

How can the internet help us?

A guide for parents and families using online childhood cancer information



The internet is a vast source of knowledge which can give information, support and help to parents and children with cancer. However, the information on some websites may not be reliable or trustworthy. This factsheet offers advice and tips on using the internet while searching for childhood cancer information.

What does the internet offer?

- You can gain knowledge, research your child's condition and explore treatment options and what to expect. It also provides information about the medicines your child will be taking and possible side effects.
- You can gain help and support from charities and other organisations.
- Some families decide to start fundraising online to raise awareness and funds using sites such as JustGiving, Virgin Moneygiving and Twitter to get their message across. In rare cases, some families decide to start fundraising online for treatment abroad but this may be unnecessary so please discuss with your child's consultant first.
- It offers an easy way of communicating with others. For example, if you need to update family and friends on your child's

condition then you can create a blog, send emails or post on social media.

- You can connect with other parents, families and young people who are in a similar situation helping you to feel less isolated.
- Your child can use the internet to chat with their friends through social networks or Facetime and Skype while on treatment.

Social networks, online communities and blogs

Social media is an excellent way to keep in touch. Sites such as Facebook and Twitter allow you to connect with others, share updates and build friendships. However, they are less likely to be factual or offer scientific information. Online communities via charities such as Macmillan Cancer Support can be a lifeline for those who want to chat about specific issues with others across the UK. Writing a blog on different aspects of life or responding to someone else's blog may also allow you to connect with others. All of the above can offer help, comfort and support from others in a similar situation. They can also reduce isolation for patients by allowing them to easily connect with their friends and to still feel part of their peer group.

Finding reliable and accurate information

Websites can cover all aspects of cancer information and care such as helpful tips for parents and children on coping with treatment, research, clinical trials, support groups, blogs, forums, charities, holiday opportunities, and much more. Some of them will have links to other sites of interest which may be useful. Many websites will give advice and information on cancer care and treatment, but 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. Our checklist can help you to do this.

The Information Standard

The Information Standard is a national quality accreditation scheme. Any websites and resources displaying the Information Standard logo have undergone a rigorous assessment to check that the information produced is clear, accurate, balanced, evidence-based and up to date.

Child safety online

To ensure your child is safe when using the internet, be involved and help them to understand the potential dangers of using social media sites. 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.

Be Careful - Be Aware checklist

- Who wrote the information - doctors, therapists, non-medics, etc? Has it been approved by a clinical expert? Is it unbiased? When reading personal accounts (testimonies) remember that every case is different.
- When was it last updated? Is the information out of date? Is it reviewed and updated regularly?
- Consider the evidence for any medical claims - are they backed up by properly regulated research? The most accurate evidence is published in a well-respected peer-reviewed academic research journal.
- Check the 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. The treatment your child will receive is what experts believe is the best currently available treatment based on research.**
- Is the site a blog, or is it a page on an established charity website? One person's experience posted on a blog can vary from your child's experience significantly.
- Be aware that other people's blogs or social media posts may not be factually accurate.
- To stay safe, ensure you are protected online by using the privacy settings on social networking sites. This will limit the potential impact of 'trolls'.
- While some teenagers may want to check what their friends are doing on social networks, others can find it upsetting to see what they are missing out on and so increase feelings of isolation.

Visit www.thinkuknow.co.uk (a National Crime Agency website) for helpful information about staying safe online.



Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent, others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Children's Cancer and Leukaemia Group (CCLG)

cclg.org.uk

Contains patient information and useful links for parents who have a child with cancer.

Child Brain Injury Trust

childbraininjurytrust.org

Offers practical information on brain tumours.

CLIC Sargent

clicsargent.org.uk

Provides a variety of support to children with cancer and their families including information and online forums.

Cancer Research UK

cancerhelp.org.uk

Contains patient information on all types of cancer, cancer statistics and has a clinical trials database.

Health Talk Online

healthtalkonline.org

youthhealthtalk.org (for young people)

Both websites contain information about cancer and have video and audio clips of people talking about their experiences.

Jimmy Teens

jimmyteens.tv

Offers a valuable resource of short films from young people with cancer.

Leukaemia & Lymphoma Research

leukaemialymphomaresearch.org.uk

Contains patient information on blood cancers and offers support.

Macmillan Cancer Support

macmillan.org.uk

Provides patient information and has active online communities.

NHS Choices

nhs.uk

The UK's biggest health website.

Patient UK

patient.co.uk

Provides information about health and disease.

Teenage Cancer Trust

teenagecancertrust.org

Provides information and support for teenagers with cancer.

The Brain Tumour Charity

thebraintumourcharity.org

Offers patient information about brain tumours and provides help and support.

Information overload

By searching online, you may find that more questions are raised than answered. It is important to address any questions with your child's consultant - they are the only one who knows about your child's diagnosis and treatment plan.

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CCLG makes every effort to ensure that information provided is accurate and up-to-date at time of printing. We do not accept responsibility for information provided by third parties.

Information in this factsheet should be used to supplement appropriate professional or other advice specific to your circumstances.



The CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

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