Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

www.cclg.org.uk ChildrensCLG CCLG_UK

Searching for information and support **online**

Help and advice for parents and families of children, teenagers and young adults 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 and questions can run through your mind day and night. For most people, searching the internet is usually the first choice to find quick and easy answers.

But the huge amount of information online can be overwhelming, and sometimes conflicting, causing even more worry and stress. It is important that parents make sure that health information is filtered and gathered from reliable, easy to understand sources.

As a parent or carer of a newly-diagnosed child, you may not feel confident when searching through cancer information. This leaflet offers advice and tips on where to start and what to look for.

In the days and weeks after diagnosis, parents and families can be left with many questions as the news sinks in.

Trying to make sense of what is happening can drive parents to look online for answers; find hope that their child and family will come through this experience; and comfort and reassurance from others who have faced the same journey.

Should I search online? I don´t know what I might find

It is a personal choice and there is no right or wrong answer to how you as parents might feel.

Some parents want to avoid looking online for many different reasons. They may not want to be distracted or worried by information that doesn't apply to their child. They may not trust everything they read and are reassured that their child's hospital team gives all the information they need.

Other parents want further background and context to the information they already have and want to look for online support. It can help them to:

- **Feel more in control** of what is happening and feel better equipped to play an active part in their child's treatment and care at home
- **Gain knowledge and advice** not only about childhood cancer but also about living and coping with cancer at home
- **Feel less lonely** and isolated by reading other patient and family experiences
- **Have a realistic understanding** of what might happen over the coming weeks
- **Feel more empowered** to make decisions about their child's health with their child's health team
- **Feel more confident** in talking to doctors by asking the questions that they want to know the answers to

Starting your **information journey**

At diagnosis, parents find that they begin an **information journey** where they may feel lost and confused with little knowledge about cancer. They may have general questions such as 'What is cancer?' and 'How is it treated?'.

As treatment progresses and time passes, information needs can become more targeted and specific such as 'What clinical trials are open?', 'What are the side effects of a particular drug?'

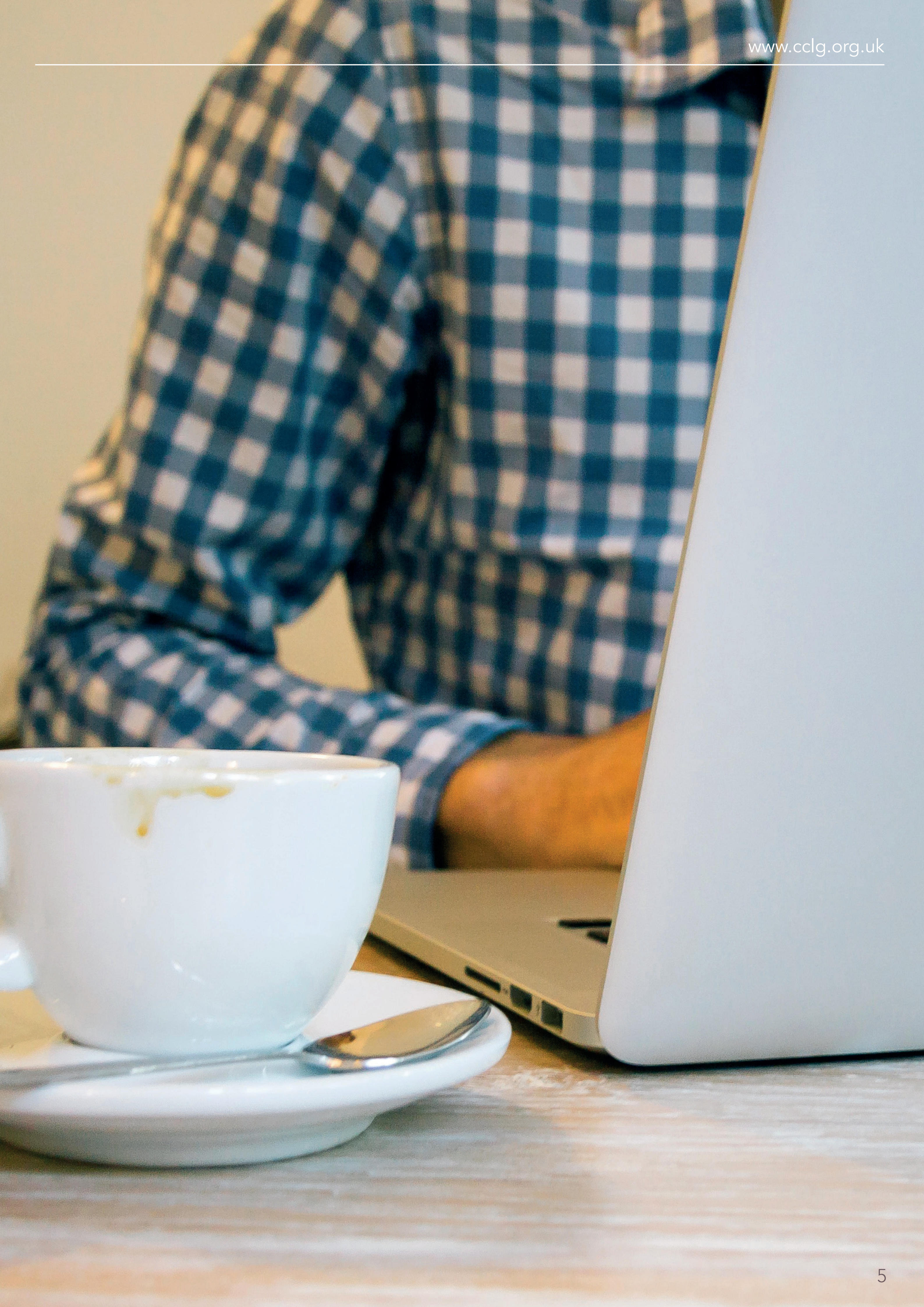
In time, parents often find that they become cancer 'experts' themselves after searching through vast amounts of information. This knowledge can help you talk to your child's doctor more effectively, helping you to ask questions and explain what issues are important to you as a parent.

! **Remember, the doctor is the expert in your child's cancer, but you are the expert in how it is affecting your child.**

"I can't stop googling for information"

It is sometimes tempting to constantly search online about your child's cancer, particularly in the middle of the night, but this can become very consuming and distracting. It can also fuel more worry and anxiety about things that might not even happen to your child. Having 'online downtime' and not going online for a day or two can be good so that you have a break from it from time to time. Many parents suggest that taking each hour and day as it comes rather than racing ahead is helpful.

If you find yourself becoming overloaded, it is a good idea to talk to your child's doctor and nurse who will help sift through the information with you to make things clearer in your mind and more relevant to your individual child.



What **information** do other parents search for online?

We list some common questions asked by other parents when searching online.

? What is cancer? What does having cancer mean? What causes cancer?

There are many websites that give detailed information about each type of cancer, symptoms and treatments (see page 11). They can give a useful starting point for parents and can fill in any information gaps they may have after talking to their child's hospital team. This information is generic and may not specifically apply to your child's individual diagnosis.

? Will my child survive?

This is one of the most commonly asked questions by parents but it is also the hardest one to answer. This is because there are so many factors to consider which are unique to your child: how the cancer is behaving in your child's body and how your child's body reacts to the cancer and treatment.

It is tempting to search for survival rates, statistics, and whether children of other families whose child had a similar diagnosis survived. But it is important to remember that these are general statistics covering all patients – they do not tell you what will happen to your individual child. Your child's doctor will be able to give more specific information relevant to your child's diagnosis.

If you wish to find out accurate statistics about children's cancer in the UK, please visit Cancer Research UK: www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers

Is my child getting the best treatment? What if I find something online that claims to cure my child's cancer? ?

While searching online, you will come across many things claiming to cure cancer ranging from diet supplements to experimental treatment overseas. Media headlines on cancer research can raise hopes about new cures and treatments but quite often the science behind the story is based on promising early trial results or results shown in the lab where it is far too early to know whether the treatment works yet in humans or in clinical practice.

Reports, adverts and online conversations about experimental or unproven treatments can also be misleading and give false claims for success. Such treatments are sold with cancer-free promises and patient stories in the hope that families will want to know more, but such treatments will usually be very expensive with no scientific evidence for their use. Sadly, such claims can create false hope costing parents' time, money, stress and energy.

A new anti-cancer diet or supplement (usually a plant extract/vitamin mix) may be harmful to your child's health or can even interfere with cancer treatment – please check with your child's doctor or pharmacist first.

Research shows each person's cancer is unique and even the same type of cancer may behave differently in another person's body. This is why one single cure is unlikely.

? Can I talk to my doctor about a cure I have found online?

Your child's doctor is the only one who knows your child's individual condition and will be in the best position to tell you about any real developments and discoveries in cancer medicine that could help your child – they will be more than happy to explain anything to you.

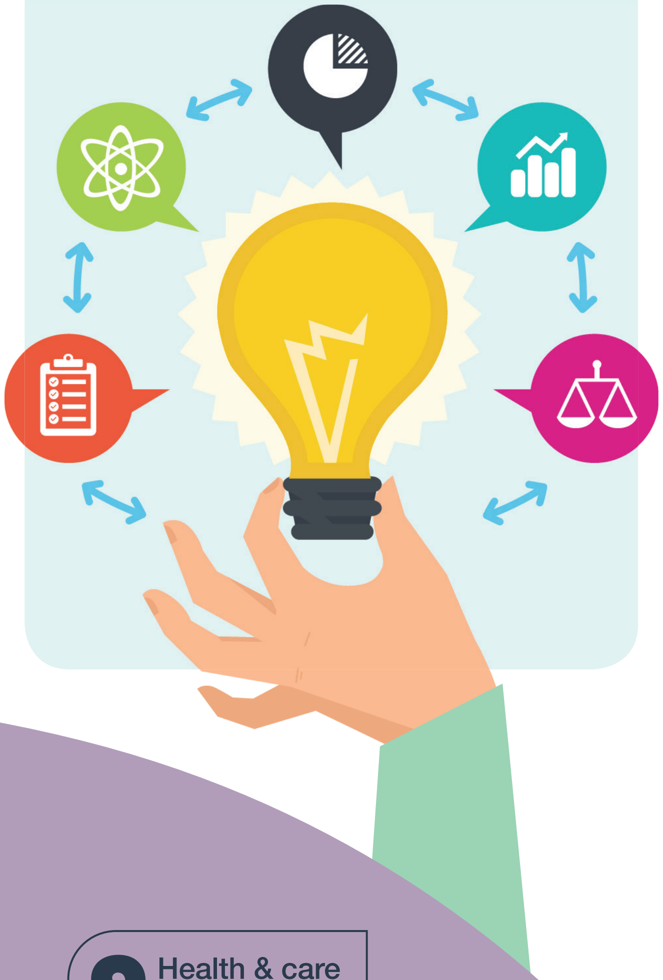
Don't worry that your child's doctor will be offended if you turn up with a list of questions about things you have found out online. They will take you seriously and give you honest, balanced advice based your child's individual diagnosis.

See our checklist for further help and advice when searching online. Always remember that information online should not take the place of medical advice from your child's hospital team.

CCLG childhood cancer **information hub**

www.cclg.org.uk/infohub

Accurate and relevant information at your fingertips



Finding **reliable** information

Health & care information you can trust
The Information Standard
Certified Member

In the UK, seeing the Information Standard logo on an information resource means it has undergone a rigorous assessment to check that it is clear, accurate, balanced, evidence-based and up-to-date. The logo usually appears at the bottom of a webpage or on the cover of a printed resource.

If an information resource has a date of publication and when the next review date is due, then this is a good indicator that the information is currently accurate and up-to-date.

Types of online **information** and **support**

Information type	Benefits	What to look out for
PDF downloads documents, information resources such as books or leaflets, research papers	Easy to print or read on screen Instant access	Check publication date, who wrote it, credentials of a qualified and reputable source
Web pages different sources including hospitals, charities, health organisations such as the NHS, general public	Large choice of information to answer most, if not all, general questions	Check the source and be aware of false information (see page 10)
YouTube videos and animations	Professional videos giving information about cancer and its treatment e.g. how a portacath is inserted Useful for sharing tips and advice, for example, coping with hair loss and make-up tips Many children love to watch videos for entertainments and some organisations have age-appropriate animations about cancer and its treatment	Check the reliability of sources. Be wary of videos from overseas where families sometimes use it as a platform to raise money for their child – the images can be upsetting. Make sure that animations and videos are age-appropriate for children and teenagers
Vlogs and blogs	Many cancer patients and parents create vlogs to tell their story Reassuring to read and watch for advice, support and knowing that others may have the same feelings as you do	It is one person's viewpoint and story and may not reflect the reality of your situation

Social media including Facebook and Instagram, online communities, chat rooms	Ideal way of keeping family and friends updated. Some parents find that posting a request asking for help with school runs, shopping and so on is very valuable. Option for posting anonymously, if preferred Connect with other parents, families and young people who are facing the same things you are Closed parent support groups on Facebook for parents of children with cancer offer a safe, comfortable and private space to share experiences, worries or fears with people in the same situation. This can help parents to feel less lonely and isolated. Such groups may be national, others might be local such as your child's cancer ward. Families also use social media to raise funds for something - whether a wish for your child, help with living costs or for a specific charity. Fundraising platforms such as Just Giving or Go Fund Me can link to social media. **Your child or teenager** can chat with friends through Facetime and social networks such as SnapChat and Instagram so they can still feel part of their friendship group	Social networks and online communities are less likely to be factual or offer scientific information Some people may pass along information that is limited or wrong Exposure to 'noise', bias or negative emotions from others that may affect how you feel so it is important to know when to step away Don't feel pressured to contribute to conversations or to donate money **For young people**, it can increase feelings of missing out, loneliness and being 'out of sync' with their friends

Be **careful**, be **aware**

Checklist... ✓

Who wrote the information – doctors, therapists, journalist?

Has it been approved by a clinical expert? Is it unbiased? When reading personal accounts (testimonies) remember that every case is different and may not even be genuine.

When was the information 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 and there should be a link to this research.

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? Don't be pressurised into trying anything for free or buying online.

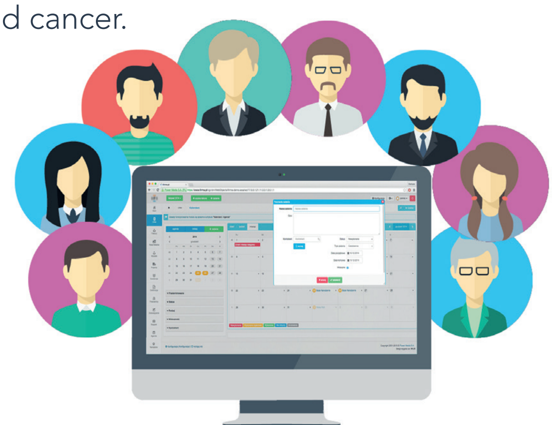
Where is the website located?

There are a lot of websites about cancer and 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 in the UK is what experts believe is the best currently available treatment based on up-to-date research.

Is the site a blog, vlog 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. They may not even have had cancer.



? Is it factually accurate?

Be aware that other people's blogs or social media posts may not be factually accurate and can also be biased

? Be aware of your child's feelings

If your child or teenager has a phone or tablet, then they will be able to access online information themselves and will see the same things online that you are. This can bring them comfort or it may make them feel more anxious if they see or read something upsetting. 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 online.

Visit **www.thinkuknow.co.uk** for information on how to stay safe online.

Does it sound too convincing? ?

Be wary of websites that blind you with science and/or convincing patient testimonials

Is the treatment only available to buy online and not prescribed by a doctor? ?

If so, look for the medical evidence before spending money.

Weigh up the financial costs, health risks and emotional costs ?

Be wary of claims giving false hope. **If it sounds too good to be true, then it usually is.**

Be aware of information overload. Take a step back, breathe and try and distract yourself for a while to help gain perspective again. ?

Sources of information

These UK charities and organisations all have Information Standard accreditation.

Children's Cancer and Leukaemia Group (CCLG)
www.cclg.org.uk

Cancer Research UK (CRUK)
www.cancerresearchuk.org.uk

CLIC Sargent
www.clicsargent.org.uk

Macmillan Cancer Support
www.macmillan.org.uk

NHS
www.nhs.uk

Patient
www.patient.info

Teenage Cancer Trust
www.teenagecancertrust.org

The Brain Tumour Charity
www.thebraintumourcharity.org

Bloodwise (for leukaemia and lymphoma)
www.bloodwise.org.uk

Leukaemia Care
www.leukaemiacare.org.uk

Bone Cancer Research Trust
www.bcrt.org.uk

Children’s Cancer and Leukaemia Group
the EXPERTS in CHILDHOOD CANCER

Children’s Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Written by the CCLG Publications Committee, comprising multiprofessional experts in the field of children’s cancer.

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, including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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Health & care information you can trust
The Information Standard
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