (TC-NET)

<http://www.acor.org/TCRC>

A huge international resource website with a forum for testicular cancer.

Talking testicles:

<http://www.talkingtesticles.org.uk>

A great education programme.

<http://checkemlads.com/>

An excellent website, with an online forum.

<http://thetesticletour.com/>

A brilliant fun awareness page detailing Darren 'one ball' Couchman's testicular cancer awareness exploits.

http://ballboys.org.uk/ballboys/Ballboys_-_UK_testicular_cancer_charity.html

A new online support group.

<http://philstoker.com/blog/>

A personal blog from a man affected by testicular cancer.

<http://lancearmstrong.com/> - The multiple winner of the Tour De France. Beat metastatic testicular cancer which had spread to his liver and brain.

Books

Love Your Nuts:

Testicular Cancer touched my Life - by Torsten Koehler (11 Oct 2010).

Nuts, Balls and Rocks:

A Year of Life from the Diagnosis of Testicular Cancer to Recovery - by Adrian Keith Jowett (2009).

One Lump Or Two A Humorous Story Of One Man's Fight Against Testicular Cancer

Winner of the AmazonClicks.com Readers Choice Award Aug 2008 , Darren Couchman (2008).

It's Not About The Bike:

My Journey Back to Life - by Lance Armstrong.

General cancer information

CancerHelp®

Offers a broad range of information and support from Cancer Research UK for everyone affected by cancer.

www.cancerhelp.org

Cancer Research UK information and support

Cancer Research UK

Angel Building

407 St John Street

London EC1V 4AD

Admin telephone number: **020 7242 0200**

<http://www.cancerresearchuk.org>

Cancer52

www.cancer52.org.uk/

A combination of rare cancer charities dedicated to increase awareness of the less common cancers which make up 52% of all cancers.

Health talk Online website

The cancer section of this website contains video and audio clips of people with the main types of cancer, so that you can share in their stories. A great section, with online interviews of testicular cancer survivors.

There is an adult cancer section at www.healthtalkonline.org/Cancer, a

teenage cancer section at

www.youthhealthtalk.org/ and a section

about taking part in clinical trials at

www.healthtalkonline.org/medical_research/clinical_trials

Isle of Man Anti-Cancer Association

Supporters of Everyman and The Institute of Cancer Research's SAFE Campaign, this Isle of Man based charity raises money and awareness, as well as offering supplementary services for cancer sufferers.

www.cancer.org.im

Macmillan Cancer Support

Telephone: **020 7840 7840**

Fax: **020 7840 7841**

Write to:

Macmillan Cancer Support

89 Albert Embankment

London SE1 7UQ

Questions/helpline: **0808 808 00 00**

Maggie's Cancer Caring Centres

The Stables

Western General Hospital

Crewe Road

Edinburgh EH4 2XU

Telephone: **0141 341 5675**

Email: enquiries@maggiescentres.org

www.maggiescentres.org/maggies/maggiescentres/home/home.html

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

(formerly the Bristol Cancer Help Centre)

Chapel Pill Lane

Pill

Bristol BS20 0HH

Helpline: **0845 123 23 10**

(Mon to Fri, 9.30am to 5pm)

Switchboard: **01275 370 100**

Email: helpline@pennybrohn.org

www.pennybrohncancer.org

Provides a programme of complementary care - The Bristol Approach to people with cancer and their loved ones.

Rarer Cancers Forum

The Rarer Cancers Forum website has several message boards so people with less common or rarer cancers can get in touch with each other. Friends and families of people with rarer cancers can also use the message boards to share their experiences, give support or get advice from people in similar situations. The website also offers general advice and information.

Teenage Cancer Trust

93 Newman Street

London W1T 3EZ

Telephone: **020 7612 0370**

www.teenagecancertrust.org

A charity devoted to improving the lives of cancer sufferers and their families.

The Cancer Counselling Trust

The Cancer Counselling Trust has now closed but their website gives details of other organisations that provide counselling services.

www.cancercounselling.org.uk

The Prostate Cancer Charity

Provides support and information to people affected by prostate cancer:

www.prostate-cancer.org.uk

Northern Ireland

Action Cancer

1 Marlborough Park

Belfast BT9 6XS

Telephone: **028 9080 3344**

Fax: **028 9080 3356**

Email: info@actioncancer.org

www.actioncancer.org

A charity which offers one to one counselling.

The Ulster Cancer Foundation

40-44 Eglantine Avenue

Belfast BT9 6DX

Telephone: **0800 783 3339** (helpline)

Telephone: **028 9066 3281** (admin)

Email: info@ulstercancer.org

www.ulstercancer.org

Provides a cancer information helpline, information and resource centre, public and professional education. Rehabilitation programmes and support groups for patients and relatives.

General organisations

Scotland

Tak Tent Cancer Support Scotland

Flat 5, 30 Shelley Court,

Gartnavel Complex

Glasgow G12 0YN

Telephone: **0141 211 0122**

(resource/information centre)

Email: tak.tent@care4free.net

www.taktent.org.uk

Offers information, support, education and care for cancer patients, their relatives and friends, and health professionals. Details of support groups throughout Scotland.

Wales

Tenovus, the cancer charity

43 The Parade

Cardiff CF24 3AB

Telephone: **02920 482 000**

Freephone helpline: **0808 808 10 10**

www.tenovus.com

Provides an information service on all aspects of cancer, and practical and emotional support for cancer patients and their families. Freephone Cancer Helpline staffed by nurses, social workers and counsellors.

Irish Cancer Support

www.cancer.ie/support/

Irish cancer website, with numerous links to support and information.

NHS Direct

Telephone: **0845 46 47**

www.nhsdirect.nhs.uk/

Information and advice on all aspects of health and treatment for people in England and Wales including a 24 hour telephone line, run by nurses.

Patient UK

The Patient UK website offers health information as provided by GPs to patients during consultations. It also has a list of patient support organisations, self help groups, health and disease information providers, etc.

www.patient.co.uk

“ It’s a long, bumpy journey but one in which you will get through and one which there will be a light at the end. There are no words that can take the pain and anguish away but hopefully the thought of family and loved ones can be the support to help pull you through. ”
S.F.



Resources...

For further information and support on male cancer, please visit the Orchid website at www.orchid-cancer.org.uk or call 0203 465 5766.

Orchid has produced a series of leaflets and Factsheets on specific issues relating to male cancer. You may find the following helpful:

- ▶ Testicular Cancer and Your Fertility
- ▶ HIV and Testicular Cancer
- ▶ Prostate Cancer: The Familial Link
- ▶ Prostate Cancer: The Big Question
- ▶ Diet: Vitamin D and Prostate Cancer
- ▶ Hereditary Prostate Cancer
- ▶ Diet and Lifestyle

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
April 2012

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

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.



ORCHID

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