

***Useful Information Sources***

***For Patients with Testicular Cancer***

This is a directory of publicly available website sources of information from various sources including cancer charity organisations. We have compiled it to help you in accessing relevant information relating to Testicular Germ Cell Cancer. Following a testicular cancer diagnosis you may have particular information needs to help you understand, and assist you in making informed choices with your care.

For example, you may want to increase your understanding of testicular cancer, or want to look at possible treatment options. Or you may want to know how your diagnosis and treatment may affect your lifestyle, or perhaps you have a specific enquiry you would like to explore. We hope this directory will aid your quest for information.

The Testicular Germ Cell Cancer Team at the Beatson West of Scotland Cancer Centre have reviewed a range of publicly available sources of information on testicular cancer using a Quality Assessment Information Tool. This tool requires review of the information relevance, content, accuracy, URL (web address) links to reputable information, intended audience, format, evidence, currency, and external links.

The websites selected where taken from the top search list in ‘Google’ which lists sites according to those most accessed. Whilst we hope you find them useful, the Beatson Cancer Centre and our team are not responsible for the contents or reliability of any of the external websites.

**Please be aware the information you may choose to access in these websites in your own independent enquiry is generalised. Please also note, that whilst our staff have assessed these information sources for quality as described above, we cannot recommend any one site above the other. For specific information relating to ‘your’ particular circumstances you should always be guided by your specialist oncology doctor, nurse specialist or GP for guidance relating to your specific health care needs.**

***Organisation*** – Macmillan Cancer Support

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

***Comments*** – This is a comprehensive cancer resource service provided by Macmillan Cancer Support which is a UK national charity organisation. You can enter this site and select ‘Testicular Cancer’ from the ‘Cancer types’ drop down menu from the ‘Cancer information’ section. Within the testicular cancer section there is information discussing-

* Testicular cancer – The Testicles, What is cancer? Types of testicular cancer, and Causes of testicular cancer.
* Symptoms and Diagnosis – Testicular Self Examination, symptoms, diagnosis, further tests, tumour markers and staging.
* Treating testicular cancer – overview of benefits and disadvantages of treating testicular cancer including surgery, surveillance, and further treatment with chemotherapy, radiotherapy and research. The information relating to BEP chemotherapy which is a regimen most often used in treating testicular cancer can be selected by clicking on ‘treatment types’ then select chemotherapy, then select combination regimens and select BEP chemotherapy.
* Living with testicular cancer – Follow- Up after treatment, sexuality and fertility advice, sperm storage, after effects of treatment, living after cancer.
* Further resources – Reference list of information and organisations

The Macmillan website has a very useful employment and financial advice section. This discusses subjects such as employment and returning to work after cancer, disability discrimination act, to comprehensive benefits and financial advice, plus advice on insurance issues.

***Format*** – Website and phone line (0800-808-0000). URL links to reputable organisations. You can print of information from the website and request free booklets and fact sheets.

***Target Audience*** –Publicly available – no restrictions, Professional Groups.

***Accessibility*** – No restrictions

***Last Update Date*** – Aug 2012

***Organisation*** – Cancer Research UK

***URL*** – [www.cancerresearch.uk.org](http://www.cancerresearch.uk.org)

***Comments*** - This is a comprehensive cancer resource service provided by Cancer Research UK which is a national charity organisation. You can enter this site and select ‘about cancer’ you are then asked to select ‘more’ and then select ‘your cancer type’ from the drop down menu. This opens the testicular cancer section which discusses –

* About testicular cancer – testicles, types, symptoms, self examination, seeing a specialist. The printable leaflet on ‘testicular self examination’ is recommended.
* Diagnosing testicular cancer – tests, further tests, ‘what to ask?’ (this highlights commonly asked questions from a patients point of view)
* Treating testicular cancer – stages, outlook and statistics, treatment types including surgery, chemotherapy, and radiotherapy. A criticism of this section is it does not discuss the treatment option of ‘surveillance’ which is recommended in stage 1 low risk testicular cancer following ‘orchidectomy’ (surgical removal of a testicle). Surveillance is however discussed in the Beatson Cancer Centre leaflet ‘Testicular Germ Cell Cancer Explained’. Some other websites also discuss surveillance.
* Testicular cancer – Clinical Trials. This is a particularly useful section on UK and international testicular cancer trials which are currently open or closed to recruitment.
* Living with testicular cancer – coping, practical issues, sexuality and fertility advice.

***Format*** – Website and phone line (0800-800-4040). URL Links to reputable organisations. You can print off information from the website and request free booklets and fact sheets.

***Target Audience*** - Publicly available – no restrictions, Professional Groups

***Accessibility*** - No restrictions

***Last Update Date*** – Feb 2012

***Organisation*** – Orchid Male Cancer Charity

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

***Comments*** – Orchid is a male cancer charity organisation based in London providing information on Testicular, Prostate and Penile Cancer. Their website provides a resource of information including interactive video clips, downloads, and a range of free leaflets, dvd’s and information available to order free of charge. When you enter the website to find out more information on testicular cancer, click on ‘about male cancer’. Then click on ‘testicular cancer’. You can also enter this sites testicular cancer micro site at ‘yourprivates.org.uk’. In this section you can read information relating to –

* Testicular Health
* Testicular cancer – signs and symptoms
* Testicular self examination – there is an excellent link to Channel 4 Embarrassing Bodies Programme which provides a step by step guide on how to examine your testicle.
* How it is diagnosed – seeing your GP, referral to urology specialist, testicular ultrasound, blood tests, chest x-ray, CT scan, stages of testicular cancer – explains if the cancer is confined to the testicle or it has spread to other areas of your body.
* How it is treated – type and stage of testicular cancer, brief information provided regarding orchidectomy (removal of testicle), chemotherapy, and radiotherapy.
* Post treatment information – effects on fertility, sex life, and your feelings.
* Testicular cancer and fertility – this is a very comprehensive section discussing treatment related effects on fertility and management options, including sperm storage.
* Read our stories – a useful section written by individuals who have been diagnosed with testicular cancer. You click on the guy’s name and there is a question and answer story of their cancer experience. It can be valuable to hear personal accounts and to know you are not alone.
* ‘Speak to our male cancer nurses’ – available to take telephone and email enquiries every Tuesday 9am-5.30pm.

***Format*** - Website. URL Links to reputable organisations. You can print of information from the website and request free booklets, DVDs, and fact sheets.

***Target Audience*** - Publicly available – no restrictions, Professional Groups

***Accessibility*** - No restrictions

***Last Update Date*** – Not stated

***Organisation*** – checkemlads. The Phil Morris and Mick Reilly Testicular Cancer awareness site

***URL*** – [www.checkemlads.com](http://www.checkemlads.com)

***Comments*** – Phil Morris and Mick Reilly are two men who have had testicular cancer and undergone surgery and chemotherapy. These men have created this website to provide the audience with information on testicular cancer from a patient perspective. You can click on individual personal stories as told by testicular cancer survivors who have posted their personal account onto the wall of ‘bollock lane’. This website is pro-active and aims to encourage men with a testicular cancer diagnosis. There are 7 sections of information within the webite –

* Section 1 – Comprehensive section on Testicular Self Examination.
* Section 2 – Testicular Cancer –explained from patient perspective.
* Section 3 – After testicular cancer
* Section 4 – Talk to testicular cancer survivors

***Format*** - Website. URL Links to reputable organisations.

***Target Audience*** - Publicly available.

***Accessibility*** - No restrictions

***Last Update Date*** – 2012

***Organisation -*** [Testicular Cancer - NHS Choices](http://www.nhs.uk/Conditions/Cancer-of-the-testicle)

***URL -*** [www.**nhs**.uk/Conditions/**Cancer**-of-the-**testicle**](http://www.nhs.uk/Conditions/Cancer-of-the-testicle)

***Comments*** This is a reputable quality assured government website produced by the NHS in England and Wales which has comprehensive information on testicular cancer. You can enter direct to testicular cancer information using the URL address above. The website also has a list of ‘links’ to other information about testicular problems not cancer related and ‘external links’ to related websites with testicular cancer information. You can also login and register with the website to post your own comments if you want. There are 7 sections of testicular cancer information.

* Overview Testicular cancer – symptoms, causes, diagnosis, treatment, prevention.
* Lifestyle – Support information including social support and support for carers.
* Real Stories – two patients’ real life experience with testicular cancer.
* Map of medicine – this section is not available outside England and Wales as the website licence is for clinical information in these areas only.
* Medicines information – list of drugs used to treat testicular cancer which is licensed and available in the UK. You can click on each drug for specific information.
* Clinical Trials – This is a list of clinical trials in testicular cancer registered with the International Clinical Trials Registry. The list tells you where the trial originates and if the trial is open to recruitment or closed.
* Community – You have to register and login to the website to look at ‘questions’ and ‘blogs’ posted by members of the public. This section is a general cancer community section and not testicular cancer specific.

***Format*** - Website. URL Links to reputable organisations.

***Target Audience*** - Publicly available. Men with testicular cancer.

***Accessibility*** - No restrictions.

***Last Update Date*** – 24 Apr 2012.

*Cached*You +1'd this publicly. Un***Organisation*** – Testicular Cancer Resource Centre (TCRC).

***URL*** – [www.tcrc.acor.org](http://www.tcrc.acor.org).

***Comments*** – This website is American and offers comprehensive coverage of testicular cancer. There are 2 main sections – General Information and Support, and Specific testing and treatment information. It is important to remember when reading information from this website, that as it is American, the recommended treatment strategies are different from what is considered best practice in Scotland, the UK and parts of Europe. So as we explained at the start of this leaflet always check specific issues or questions with your Beatson Oncologist or Specialist Nurse.

However the information is very detailed and the website is well structured and resourced. Particular areas of strength in this website are the sections on surveillance stage 1 disease treatment options, chemotherapy section, TCRC glossary and search engine. You can type a search word in to the TCRC search engine box.

General info section –

* Testicular self examination
* The testicular cancer primer
* TC-Net – email support group plus individual expert contact list.
* The testicle.
* TCRC Dictionary – Glossary of terms.
* Questions to ask?
* TC Link and Articles – Virtual Library.
* TCRC – search the TCRC – search engine where you can enter one specific word to narrow your specific enquiry.

Treatment Information section –

* The orchidectomy.
* The pathology report.
* Staging – comprehensive information on TNM staging and IGCCCG prognostic staging classification used by health professionals.
* Surveillance.
* Chemotherapy.
* Radiotherapy.
* RPLND Surgery – Retro Peritoneal Lymph Node Dissection
* Life after treatment
* Follow-Up.

***Format*** - Website. URL Links to reputable organisations.

***Target Audience*** - Publicly available. Men with testicular cancer.

***Accessibility*** - No restrictions

***Last Update Date*** – Feb 2008 and Sept 2010.

***Organisation -* click4tic**

***URL*** – [www.click4tic.org.uk](http://www.click4tic.org.uk)

***Comments*** – click4tic is a cancer information website from Macmillan Cancer Support which provides age appropriate information for teenagers and young adults with cancer. Macmillan ensure that all information is reviewed by expert advisors prior to publication

There is no other similar resource providing age appropriate information. However this resource is more suited to the younger teenage group. The website covers many topics in relation to cancer, treatment, side effects and includes a specific section dedicated to testicular cancer.

The information within the website provides practical advice and hints and tips to help you cope with your illness. You can join their online community and share your experiences with others. There is also a section to help your friends and family understand what is happening to you and what you’re dealing with.

***Format*** - Website. URL Links to reputable organisations. You can print of information from the website and request free booklets, DVDs, and fact sheets.

***Target Audience*** - Publicly available – Teenage and young adults with cancer.

***Accessibility*** - No restrictions

***Last Update Date*** – June 2012

***Organisation*** – LIVE**STRONG**

***URL*** – [www.livestrong.org](http://www.livestrong.org)

***Comment*** –

At age 25, Lance Armstrong’s doctors told him he had cancer. The diagnosis was testicular cancer. During his treatment he created the Lance Armstrong Foundation, now known as LIVE**STRONG.**

The livestrong website is American based, with a resource section to organisations in America. There is also an online shop where items are priced in dollars and can be shipped. However LAF has lots of potentially useful information, with reputable links to other credible sources of information. The livestrong foundation also has a lot of information for people who are cancer survivors, and attempts to inspire people to be pro-active in recovering from and living with cancer.

There is information on

* Physical, emotional, practical, and support needs with cancer.
* Livestrong Guidebook - information and fact sheets.
* Survivor interview video clips.
* Survivor caregiver video clips.
* Employment, insurance, and financial advice.

***Format*** - Website. You can print off information from the website and shop online for livestrong products. Non UK Links to American Organisations.

***Target Audience*** - Publicly available.

***Accessibility*** - No restrictions.

***Last Update Date*** – Nov 2010.

***Organisation*** – National Cancer Institute

***URL*** – [www.cancer.gov](http://www.cancer.gov) National Cancer Institute

***Comments*** – This is an American Website which is comprehensive with information relating to testicular cancer. Initially when you visit this website you select ‘All Cancer Types’ , then select ‘A-Z list of cancers’, then select ‘T’, and then select ‘Testicular Cancer’. When you reach this destination you can select comprehensive information specific to testicular cancer.

This site could be useful to men who have high information needs. There are reputable links to other sources of information, and particular strengths of this site relate to the information on staging, screening and treatment modalities in testicular cancer. However, it is important to remember the information is American based, and therefore there are differences in treatment recommendations compared with Scotland, UK and parts of Europe. Again, as we have said earlier it’s important to discuss any questions about this with your own oncologist and nurse specialist. Some of the information is aimed at the health care professional.

Information is available on –

* Treatment of testicular cancer – surgery, chemotherapy, radiotherapy, testicular cancer drugs, and treating testicular cancer which has spread. This is known as metastatic testicular cancer.
* Prevention, genetics and causes of testicular cancer.
* Screening and tests involved in testicular cancer.
* Clinical Trials in testicular cancer.
* Testicular cancer statistics – these are American.
* Cancer Literature – in PubMed Database.

***Format*** - Website. URL links to other organisations. You can print information from site.

***Target Audience*** - Publicly available.

***Accessibility*** - No restrictions.

***Last Update Date*** – Jan 2013.

***Organisation*** - Scottish Intercollegiate Guideline Network (SIGN) 124. Management of adult testicular germ cell tumours. A national clinical guideline.

***URL*** – [www.sign.ac.uk](http://www.sign.ac.uk).

***Comments*** – SIGN Guideline, number 124 ‘management of adult testicular germ cell tumours’ are produced to provide Health Care Professionals with recommendations, based on current evidence for best practice in the management of testicular cancer. The SIGN Network is part of NHS Health Improvement Scotland. Production of guidelines involves the guideline development group to review research findings, to establish best practice recommendations to manage testicular cancer. The guideline development group consists of Doctors, Nurses and Patient Representatives from Scotland. The Guideline is valid for 3 years from publication.

SIGN 124 guideline is comprehensive and intended for healthcare professionals. However this publication may be of interest to patients and people with high information needs. The guideline includes a list of network members involved in creating the guideline. There is also an abbreviation list, and you can print the guideline in PDF format.

***Format*** - Website. You can print guideline and request paper copy of the guideline.

***Target Audience*** – Healthcare Professionals. Anyone involved with testicular cancer. May be of interest to patients. Publicly available.

***Accessibility*** - No restrictions.

***Last Update Date*** – March 2011.

***Organisation –*** Cahonas Scotland - Male Cancer Awareness Charity.

***URL –*** www.tartanchecks.org

***Comments –*** Cahonas Scotland is a registered charity who have launched a new campaign ‘what’s under your kilt’ and website to highlight the importance of early detection of Testicular Cancer. This new website offers a step by step guide to testicular self examination and information downloads to website visitors seeking advice. The website does not offer any information if you have been diagnosed with testicular cancer.

***Format*** - Website. .

***Target Audience*** – Publicly available.

***Accessibility*** - No restrictions.

***Last Update Date*** – August 2013.

***Maggie’s Glasgow Maggie’s Glasgow***

***The Gatehouse Gartnaval***

***Western Infirmary Gartnaval General Hospital***

***10 Dumbarton Road 1053 Great Western Road***

***Glasgow Glasgow***

***G11 6PA G12 0YN***

***Telephone: 0141-330-3311 Telephone: 0141-357-2269***

***Email*** [***Glasgow@maggiescentre.org***](mailto:Glasgow@maggiescentre.org)

The Maggie’s Centre provides free cancer support programmes for patients and relatives living with and coping with cancer. Open Monday-Friday 9am-5pm. Services available include Benefits Advice, Nutritional Workshops, Support Groups, Living with cancer programme, Stress Reduction and Relaxation Techniques, Networking Groups for teenagers and young adults with Cancer, Yoga and Tai Chi. Drop in or email welcome.

***Macmillan Cancer Support***

***Cancer Care Line: 0808-808-0000 - Mon-Fri 9am-8pm.***

Macmillan is a charitable organisation which provides a range of support concerning emotional and practical aspects of living with cancer. They offer a ‘*Listening Ear’* Service, Advice Service, and can assist with informing you of what specific ‘Financial Help’ may be available if you have a cancer diagnosis. They also provide support groups in the physical form and have online forums. The support groups and online forums are not specific to people with Testicular Cancer; they are open to any cancer type.

***Cancer Support Scotland “tak tent”***

**The Calman Cancer Support Centre**

**Cancer Support Scotland Tak Tent**

**Gartnaval Hospital Complex**

**Free phone 0800 652 4531 or Telephone 0141-337 8199**

**Email –** [**taktent@gmail.com**](mailto:taktent@gmail.com)

**URL –** [**www.cancersupportscotland.org**](http://www.cancersupportscotland.org)

Tak Tent is a charity organisation offering services such as counselling, complementary therapies, and tak tent support group meetings (not testicular cancer specific). You can self refer and make contact via phone, email, or website. There are no set fees for counselling or complimentary treatments, payment is with donation to Cancer Support Scotland**.**

**Human Fertilisation and Embryology Authority**

[www.hfea.gov.uk](http://www.hfea.gov.uk)

This site provides useful information relating to guidance on sperm storage, and specialist fertility clinics / treatments.

This information resource was produced by The Beatson West of Scotland Cancer Centre, Germ Cell Team.

Created July 2013

Review Date – July 2015

QA Edit and Approved by L. Webster Feb 2013