



About diagnosis: Sources of medical information

How to find safe and reliable information about your child's condition

- Using the internet
- Judging quality
- Reliable information
- Useful websites

Families with a child who has a disability or health condition often use the internet to search for information and support.

Websites are aimed at different groups of people, for example professionals, academics, members of the public. Detailed pieces of academic research can be confusing, and may not be helpful. Think about who the website is aimed at and how useful the information will be.

This guide can help you judge if a website provides relevant, quality information.

Reliable sources of information

If you already have a diagnosis, then you may now be looking for specific information. To reduce the uncertainty and fear of the unknown, it is often helpful to try and find out as much information about the diagnosis as possible.

However, not all information you may come across will be accurate, up to date and written by appropriately qualified health professionals. Some might include personal views or experiences which, although may be of interest to you, may not always be a reliable source of information that you can use to relate to your child's situation. Even people with the same medical condition can be affected in very different ways.

For information that you can be confident about, get as much support as you can. This can be from the contacts mentioned in this guide, our freephone helpline and from the healthcare team looking after your child.

Be careful when looking on the Internet

Be careful about turning to the Internet. You may come across information which is upsetting to read – most information about conditions includes a spectrum of how someone might be affected including the most severe cases. If the professionals involved in your child's care seem unsure of the underlying condition it can be tempting to do your own research. Many conditions share features and you may come across something that sounds just like your child. Be wary of this. You risk going down the wrong route entirely. Always go back to the health professionals and ask them to relate the information you have found to your child.

"I spent hours looking for information on the internet. In the end I realised I was just torturing myself. My time is better spent with my children."

Parent

Contacting others on the internet

Many support group websites have good information. Here are a few things you should keep in mind when using a support group website or contacting other parents on the internet:

- can you find clear contact details for the organisation on the website?
- if there are e-mail lists, bulletin boards and chat rooms, you are likely to be in touch with people who are genuine, but remember, some may have extreme views
- check that personal information will be kept secure and not shared with others
- see if your personal details are being logged when you access the website
- can you contact the website manager to report technical problems and provide comments about the site?

Assessing the quality of information

There are things you can look out for when assessing the usefulness and reliability of information. A range of expert information on conditions, including rare disorders, can be found from verifiable sources such as universities, government libraries or hospitals and the information is often posted on their websites. Information from other sources should give details of date of writing and authorship.

Key points to remember

- Conditions affect children in very different ways. Information on the internet about symptoms or treatment may or may not be relevant to your child.
- Look for evidence of who wrote the medical information, names and qualifications of professionals.
- Websites can be set up by anybody. Look for contact details and registered charity numbers to help you decide if the website belongs to a respected organisation or a commercial one that may have biased information to sell a treatment or product.
- Information on the internet can be out of date or even factually incorrect.
- It is a good idea to discuss medical information found on the internet with a health professional.
- Some information on the internet is very academic and specialised, some is sensational and extreme.
- Information from outside the UK might not be relevant in this country.

This leaflet is based on guidelines produced by Contact a Family and the Information Management Research Institute (IMRI).

The Contact a Family Directory

Contact a Family produces a directory which has information on over 1,000 childhood conditions and related support groups, if there is one.

Information from groups

Contact a Family has a database of many specific conditions and rare disorders in addition to those listed in the Directory. For some of these conditions there are support groups that can provide more detailed information about your child's condition.

For information about a specific condition or rare disorder, including support groups that can help with information, call our helpline on Tel: 0808 808 3555 or visit Web: <http://www.cafamily.org.uk>

You can also find verifiable information from:

- **NHS Choices** – a site providing information on conditions, treatments, local services and healthy living.
Web: <http://www.nhs.uk>
- **Orphanet** – an online public database of information on rare diseases and treatments
Web: <http://www.orpha.net>
- **National Organization for Rare Disorders** – American site which has information on a huge range of disorders (support networks listed on this site may be useful where there is no UK network).
Web: <http://www.rarediseases.org/search/rdbsearch.html>

Getting in contact with us

Free helpline: **0808 808 3555**
Open Mon–Fri, 10am–4pm;
Mon, 5.30–7.30pm

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:
209-211 City Road, London EC1V 1JN

Tel 020 7608 8700
Fax 020 7608 8701
Textphone 0808 808 3556
Email info@cafamily.org.uk

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Other guides in this series

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