



# How can the internet help us?

A GUIDE TO CHILDHOOD CANCER RESOURCES ONLINE



**The internet is a rapidly growing source of information, some of it good and some of it not so good.**

**To help you find information on cancer care and treatment for young people and children that is reliable and user-friendly, the Children's Cancer and Leukaemia Group (CCLG) has produced this leaflet.**

**The internet provides information, support and help. Use it sensibly.**



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## What does the internet offer?

- It allows you to gain knowledge, to research your child's condition and to explore treatment options while learning what to expect. It also provides information about the medicine your child will be taking and possible side effects.
- It enables you to gain help and support from charities and organisations.
- It provides a means of communication. If you need to update family and friends on your child's condition, you can create a blog, send emails or access a Facebook page.
- Your child may be old enough to use the internet to feel connected with their friends through Facebook and other social networking sites.
- There are also sites designed for young people to enable them to communicate with others undergoing similar treatment; they can learn about their condition and feel less isolated.

## Be careful, be aware and be informed

The websites recommended here cover all aspects of cancer information and care: helpful tips for parents and children on coping with treatment, research, clinical trials, support groups, help lines, blogs, message boards, charities, holiday opportunities, and much more.

All of them have links that instantly connect you with other sites of interest. The number and range of these is enormous.

Many of the websites and all of the major cancer charity sites, also provide information booklets and leaflets that can be ordered online (mostly free of charge) or downloaded from the site. The CCLG website has a lot of leaflets and information that can be downloaded.

There are many sites on the internet giving advice and information on cancer care and treatment. Not all of these have the input or support from qualified sources. Some information can be misleading and identifying the good from the bad can be challenging.

Use our 'be careful, be aware' checklist:

- Who wrote the information – doctors, therapists, non-medics, etc? When reading personal accounts (testimonies) remember that every case is different.
- When it was last updated – is the information out of date?
- Evidence for any medical claims – are they backed up by properly regulated research?
- Feedback and contact information – are you communicating with specialists or private individuals? Remember always refer questions back to your child's consultant or care team.
- Is the information about childhood or adult cancers? Treatment for cancer in an adult is very different from that for a child even for the same type of cancer, for example, leukaemia. So make sure the information you are sourcing is specifically about the treatment of children.
- Is the site trying to sell you something? Is the website sponsored by a company or individual trying to get you to use a particular product or service?
- Where is the website located? There are a lot of US websites about cancer and cancer care. Children are treated differently, sometimes completely differently in other countries even when they have exactly the same type of cancer. It can be tempting to use the internet to search for second opinions or alternative treatment from overseas.  
**Be aware that there will be other treatments out there but just because a treatment or protocol is *different* does not make it better.**
- Is the site a blog, or is it a page on an established cancer charity website? One person's experience that has been posted on a blog can vary from your child's experience significantly.

To ensure your child is safe when using the internet, be involved and help them understand the potential dangers, especially if accessing chatrooms. Talk to them about the type of websites you think are suitable and be aware of the information they may be accessing about their condition.

# WEBSITES FOR PARENTS

## INFORMATION OVERLOAD

You may find that you gather so much information that instead of helping to make things clearer, more questions are raised than answered. **At this point you should always refer back to your child's consultant or care team with any queries relating to the information you have found.** They are the only ones who know all aspects of your child's diagnosis, care and treatment.

### CLIC Sargent

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

A very informative and useful website covering all aspects of caring for young people with cancer, and for their families. It also contains detailed regional information about the facilities of all specialist and shared-care hospitals, including travel information.

### Children's Cancer and Leukaemia Group

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

This site has comprehensive information on clinical trials and the frequently asked questions about them. It also has guides for parents and children that can be downloaded and useful links for support groups, charities and hospices.

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

This site has a range of CCLG publications for all family members and teachers which can be downloaded from the site.

### Cancer information - We Are Macmillan

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

Macmillan provide high quality, up-to-date cancer information for cancer patients, their families and carers. All of their information is written and reviewed by specialists.

### CancerHelp UK

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

CancerHelp UK is Cancer Research UK's patient information website with comprehensive, free, information about cancer and coping with cancer. The information is specifically written for people with cancer and their families and is reassuring, sensitive and easy to understand. It has information about children's cancers, treatments and coping with cancer, as well as a unique database of UK cancer clinical trials, written in plain English.

### Leukaemia Care

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

Has easy access to a large range of information booklets that can be ordered by phone, and medical information that can be downloaded online.

## NHS Choices

[www.nhs.uk/Conditions/Cancer/Pages/News.aspx](http://www.nhs.uk/Conditions/Cancer/Pages/News.aspx)

This site has a 'Health A-Z' index which provides information on many different types of cancer along with useful links. It also has a helpful breakdown of all medicines used in cancer treatment, news items and clinical trials.

## US websites

### Teens Living with Cancer

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

This US site offers information on dealing with cancer, body issues, school, nutrition advice, dealing with family and friends. They also have an online community for teens with cancer to share information and support each other. Comprehensive and user friendly. Plenty of useful links. Teens Living with Cancer is supported by Melissa's Living Legacy.

### The Ulman Cancer Fund for Young Adults

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

This site aims to enhance lives by supporting, educating and connecting young adults and their loved ones, affected by cancer. Cancer patients and caregivers are able to create free, customized websites with the aim to enable patients to build an online support community.

### Starlight Children's Foundation

[chemo.starlight.org](http://chemo.starlight.org)

Vibrant, well put together site. Coping with Chemo is a series of webisodes written by teens with cancer to help other teens dealing with cancer. Each webisode addresses a different topic - getting diagnosed with cancer, side effects of chemotherapy and other treatments, telling your friends and celebrating your last treatment. Coping with Chemo also has an FAQ resource section to answer many of the questions you, your friends and family may have. Also provides an online social network community with lots of resources and links.



# WEBSITES FOR YOUNG PEOPLE AND CHILDREN



## CLIC Sargent

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

Offers many sections on cancer, including treatment and side effects and services available for young people. This is a comprehensive site containing a lot of useful information on childhood cancer plus the services they offer.

## Trekstock

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

Trekstock engages with young people by fundraising through fashion and music and donates its profits to Cancer Research UK's research into cancers that affect children and teenagers. Trekstock aims to raise awareness of cancer in young people, ensure young people with cancer get the information they need about their disease and raise money to help fund specific research into the cancers which specifically affect this age group.

## Captain Chemo

[www.royalmarsden.org/captchemo](http://www.royalmarsden.org/captchemo)

This is a really good website, with clear and detailed information, for children and young people. The site is easy to navigate and on every page there are option buttons for children to switch between accessing information in simpler detail and language for younger children or a more detailed level for teenagers. Based on the cartoon Adventures of Captain Chemo and Chemo Command, it also offers quizzes and interactive games.

## Click 4 Tic

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

The Teen Info on Cancer site (sponsored by Macmillan Cancer Support). Under headings of - Understand it, Deal with it, Share it - this site covers basic info and also has a message board for communicating with other young people as well as emailing questions to medical professionals. Good links to other worldwide teenage support sites.

## Teenage Cancer Trust

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

An excellent site offering information, advice and support with useful links and message boards. Comprehensive information which aims to empower young people in dealing with their cancer and treatment.



### Jimmy Teens TV

[www.jimmyteens.tv](http://www.jimmyteens.tv)

This is an information sharing site for teenagers with news, blogs and videos recorded by young people having treatment. This site is sponsored by the Teenage Cancer Trust.

### CCLG

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

This site has a section for children and young people which offers a number of booklets and leaflets written specially for them. There are also booklets and leaflets to help the brothers, sisters and friends of young people with cancer. Also offers on-line copies of *Contact* magazine. It is produced by the Children's Cancer and Leukaemia Group. There are also free downloadable resources for parents, siblings, grandparents and teachers.

### After Cure

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

There are now over 20,000 adult survivors of childhood cancer in the UK alone. This website and booklet has been produced to help answer some questions young people might have and explain why they may still need to be followed up.

### Macmillan Youthline

[www.cancertalk.org.uk/support/youthline.html](http://www.cancertalk.org.uk/support/youthline.html)

A helpline for young people between 12 and 21 years old.  
Telephone - 0808 808 0800  
Mon to Friday, 9-am -10pm  
Email: [youthline@macmillan.org.uk](mailto:youthline@macmillan.org.uk)

This site also has discussion forums and links to further information on the Macmillan website.

### Headstrong - All about brain tumours

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

An excellent website for children and young people diagnosed with brain tumours, providing information on treatment, as well as games and top tips on how to cope.

**Please note this is a selection of the most useful and relevant websites specifically for childhood cancers. The list of sites on this leaflet has been approved by CCLG as of December 2010.**



*Any new sites of interest that are created after this date will be published on the CCLG website [childcancer.org.uk](http://childcancer.org.uk).*



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