

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Finding reliable medicines information on the Internet

Points to consider

There is a vast amount of information on the Internet about medicines. Some of it is reliable and relevant to medicines in the UK, but some of it is not. This information sheet gives you a few hints and tips on finding reliable medicines information. Please let us know what you think of them.

It is vital to remember three things when you're looking for medicines or other information on the Internet:

- No one is in overall charge of the Internet anyone can post information and although some sites are careful about checking information posted, this may not be true for every website.
- There are some people who use the Internet to make money, either by selling medicines illegally or recommending a wonder cure that does not work.
- Remember that healthcare in other countries is organised in different ways to the UK.

 Some treatments might not be available in the UK or be offered to different people. In addition, some conditions or medicines have different names in different countries.

There are other points to consider as well when you are looking for information about medicines on the Internet:

- The dose prescribed by your doctor may be different from the information in the patient information leaflet in the package. Always follow the directions on the dispensary label or your doctor/pharmacist as the dose has been checked and tailored to the patient.
- Medicines have two names: a generic name and a brand name. For instance, ibuprofen is a generic name and Nurofen® is a brand name. You may also hear medicines referred to as 'proprietary'. This is the same as a brand name medicine.
- Medicines sometimes have different names outside the UK they may be known by their generic name or the manufacturer may use a different brand name. For instance, the generic medicine paracetamol is known as acetaminophen in the USA.
- Some medicines were originally developed to treat one condition but were found to help a completely separate condition so any information you find might seem misleading.
- When you read any information, you might also read that the medicine is not licensed for children and young people. You can be assured that an unlicensed medicine has only been prescribed because no licensed alternative is available. This does not mean that the medicine cannot be used safely



in children. It means that the drug company does not have a licence for the product for use in children so is not allowed to recommend this use. For further information about unlicensed medicines, please visit the Royal College of Paediatrics and Child Health webpage on medicines for children at www.rcpch.ac.uk/child-health/childrens-medicines/childrens-medicines.

■ The majority of side effects are identified when the medicine is being tested, and they are all included in the patient information leaflet. This can make for worrying reading, but remember that some of the reported side effects are extremely rare.

People you can ask

Your pharmacist should always be your first port of call if you have any questions about medicines. Most community pharmacies have a quiet room where you can talk to a pharmacist in private. Many hold a selection of health information leaflets as well.

Outside of opening hours, you can call NHS Direct or NHS Direct Wales on 111 from any landline or mobile phone free of charge for advice about medicines. Please note that in some areas, you should call 0845 46 47. In Scotland, you can call NHS24 on 08454 24 24 24. In most cases, the operator will take your name and telephone number and a qualified nurse will ring you back to answer your questions.

Search engines

It is the easiest thing in the world – just type in a few words into a search engine, such as Google or Yahoo, and get lots of web pages back in seconds. However, using a search engine is not always the most reliable way of finding medicines information on the Internet. We would suggest trying the websites listed in the next section first, as they contain reliable, regulated and safe medicines information.

Useful websites for medicines information

Most medicines come with patient information leaflets provided by the manufacturer, some of which are available on the Electronic Medicines Compendium website at www.medicines.org.uk/emc. Versions of patient information leaflets for people with visual impairments are available at X-PIL at xpil.medicines.org. uk. Most patient information leaflets are written in plain English but other sections are harder to understand. The information given about a medicine usually includes:

- the name and manufacturer of the medicine
- why it is usually prescribed
- how it is given
- interactions with other medicines
- contraindications, that is, circumstances when the medicine should not be taken
- possible side effects
- what to do if too much is taken
- the active ingredients in the medicine and how they work
- storage instructions.



The **British National Formulary** is the main reference guide used by health professionals in the UK for prescribing, dispensing and giving medicines. It is updated twice a year and is available at www.bnf.org. The information is written for health professionals but the information is laid out in a clear and consistent way. There is also a version for children's medicines at www.bnfc.org.

GOSH produces a range of information sheets on medicines, particularly those that do not contain a patient information leaflet in the packaging. Visit www.gosh. nhs.uk/medical-information/medicines-information/ for further information.

NHS Choices (www.nhs.uk). This website contains information on conditions, treatments, local services and healthy living.

Patient.co.uk uses the same information system that is used in most GP surgeries. Information sheets about most commonly used medicines are available at www. patient.co.uk under Medicines and drugs.

NetDoctor (www.netdoctor.co.uk) is a website run by a group of qualified health care professionals who aim to improve communication between doctors and patients. Their website contains a section on medicines information that contains details of specific medicines indexed by both generic and brand names and also general information on taking medicines safely.

Support organisations for specific conditions can also provide useful information on medicines. Get in touch

with **Contact a Family** (www.cafamily. org.uk), the umbrella organisation for support groups in the UK, to see whether they can help. You can ring them on 0808 808 3555 or visit their website.

Evaluating other websites

When you find a website covering your area of interest, you need to ask yourself a series of questions before accepting what the website says. Remember to be cautious when reading any information on the Internet. A website that appears to be credible might not be all it seems. Learning to think critically about information is a vital skill in using information well. The sorts of questions you should be asking include:

- Who has produced the information and posted it on the internet? Follow any links on the site that say 'home' or 'about us' to find out more. Visit websites produced by organisations you trust first, those from academic, professional or NHS organisations should be the most reliable UK ones.
- Look at the date **when** the information was produced and/or posted. As a general rule, be wary of any information produced more than four years ago. Information about specific medicines should be updated more frequently than this, often once or twice a year.
- Ask yourself **why** the website is there. Is it trying to recommend a particular product to you or a specific company? If the website is selling something, the information it provides may be biased.



Using the information you find

Once you have found the information you were looking for, you need to decide what to do with it next. It's easy to find lots of credible websites but you end up with only a pile of paper and no idea what to do next.

Talk to your doctor or pharmacist about the information you have found. Be wary, though, of taking a large pile of print outs along to an appointment. This can be very off-putting for some people. It might be less intimidating if you use the information you find to put together a list of questions to ask. The Department of Health has produced a leaflet called 'Questions to ask: getting the most out of your appointment' to get you started. Visit www.nhs.uk/NHSEngland/

AboutNHSservices/questionstoask/Pages/ Makethemostofyourappointment.aspx for further information.

Make a note of where you found the information. Most web browsers can be set up to print the web address of any pages you print. Make sure the date is included as well. Information on the Internet can change daily and there's no guarantee that if you go back to a website a few weeks later than the same information will still be there.

Further Information

Call Pharmacy Medicines Information at GOSH on 020 7829 8608 - Monday to Friday from 9am to 5pm.

Notes	

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