The Children &
Young People's
Cancer Association

Searching for information and support online

Help and advice for parents, carers and families of children and young people with cancer

When you are told your child has cancer, life turns upside down in an instant. You can be left feeling shock, fear and confusion, while questions can run through your mind day and night. For many people, searching online is the first choice to find quick and easy answers. Online communities may also be a source of hope, comfort and reassurance from others who have faced the same journey.

The amount of information online can be overwhelming, and sometimes conflicting, causing even more worry and stress. It is important to make sure that information you gather is from reliable and easy to understand sources. There are many websites that give detailed information about cancer types, symptoms and treatments. These can be a useful starting point.

Remember that information may not always apply to your child's individual diagnosis and should not take the place of advice from your child's hospital team.

Should I search online?

It is a personal choice, there is no right or wrong.

Some people want to avoid looking online. They may not want to be distracted or worried by information that doesn't apply to their child. They may not trust what they read, and are reassured that their child's hospital team gives them all the information they need. They may finding going online confusing and stressful.

Other people want further background and context to the information they already have. It can help them to feel more in control of what is happening, and feel better informed and equipped to play an active part in their child's treatment and care at home. It can help them to feel less lonely and isolated by reading about other patients' and families' experiences.

Be aware of information overload. Take a step back, breathe and try to distract yourself for a while to help gain perspective again. If you feel overloaded, it's a good idea to talk to your child's team. They will help sift through the information with you to make things clearer in your mind and more relevant to your child.

Be careful, be aware

Information is not always what it seems. We've put together below some things to bear in mind when searching.

Will my child survive? What are the statistics?

It is tempting to search for survival rates. But it is important to remember that these are general statistics – they do not tell you what will happen to your child. This is because there are so many factors that are unique to your child, including how the cancer is behaving in their body and how their body reacts to the cancer and the treatment. Your child's doctor can give more specific information relevant to your child's diagnosis.

Visit **www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers** to find accurate statistics.

What else is out there? Is my child getting the best treatment?

Information about experimental treatments, complementary therapies and claims for cure can be misleading and make false claims. These range from supplements and diets to treatment overseas, all of which can be expensive and are not based on scientific evidence. Sadly, these can create false hope and cost parents time and money, as well as causing stress and anxiety.

A new anti-cancer diet or supplement (usually a plant extract/vitamin mix) may be harmful or even interfere with your child's treatment – always check with your child's doctor or pharmacist before making any changes.

What's the latest research?

Headlines about research are often based on promising early trials or results in the lab where it is too early to know whether the treatment works in practice. Research shows each person's cancer is unique and the same type of cancer may behave differently in another person. This is why one single cure for cancer is unlikely.

Talking to your doctor about information you find online

Don't worry that your child's doctor will be offended if you turn up with a list of questions about things you have found out online. They will take you seriously and give you honest, balanced advice based your child's individual diagnosis. Your child's doctor knows your child's condition well and has access to networks of experts. They will tell you about any treatment developments and clinical trials that could help your child – they will be happy to explain anything to you.

Always remember that information online should not take the place of medical advice from your child's hospital team.

Online safety for children and young people

If your child or teenager has access to online information themselves, they may see the same things online as you. This can bring them comfort, or it may make them feel more anxious. Make sure your child has all of the right information appropriate for their age from you or their hospital team to lessen the risk of them searching alone. You can help them source trustworthy and accurate information for themselves by sharing our checklist with them.

Visit **www.nspcc.org.uk/keeping-children-safe/online-safety** for advice about online safety for children and young people.

Finding reliable information

It is important to know that what you are reading is reliable. Use this checklist to help you know whether information can be trusted.

How can I tell if information is accurate?
How do I know which information I can trust?

☑ **Who wrote it – doctors, therapists, journalists, families?**
Has it been written or approved by a clinical expert? Is it unbiased? When reading personal accounts, remember that they may not be factually accurate. Every case is different and some may not even be genuine. Check if there is a way to give feedback or to contact the publisher.

☑ **When was it last updated?**
Is it reviewed and updated regularly? PIF TICK recommends reviews take place every three years.

☑ **Does it have evidence for any medical claims or statistics?**
The most accurate evidence is published in a well-respected peer-reviewed academic research journal, and there should be a link to this research. References and sources of information should be detailed so that you can see where numbers are from. Look for medical evidence before spending money. If it sounds too good to be true, then it probably is.

☑ **Is it 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.

☑ **Is the website sponsored or trying to sell you something?**
Don't be pressurised into trying anything for free or buying a product or service online.

☑ **Where is the website located?**
Children are treated differently, sometimes completely differently, in other countries even when they have exactly the same type of cancer. 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 has in the UK is what experts believe is the best currently available treatment based on up-to-date research.

In the UK, seeing the PIF TICK logo on an information resource means it has met ten key checks, including that it is accurate, evidence-based, balanced, up-to-date and easy to read. The logo usually appears at the bottom of a webpage or on the cover of a printed resource.

Websites and publications providing trusted health information should have a date of publication, and show when the next review is due. PIF TICK guidelines recommend reviewing information every three years.

Trusted
Information
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Patient Information Forum

CCLG: The Children & Young People's Cancer Association's information is PIF TICK accredited. Our publications on a variety of topics relating to children and young people's cancer are available free of charge from your hospital or from our website.
www.cclg.org.uk/publications

Sources of trusted information

CCLG: The Children & Young People's Cancer Association
www.cclg.org.uk

Young Lives vs Cancer
www.younglivesvscancer.org.uk

Teenage Cancer Trust
www.teenagecancertrust.org

Cancer Research UK (CRUK)
www.cancerresearchuk.org

Macmillan Cancer Support
www.macmillan.org.uk

NHS
www.nhs.uk

PIF TICK
www.piftick.org.uk/finding-trusted-health-information

The Brain Tumour Charity
www.thebraintumourcharity.org

Blood Cancer UK
www.bloodcancer.org.uk

Bone Cancer Research Trust
www.bcrt.org.uk

Child Eye Cancer Trust
www.chect.org.uk

Kidney Cancer UK
www.kcuk.org.uk

Leukaemia Care
www.leukaemiacare.org.uk

Lymphoma Action
www.lymphoma-action.org.uk

Neuroblastoma UK
www.neuroblastoma.org.uk

Sarcoma UK
www.sarcoma.org.uk

Solving Kids Cancer
www.solvingkidscancer.org.uk

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Trusted Information Creator
Patient Information Forum

This factsheet was reviewed by the CCLG Information Advisory Group, comprising parents, survivors and multiprofessional experts in the field of children and young people's cancer.

We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care, and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Our work is funded by donations. If you would like to help, visit www.cclg.org.uk/donate or text '**CCLG**' to **70085** to donate **£3.** You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.

We want our information resources to be relevant and useful. Tell us what you think by scanning this code to complete a short survey or contact us at publications@cclg.org.uk