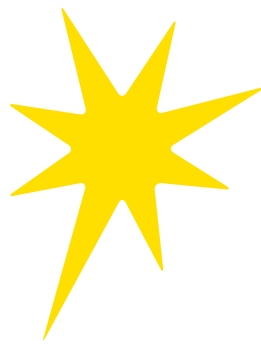




Finding & Appraising Information & Evidence on the Internet

A guide for parents



Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don't believe there's any challenge that can't be overcome.

So we listen to families, we learn from them. We carry out research, we design and innovate, we make and share. From new equipment to new learning resources, to new ways to play and support each other, everything we find out together makes life better. It opens doors to discovering the world.

It's an incredibly rewarding journey for everyone involved. Why not be a part of it? You never know what we'll discover together.

www.cerebra.org.uk

Our guides for parents help you find the answers you need. You can view and download the full series of our guides and factsheets completely free from our website www.cerebra.org.uk.

If you would like to make a donation to help cover the cost of producing our guides please just text **CERE12** and the amount you want to give to **70070** or give us a call on **01267 244216**. You can also donate online.

Thank you.

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Introduction

Families of children with a brain condition are often keen to look for more information about their child's condition, therapies and treatments, or other services that might be available, and the legal rights that they and their child have.

The internet provides a huge amount of information, much of which is freely available and easy to access if you know how to search. Although there are many reputable websites that provide good quality, reliable information, there are also websites which are less reliable and should be treated with considerable caution. It can sometimes be difficult to tell whether information is trustworthy, but we present in this guide some tips which can help.

This guide outlines some suggestions to help you search efficiently on the internet, and to appraise whether the websites you find present reliable and unbiased information.

Before you begin any search it is important to think about what exactly it is that you are searching for. This guide begins with some ideas to help you think this through.

There are websites that are known to provide reliable, impartial information. Using websites that are recommended will make your search quicker, and more importantly you will feel confident that you can trust the reliability of the information that you find.

This guide will also provide guidance about appraising information that you find. This is general guidance that can be applied to any health information for which you are searching. It is based on principles that we use in our every day work as researchers within an academic research unit.

Much of the information that you find through the Internet or elsewhere may be research evidence, particularly when you are looking for information about treatments and therapies. We offer some guidance about appraising research evidence, and a link to some useful checklists to assist with this.



Finding information on the internet

Searching

Where possible use a website that has been recommended by a health professional, or that you know is a reliable source of information (see pages 6–8).

- Where possible use a website that has been recommended by a health professional, or that you know is a reliable source of information, such as those listed later in this section.
- On some websites you can use the terms AND, OR and NOT, which are known technically as 'Boolean operators'.
 - ◆ If you use AND between each search word you will only get results that contain both words (so AND narrows the search).
 - ◆ If you use OR between each search word you will get results which contain either one word, or the other, or both (so OR broadens the search).
 - ◆ If you use NOT before a search word you will exclude results which contain this word.
- Define your search terms before you start. It may help to think about what you are trying to find out in relation to the following:
 - ◆ The group you are interested in (e.g. children with autism),
 - ◆ The specific intervention/treatment/therapy/service that you would like to know more about,
 - ◆ Whether you want to know about this in comparison to any other treatment (for example the usual care that you would expect your child to receive),
 - ◆ Outcomes that you are interested in (i.e. what effect would you like the intervention/ treatment/service to have).

The answers to these questions can be used as 'Key Words' which you can type into the search facility of a website, or a search engine.

Example:

If you want to know whether your 5 year old with cerebral palsy would sleep better following massage therapy you might search for : cerebral palsy AND (child OR infant) AND massage AND sleep.

- Brackets can be helpful, for example if you want to search for two descriptions of a condition and a therapy, e.g. (autism) AND music therapy.
- Inverted commas can be used to search for an exact phrase, e.g. "Cranial Osteopathy."
- Most databases will give you the option to limit your search to within a specific date range which can be helpful.
- 'EVIDENCE' and 'GUIDELINE' can be good search terms to add in if you are looking for specific interventions, treatments or therapies.
- You may want to add the term UK to find information relevant to the United Kingdom.
- If you search using search engines such as Google or Yahoo then you will almost certainly come across websites that are based on an individual's personal experiences. This might be of interest to you but may not always provide a reliable source of information that is relevant to your child's condition. Even children with the same diagnosis may be affected in very different ways.

Websites providing reliable, impartial information

The websites listed here are known to provide reliable, impartial information. They are listed in sections in relation to specific reasons that people might look for information.

General search engines such as Google are also popular when searching for information on the internet, and it is ok to use them as long as you bear the following in mind:

- Search engines trawl through the internet and automatically create collections of sites with no regard for the quality of the information that they find.
- Be aware that many organisations pay so that their website appears at the top of the first page of results.
- Many search engines do not access the latest information that is available.
- Use the guidance in the 'Appraising Information' section on page 9 to ask yourself questions about any information that you find through a search engine to ensure that it is a reliable and trustworthy source.

Information about a condition

At the point of diagnosis many families feel that they want to search for more information about condition or diagnosis. A logical first step is to ask the professionals who know your child. They should be able to provide you with the latest information that is relevant to your child, and direct you to a reliable website for further information. At this stage it is strongly recommended to use websites that have been endorsed by a health professional.

Contact

www.contact.org.uk

Contact is often a good place to start if you are searching for information about a condition. They provide information on over 1200 disabilities and conditions, and also give details of relevant support groups. The information on each condition has been written or edited by a member of the Royal College of Paediatrics and Child Health.

NHS A-Z

www.nhs.uk/Conditions

NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and provides an A-Z list of conditions with lots of details about symptoms, causes, diagnosis and treatments.

Health Talk Online

www.healthtalkonline.org

This is the website of the DIPEX charity, where you can read, watch or listen to more than 2000 peoples' experiences of over 60 health-related conditions, and find reliable information about specific conditions. The information is based on qualitative research (usually interviews) into health experiences, led by experts at the University of Oxford.

Charities for specific conditions

There are often charities associated with specific conditions and these can be useful sources of information about those conditions. Use the guidance about appraising the information you find to assess whether the charity website is a reliable source of information.

Information about treatments and therapies

When considering treatment options for a child it might be interesting to find out what treatment is likely to be available, and what treatments are known to be effective for the particular condition.

Choice of treatments, therapies and interventions:

NHS

<https://www.nhs.uk/>

The NHS website gives lots of information that might be helpful when you need to make choices about your child's health, including information about conditions and treatments that are likely to be available through the NHS.

Effectiveness of treatment, therapies and interventions:

The Cochrane Library

www.thecochranelibrary.com

The Cochrane Library is a database of systematic reviews. Systematic reviews summarise and interpret the results of high quality medical research. You can use this website to find the most up-to-date evidence about the effectiveness of a given intervention.

Healthtalk

<http://www.healthtalk.org/>

Healthtalk provides free reliable information about health issues by sharing peoples real life experiences.

National Institute for Clinical Excellence (NICE) guidelines

www.nice.org.uk

NICE is an independent organisation responsible for providing national guidance to the NHS on promoting good health and preventing and treating ill health. You can use this website to search for guidance that has been produced on a particular topic, procedure or treatment.

Patient

<https://patient.info/>

Patient provides health information for patients and professionals around the world. The site contains over 4000 health information leaflets and thousands of discussion forums.

PenCRU

www.pencru.org

The Peninsula Childhood Disability Research Unit (PenCRU) responds to questions from families about therapies and health services for children affected by disability. The website provides summaries of the available evidence in response to specific queries from families and information about research and what different terms mean.

TRIP Database

<https://www.tripdatabase.com/>

The TRIP Database is a clinical database which allows you to search for the highest quality clinical evidence for clinical practice. The results are organised by the level of evidence.

Information about services

The local services that are available for a child will vary depending on geographical location. There will usually be a website linked to the local or county council which should provide information about services that are available.

Information about rights/legal advice

Council for Disabled Children

<https://councilfordisabledchildren.org.uk/>

The Council for Disabled Children (CDC) works to influence national policy that impacts on children with disabilities and their families. The website provides a wide range of resources and information for families, including the publication 'Disabled Children: A Legal Handbook' which is an accessible guide to the legal rights of disabled children and their families in England and Wales.

Cerebra

www.cerebra.org.uk

Cerebra have teamed up with Leeds Law School to develop a series of guides and factsheets to help families of children with brain conditions with common problems they may be facing. Covering a range of legal, social and financial issues, these are useful tools in helping you understand your situation regarding your rights and entitlements. They offer comprehensive, up-to-date advice and strategies to help.

Cerebra also have a useful DLA (Disability Living Allowance) guide which takes you through the form step by step offering guidance about how to complete it.

Citizens Advice Bureau

www.citizensadvice.org.uk

The Citizens Advice Bureau (CAB) provide free, independent and confidential advice about a range of issues, including Money, Family, Daily Life and Rights. There is lots of advice on the website, as well as information about their telephone service and how to find your local CAB office.

Disabled Children's Partnership

<https://disabledchildrenpartnership.org.uk/>

The Disabled Children's Partnership (DCP) is a growing coalition of more than 70 charities who have joined forces, working closely in partnership with parents, to campaign for improved health and social care for disabled children, young people and their families.

Information about support

Families may often seek out support from other families in similar positions or who have children with the same condition. There are a range of condition-specific support groups to choose from and many of them have websites with forums which can help families to stay in touch even if they do not live in the same area. Contact have produced specific guidance about assessing support group websites: <https://contact.org.uk/advice-and-support/local-support/parent-support-groups/>

Special Kids in the UK

www.specialkidsintheuk.org

Special Kids in the UK is a registered charity whose main focus is an online parent support forum. Parents can post questions for others and share information.

NHS Choices

<https://www.nhs.uk/conditions/pregnancy-and-baby/services-support-for-parents/>

NHS Choices includes a section dedicated to parent support. There is information about where you can access support, and links to other websites that might be of interest.

Appraising information

Once you have found relevant information, there are a few questions that you can ask yourself about the website or material that you have found. This will help you to decide whether it is reliable, useful and relevant for you. It is not always possible to answer all of these questions but they may help you to think about the purpose of a website and whether the information is likely to be biased in some way.

How accurate is the information?

- Can you verify the information?
- Does the website or written information give references for the sources that have been used?
- How does the information compare with what you already know, or what you have read from other sources?
- Can you tell whether the information has been edited or checked by someone other than the author?
- If the information is historical or biographical, are the dates of events accurate?

How accurate is the information?

- Is there a date that the information was created, last updated or checked?
- Do the links to other sites work or have they have expired?

Whose point of view is being represented?

- Is the information composed mainly of testimonials or personal experiences?
- To what extent is the information trying to sway the opinion of the reader?

Are details of additional sources of support or information provided?

- Are there suggestions for further reading?
- Are there links to other sources of information or advice about conditions or treatment options?

How relevant is the information to you and your family?

- The same condition can affect individuals in very different ways; is this taken into account?

Cautionary note:

Be cautiously sceptical when you come across websites with information about specific therapies. They will often have been written by the person who developed the treatment or therapy, and they may be selling the therapy. Therefore the website may not provide impartial or reliable information. Use a reliable website, such as the ones listed in this guide, to see whether the therapy in question has been subject to any high quality research.

- If you are searching for information about a condition then you will probably find that the information given is about the whole spectrum of how someone might be affected, not all of which will necessarily be relevant to your child.
- Information about treatments may also be irrelevant to you, particularly if the source of the information is a website based on a personal story.

Other guidance

There are other organisations which have produced guidance about appraising information that you find on the internet. Of particular note, Contact have a section on their website entitled 'Finding medical information on the internet'. They include a section on judging whether support group websites are genuine and a few cautions for looking at websites that include people's personal experiences. The information is available on their website, or by following this link: <https://contact.org.uk/advice-and-support/health-medical-information/finding-medical-information/>

Appraising research evidence

When you are looking for information on the internet, particularly information on treatments, therapies and services, you will probably come across reports about research. It can be difficult to assess which research might be useful, and whether it is of a high quality.

The Critical Appraisal Skills Programme (CASP) has produced freely available checklists which you can use to appraise different types of research. This will help you to make decisions about whether it is a high-quality, reliable and useful piece of research. The checklists can be accessed at: <https://casp-uk.net/casp-tools-checklists>

In addition, the Centre for Evidence-Based Medicine provides critical appraisal sheets for appraising systematic reviews and randomised controlled trials (RCTs). These are types of research that you might come across. The critical appraisal sheets can be accessed at <https://www.cebm.ox.ac.uk/resources/ebm-tools/critical-appraisal-tools>

You need to use slightly different guidance for research that uses different methods and designs, but in general it is useful to think about the research in terms of:

1. What are the results?
2. Are the results valid?
3. Are the results relevant to you?

The checklists recommended on page 9 will help you to answer these and other questions relating to the quality of the research that you are looking at.

- Did the children receiving the treatment, therapy, service, etc, being tested have a condition that you are interested in, i.e. if the children involved in the research had a diagnosis of autism and your child has a diagnosis of global developmental delay then the results may not be relevant. There is no guarantee that children with different diagnoses will respond in the same way to a treatment, therapy or service.
- What outcomes does the research look at? For instance, if you are interested in the effect of a treatment or therapy on the time taken to get to sleep but the research you have found measures hours spent asleep then you will need to think carefully about whether this finding is relevant to you.

Information about the authors

The Peninsula Childhood Disability Research Unit (PenCRU) carries out a broad programme of applied research that aims to improve the health and wellbeing of disabled children and their families. They involve families affected by childhood disability in all aspects of their research and related activities through their Family Faculty.

PenCRU responds to questions from families about therapies and health services for children and young people affected by disability or who have special or additional health needs. They provide summaries of the evidence of the effectiveness of therapies to help families make decisions about treatments. Where the evidence is lacking they seek funding to conduct research to assess the effectiveness of interventions on outcomes that families tell them are important, such as functioning, social inclusion and participation, and quality of life. For more information see www.pencru.org.

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