

## Advocacy toolkit

### Using the internet to find information

A simple google search for 'leukaemia' yields over 6 million results, but with so much information available at the touch of a button it can sometimes be difficult to know what is accurate, relevant and up-to-date. In this toolkit, you will find guidance about how to find trusted information on the internet.

#### Webpages

The chances are if you're looking for more information the first place you'll go is Google, or another search engine unless you have been directed to a specific webpage.

There are a few tips that you can use to get better search results:

- Be specific with your search – Using more terms within your search will narrow down the results and help you to more easily find the information you are looking for. For example, searching childhood acute lymphoblastic leukaemia will direct you to more relevant pages than simply searching leukaemia.
- Set your search to UK results – International webpages do provide good information, but it is not always relevant to the UK healthcare system and won't help to point you in the right direction for local support.

Google's search platform is designed to ensure that trusted webpages are at the top of searches, but there can also be advertised pages that have paid to be at the beginning of a search.

There are a number of ways that can help you to identify trusted webpages:

- Identify who runs the webpage - The website URL can help you to identify who runs the page.

.ac.uk or .edu	Educational institute
.gov	Government
.nhs.uk	NHS
.org	Charity or not-for-profit organisation
.com	Commercial company
.net	A network organisation

- Identify the purpose of the page – Each website should have an 'about us' page that tells you the purpose of the organisation and their website. If it is designed to promote or sell a product there could be biased information.

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From this point, it is most important to check that the information is reliable and up-to-date. The following questions can help you to assess this.

#### 1) Does the webpage have The Information Standard quality mark?

In response to the large amount of healthcare information available on the internet, NHS England developed The Information Standard. Organisations can become a member of this organisation, following rigorous assessment to check their information is of high-quality (i.e. it is clear, up-to-date, evidence-based and accurate).

#### 2) Is the information referenced?

Checking the references for information will direct you to the original source. References are sometimes mentioned or linked to within text but will normally be found at the end of a document.

#### 3) Is there a published or review date?

This is good to check to ensure that the information is relevant and up-to-date, as changes in healthcare can happen regularly. If the information is more than a couple of years old, it may be worthwhile cross checking it with more up-to-date information.

#### 4) Can you see who wrote the information?

You should be able to find out who wrote the information and who was responsible for reviewing the information. It may be worth looking at the qualifications of the author, particularly if you are reading an opinion piece or blog.

If you have read something online it is often worthwhile discussing this with a member of your healthcare team, or a healthcare professional you can contact via a charity. Even if the information is accurate and up-to-date it may not always be relevant for your individual circumstances, often information is written for a wider, general audience.

If you are struggling to know what websites to trust, your healthcare team should be able to point you in the right direction.

Some general websites that could be helpful are:

- [www.nhs.uk/Livewell/cancer/Pages/Cancerhome.aspx](http://www.nhs.uk/Livewell/cancer/Pages/Cancerhome.aspx) (this is a good starting page for basic information, they also provide external links to other trusted organisations)

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- <http://www.leukaemiacare.org.uk/resources/filter-by-resource-type/information-booklets> (Leukaemia Care information booklets available online or can be ordered)
- [www.macmillan.org.uk/](http://www.macmillan.org.uk/) (good for providing financial information in particular)
- [www.cancerresearchuk.org/](http://www.cancerresearchuk.org/)
- [patient.info/](http://patient.info/)
- [www.cancer.gov/](http://www.cancer.gov/) (this is an American site, but does provide very good information on different cancers)

## Online support groups

Online support groups can be a great way for you to ask questions to other people within your community who have been through, or are going through, a similar situation. Quite often these communities may include healthcare professionals, or others who oversee the community and are able to provide more information.

You must, however, exercise caution in the information people are sharing, as people are often posting their own views and opinion. This may make the information bias, or they may point you towards inaccurate sources. It is often sensible to discuss things you have read with your care team.

Some leukaemia specific support groups you may wish to join are:

- CLL - [healthunlocked.com/cllsupport](http://healthunlocked.com/cllsupport) (run by CLLSA)
- CML - [www.facebook.com/groups/cmluk/](http://www.facebook.com/groups/cmluk/)
- Acute leukaemia - [healthunlocked.com/leukaemia-care](http://healthunlocked.com/leukaemia-care)
- Acute promyelocytic leukaemia - [www.facebook.com/groups/AcutePromyelocyticLeukemia/](http://www.facebook.com/groups/AcutePromyelocyticLeukemia/)
- General Leukaemia - <http://bit.ly/Facebook-SupportGroup> (run by Leukaemia Care)

#### Social Media

Using social media can be a great way to stay connected and certainly throughout a cancer journey it can be useful to overcome feelings of isolation. There are many groups designed for patients with the same type of diagnosis to join and these can be very helpful.

However, many people use social media to share their personal experiences, which can significantly differ between patients. Therefore, if you are seeking information from social media, it is better to follow trusted and verified pages, such as those from charities or government organisations. Just look out for the blue tick that shows it is the verified page ran by the organisation.

This can, also, be a good way to get updates on the latest healthcare news from a trusted source.

#### The news

There are often breaking news stories that cover latest healthcare news, such as CAR-T therapy hitting headlines after its approval for use in the USA and, more recently, a headline from BBC news in response to early results of a trial which said "Have they found a cure for our cancer?".

While journalists are supposed to report accurately and without bias, headlines and stories can often be overhyped to ensure that the story is 'newsworthy'. There are a few ways that you can check a news story is providing accurate coverage of healthcare:

##### 1) Check the reference

A news story reporting on breaking research or new treatments should reference the original source. It is often sensible to read this, because the 'newsworthy' angle may portray the research in a different light.

##### 2) Who is the journalist?

Some journalists have significant experience in reporting on health-related news, whereas other may not have the best understanding and this can alter the way in which the story is written.

##### 3) Is a specialist quoted within the news report?

Ensuring that a specialist is quoted within the report improves the accuracy of communication.

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#### 4) Is the article unbiased?

Not all stories require a balanced argument, but the story should cover the opinion of a separate and independent specialist who can provide an unbiased input into the story.

#### 5) Is the story sponsored or sold in by an organisation trying to sell you something?

Something that is increasing in popularity is adverts written to look like news articles, but are actually paid for by an organisation to promote something. This often presents a distorted and bias view of the facts.

#### 6) Has there been a response from trusted charities or organisations?

If there is a breaking news story relating to cancer, many of the charities will put out a response. For example, a recent story covered research into the development of a blood test that could detect cancerous cells from solid tumour cancers. This is very early research and Cancer Research UK put out a response online and on their social media to tell the full, scientific story .

## Latest research/journals

The latest research papers are often the earliest indication of treatments that are forthcoming and give new insight into how a cancer arises and functions. However, journal papers are aimed at the clinical community and academics and are, therefore, set at a level suitable for people who have expert knowledge on the subject and the various research techniques.

You may wish instead to stay up-to-date with research by reading articles from organisations or health/research specific news sites, such as science daily or PharmaTimes.

If you do wish to view journal papers, there are a few sites that you could use:

- Pubmed ([www.ncbi.nlm.nih.gov/pubmed/](http://www.ncbi.nlm.nih.gov/pubmed/)) - this is a search engine that directs to global research papers from different journals.
- Blood Journal ([www.bloodjournal.org](http://www.bloodjournal.org))
- The Lancet Haematology ([www.thelancet.com/journals/lanhae/issue/current](http://www.thelancet.com/journals/lanhae/issue/current))

A large number of journal papers require you to pay in order to access them, however, some are open access and the full text can be viewed freely.

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#### Further information on using the internet

The following pages may help you to learn more about how to use the internet for finding information:

- <http://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/information-on-web>
- <https://www.cancer.org/cancer/cancer-basics/cancer-information-on-the-internet.html>

#### Further questions

If you have any further questions about using the internet to find further information then you can contact our Campaigns and Advocacy team. They are available Monday to Friday from 9:00am - 5:30pm. If you would like to speak to them, you can:

- Call our office line on 01905 755977 - Send them an email at [advocacy@leukaemiacare.org.uk](mailto:advocacy@leukaemiacare.org.uk) - You can also call the help line, free of charge on 08088 010 444. The team will pass your enquiry onto the Campaigns and Advocacy team.

Please note that our Campaigns and Advocacy team are unable to provide: - Detailed medical advice or recommendations - Legal advice - Advocacy for a course of action which is contrary to the aims and objectives of Leukaemia Care.