

Some useful websites

- **Contact a Family Directory**
An online directory of specific conditions and rare disorders affecting adults and children. Each entry is approved by an appropriate medical specialist and regularly reviewed.
www.cafamily.org.uk
- **NHS Direct Online** A NHS produced website with online health enquiry facility.
www.nhsdirect.nhs.uk
- **Patient UK** A directory of UK health websites. Contains information about conditions and support groups plus other information materials. Also locations of GP practices and hospitals.
www.patient.co.uk
- **Organising Medical Networked Information (OMNI)** A free searchable catalogue of quality websites on health and medicine. Details of sites produced for health professionals, researchers and health service users.
www.omni.ac.uk
- **National electronic Library for Health (NeLH)** Produced by the NHS. Contains quality information with evidence for health care. Aimed at the health professional however, most is freely available to the public.
www.nelh.nhs.uk

Key points to remember

- Conditions affect children in very different ways. Information on the internet may or may not be relevant to your child.
- Information on the internet can be out of date or even factually incorrect.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 full guidelines can be found at www.judgehealth.org.uk

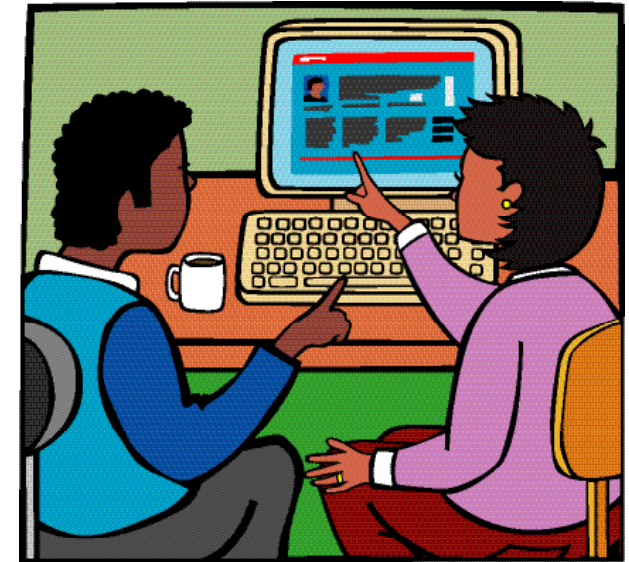
Large print versions of this leaflet and further copies of this version are available from Contact a Family on request.

Freephone 0808 808 3555 or email helpline@cafamily.org.uk



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finding medical information on the internet



- ☐ Families with a child who has a disability or health condition often use the Internet to search for information and support.
- ☐ The Internet can be a very useful source of information, but the large amounts and types of websites can result in confusion.
- ☐ This leaflet aims to help families judge if a website provides relevant, quality information.



contact a family
working with The Royal College
of Paediatrics and Child Health
parents & paediatricians together

Who produced the website?

Websites can be set up by anybody, from respected organisations and experts to people with extreme views or companies trying to sell you something.

Things to look out for:

- the name, address and contact details of the organisation.
- the registered charity number (if relevant).
- the aims and purpose of the organisation.
- the names and qualifications of any professionals contributing to the website. Is there an Advisory Panel, Review Group?
- websites should state clearly if they are based on personal experiences.
- websites sponsored by commercial organisations may show a bias to certain treatments or products. Adverts that appear on a website might also reflect this.

Websites from outside the UK can be useful but may refer to medicines using different names from those used here, or ones not licensed for use in this country.

Who is the website for?

Websites are aimed at different groups of people, e.g. 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.

How reliable is the medical information?

Things to look for:

- The author's name, job title, workplace, and any formal or professional qualifications.
- The date – medical information can become out of date very quickly.
- Is it aimed at getting you to buy something?
- Does it acknowledge that specific conditions affect people in different ways ranging from mild to severe.
- Check whether it is written by an individual based on personal experiences. How the condition affects your child may differ from other people's experiences.
- Do the contents sound sensational or extreme?

What to look for on support group websites?

Being able to get in touch with other people is a strength of support group websites.

Things to look out for:

- 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.
- The way a medical condition affects a child can vary enormously.
- When individuals recommend treatments they may not suit every child.
- 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?

Contact a Family can signpost people to national support groups for particular conditions. See www.cafamily.org.uk or freephone 0808 808 3555