

Finding and using information about health and medicines

A guide for patients, medicine users and carers



The Association of the
British Pharmaceutical Industry
www.abpi.org.uk



www.askaboutmedicines.org

Introduction

All of us should be able to take part in decisions about our own health and whether a medicine is right for us. If we are caring for someone, we may need to take part in or help them with decisions about their healthcare and use of medicines. To do any of this, we need good information. These days there is so much information about health and medicines that it can be hard to know where to start or how to tell whether it is any good. This booklet has been written to answer the need for information, by a group of people representing health professionals, patient organisations, the NHS and the pharmaceutical industry.

There are three parts to this booklet. The first part gives advice on how to find information about health and medicines, and how to decide if the information tells you what you need to know. The second part contains general information about medicines. Finally, there is a list of websites and phone numbers where you can find information about health and medicines. There is an interactive version of the Directory, with internet links to the websites listed, at the Ask About Medicines website (www.askaboutmedicines.org). You can also download a copy for printing from the same website.

Whether or not to take medicines is your decision. But please remember: before you make any changes in your medicines or other treatment, make sure you have the best possible information to back up your decision. If you are taking a prescription medicine, you are strongly advised to consult your doctor or pharmacist before stopping it or changing the dose.

We hope you find this booklet useful and we wish you success in your search for reliable and helpful information about health and medicines.

Part 1: How to find and judge the quality of information

Here we aim to answer some important questions people often ask themselves when they want to get hold of information about health and medicines.

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You may have other questions, but we hope these will get you started. Once you have answers to these questions you can start to make sense of what the information you find means to you and how you can use it when making decisions about your health.

1. Who can I talk to about my health concerns and any questions I have about my medicine?

There are a number of people you can talk to, including health professionals, health charities, patient support groups and the company that makes your medicine. Any of these people can answer questions about health conditions and medicines, though some of them are restricted in what they are allowed to discuss with you.

Health professionals

These include:

- Doctors, including GPs and hospital specialist consultants
- Nurses, including practice nurses, district nurses, clinical nurse specialists and health visitors
- Pharmacists (the chemist)
- Dentists

Health professionals can help you understand information about your health. You may have specific questions that only a health professional who has access to your medical history can answer. Other questions may be more general and easier to answer by health professionals not directly involved in your care. You can feel confident about asking questions and discussing your health concerns with a health professional.

Tips for asking questions

Health professionals will listen to your views and concerns and answer your questions, but they may have a limited amount of time. To make the most of your time with them, you could try the following:

- Write down any questions you have before you visit or phone.
- Ask the most important questions first.
- Ask about any terms or jargon you don't know.
- Request a simple explanation if you don't understand what was said.
- Write down the main points quickly afterwards, as a reminder.
- Phone or visit again if you have any other questions.

Pharmacists are experts in medicines. As well as answering your questions about medicines, they can also offer advice about general health conditions that may not be serious enough for a visit to the doctor (for example, headaches or colds).

Questions you could ask

- What does this medicine do?
- Why is it important that I take this medicine?
Are there any other treatment options?
- When and how should I take it?
- How long should I take it for?
- What should I be aware of when taking this medicine?
(Possible risks, side effects, taking medicine with certain foods/drinks/activities, what to do if I don't feel well while taking it, how to store it safely, and so on.)
- Where can I go for more information?

Asking about your medicines

- Ask if you need help getting a regular supply of your medicines.
- Share any questions or concerns about medicines you are prescribed or buying – and ask about other options.
- Tell a health professional about any medicines you are already taking. This includes medicines bought over the counter without a prescription, and herbal and complementary medicines.
- Tell a health professional if you think the medicines you are taking aren't working, or are giving you side effects.
- Ask if you are unsure how to take your medicines or for how long.

Health charities and patient organisations

Health charities do a number of things, including medical research, campaigning, service delivery, and giving information, advice and support.

Patient organisations consist mainly of other people with the same condition, or carers looking after someone affected by it. They can offer you practical tips for living with your condition, or you may just find reassurance from sharing your experiences and concerns with someone in similar circumstances.

Health charities or patient organisations with an information and advice service will be used to answering all sorts of questions. Don't be afraid to ask about whatever is bothering you. They will not answer questions about personal medical matters, but they will know when (if necessary) to refer you on to other sources of information and advice.

When discussing health concerns

- Be honest about your concerns.
- Ask what tests there are, if there are other medicines or treatments available and how effective they are in comparison.
- Write down your concerns in a letter if you feel they are too embarrassing or difficult to discuss in person.
- Ask if you could tape the consultation so you can remind yourself later of anything you've forgotten.
- Tell them if you don't read or speak English well, or if you have trouble hearing or seeing. Ask if any reading material is available in your language, or on audiotape or in large print.
- Take along a friend to help you understand, or to take notes while you concentrate on talking to the doctor.

The company that makes your medicine

Another source of information about your medicine is the pharmaceutical company that makes it. The government controls and regulates the information provided by pharmaceutical companies to make sure that it is factual, accurate and balanced and that the company does not advertise medicines to the general public.

Although it is normally best to talk to your health professional first, medicine manufacturers all have a Medical Information Department, which can answer questions about the medicines they make.

Companies are not allowed to give you advice on personal medical matters. The only information they can give is about the medicines they make, so you need to look elsewhere for information on different medicines or treatment options. Companies may have to provide the information you have requested to your doctor rather than directly to you. Your doctor will then discuss the information with you.

2. Where can I look for health and medicines information?

You can get health and medicines information in many places, including:

- The leaflet that comes in your medicine pack
- On the internet
- By telephone
- Leaflets in doctors' waiting rooms, pharmacies and hospitals, among others
- Patient information services within hospitals
- Local and NHS libraries
- Local community or cultural groups
- In the media

Leaflet in your medicine pack

The Patient Information Leaflet in your medicine pack is changing so as to be more useful to patients. It contains important information about your medicine and how you should take it. By law, every medicine must have a leaflet. It is written by the company that makes the medicine, under strict guidelines, and is checked by the Government's medicines regulator (see the box headed 'Making sure medicines are safe' on page 16 for more information). If you do not get a leaflet with your medicine, ask your pharmacist to provide one. The information in the leaflet may change as new things are learnt about the medicine, so read it again when you get a new supply.

The leaflet will tell you how the medicine is intended to help your condition. It also describes possible side effects and things to look out for. The list of side effects can look quite daunting, but pharmaceutical companies are required by law to list them all, even if they are very rare. Not everyone will experience side effects, but if you are concerned in any way, talk to your health professional.

Doctors are allowed to prescribe medicines differently from the leaflet, if they judge it necessary – for example, to different age groups, in different dosages or for different conditions. This is called “off-label” or “off-licence” use. The main reason for off-label use in children is that it is difficult to carry out drug trials in young people. Sometimes, too, it happens when a medicine is found to have a beneficial effect for a different disorder from the one for which it was originally developed. Off-label use is not necessarily risky, but it should be explained and agreed before use. Please talk to your doctor or pharmacist if you are worried about this kind of use.

The Internet

The internet can be an excellent source of health information, if you are able to use it. Many health websites are of high quality and offer balanced information based on evidence. But remember that anyone can put anything they want on the internet. So don't just go to the first site listed when you search for information. Check the other sites listed by the search engine as well, to find information that is reliable, quality-controlled and really meets your needs. See the points listed in Section 3 to help you assess the quality of the information on a website.

It is not advisable to buy prescription-only medicines online as they may not have been checked for quality or safety, or may be counterfeit (fakes). If anything goes wrong the law may not be able to help you.

Some organisations have written information about medicines especially for people with learning disabilities. Four websites that do this are listed in the Directory section of this booklet, under “Learning Disabilities” (see page 25).

Telephone helplines

There are various different types of telephone helpline. Some consist of recorded messages that you can access at any time. Others are staffed, often by nurses; these usually operate during office hours or at specific times of the day. Some also respond to emails. They may be run by patient organisations, charities, the NHS (such as NHS Direct) or companies offering specific advice on their products.

Make sure you know which organisation runs the helpline and that you understand their interest in the particular health field.

Helpline staff may be volunteers or employees; they may be qualified nurses, counsellors or trained information specialists. They will all be used to dealing sympathetically with health-related queries on the telephone, and will know who to refer you to if they cannot answer your question. Most helplines operate on a local or free rate, but some operate on premium rates, where you could run up an expensive bill. It is worth checking the call rate at the start of your call.

You may find details of a helpline on the leaflet in your medicine pack, or your local hospital may have a helpline you can call with questions about your medicines.

Doctors' waiting rooms, pharmacies, hospitals and other waiting areas

You may see leaflets in a waiting room or on the pharmacy counter. These are often distributed in partnership with health professional organisations, and can be a very useful source of information. So if you see one that looks interesting, pick it up and have a read.

Patient information services within hospitals

Many hospitals now offer Patient Advice and Liaison Services (PALS) and information services for patients. PALS will not necessarily offer information about medicines, but they can tell you how and where to contact someone who can help you. Information services may cover all health conditions, or just a specific condition such as cancer. Staff in the service will be able to talk through medicines information and other health-related information with you. Some hospitals have a dedicated Medicines Information department, so ask the PALS if one exists at your hospital.

Local and NHS libraries

You may be able to find information and contact details about sources of local support and health information from your library. A good library will also have a range of books, newspapers, magazines and audio-visual materials. Many libraries have internet access, which may be free or at a reduced cost for some people. Library staff will be able to show you where to find the information you need. All should have a copy of the Telephone Helplines Directory, which lists over 1,000 helplines covering a wide range of issues. NHS libraries are now being encouraged to provide services for members of the public.

Local community or cultural groups

There may be hospital or community-based groups for specific conditions (for example, diabetes, Parkinson's disease, cancer and so on) or community organisations for people who share a common culture or ethnic background. These can be a good source of information and can also help put you in contact with appropriate health professionals for further help.

The media

Newspapers, magazines, TV and radio sometimes seem to be full of health stories. Some are useful, but sometimes health 'scare stories', or stories that exaggerate the effects of a medicine, make headline news. The National Library for Health (www.library.nhs.uk) has a helpful section called "Hitting the Headlines" which analyses the facts behind such stories. If you are worried about anything in the media that concerns a medicine you are taking, and you are thinking of stopping or changing the dose, do check with your health professional first. Suddenly changing a prescribed dose can be dangerous and you need to understand all the advantages and disadvantages before you do so.

3. How can I judge the quality of information?

Here are some questions you can ask yourself when using health information.

- **Who produced the information?**

Look for information from reliable sources, such as the NHS, health professional organisations, health charities, patient organisations and the manufacturer of the medicine. If using a website, check to see if there is any sponsorship, and who has editorial control over the information it contains. Information provided directly to the public by manufacturers of medicines (including the leaflet in the pack) is regulated and monitored by the Government, to ensure that it is factual and balanced.

- **What is the aim of the organisation providing the information?**

Look to see if the provider of the information has a specific interest that might bias the information, such as fund-raising or selling a product. This would not necessarily mean that the information is not reliable, but it may affect how much information you decide to seek from other sources. For example, the information given may be correct but the website may not mention alternatives that you might want to consider.

- **Does the information match your needs?**

Have all your questions been answered? Has it raised other questions in your mind? Should you be looking for information in other places such as leaflets or websites?

- **How is the information written?**

Is it easy to understand? Does the information discuss the different sides of an issue? Does it describe the benefits and limitations of any research and provide a balanced view?

- **Does the information contain references?**

Look for references to the original source of the information. If there are references, it means that the information is based on fact as well as opinion. The references will tell you what the source of the information is (for instance, medical research or market research).

- **Does the information show a date?**

Look for the date when the information was first published or when it was last updated or reviewed. Information published some time ago is not necessarily out of date, but you might want to look for newer information.

- **Can you contact the organisation that issued the information?**

Is the source of the information clearly shown? Is there a postal address, telephone number, website or email address where you could get more information if you needed it?

- **If it is a website, does it subscribe to a code of conduct or display a kitemark?**

A kitemark or stamp of approval can reassure you that the information meets certain standards. In England, the Department of Health is exploring the possibility of introducing an information accreditation scheme. Internationally, Health on the Net (HON) allows you to search at **www.hon.ch** for websites that comply with its code of ethical conduct. This has eight standards including transparency, justifiability and supporting the doctor-patient relationship. Kitemark schemes for websites are difficult to design and police, and it is best if you make sure you know how to judge the quality of a website yourself.

4. What can I do if the information is confusing?

Knowledge about health and medicines changes all the time, as scientific understanding grows. Information from reliable sources, that has been checked by experts, is likely to be the best available at that time. But science is a process of discovery, and opinions can vary widely even amongst health professionals and researchers. Different people with the same condition may have different views and experiences. So where does this leave you?

If you are confused by the information you have found, the best advice is to discuss it with your health professional. Sometimes you will just feel that a treatment is 'right' or 'not right' for you. It is important, however, that you understand the options. For example, if you are concerned about the side effects or possible risks of taking a medicine, you owe it to yourself to make sure you also understand what might happen if you don't take it. You and your health professional can then discuss advantages and disadvantages and consider any other options, so that your decision is as well informed as possible.

It can be helpful to make notes as you read the information. When you look back at them, it might become clear what you should do. You could also take your notes (rather than a pile of printouts) when you see a health professional. Some health professionals prefer this and are more likely to spend more time answering your questions than reading what you have printed.

Always discuss information and/or advice you've found about your treatments with your health professional before making any changes to your medicine.

5. Does the information meet my needs?

Does the information you have found help you by:

- Answering your questions?
- Giving you a better understanding of your health condition and/or treatment?
- Helping you to make choices and decisions about your health?

Only you can say whether or not the information meets your needs. Each of us is an individual, and what is right for one person will not necessarily be right for another. Other people's opinions and advice can help you understand the options better, but do consider all the information carefully in light of your own experience, lifestyle and preferences. If you do this, and use accurate, unbiased sources of information, you will have the best chance of making wise decisions about your health and medicines.

You may also find that your information needs change over time. As your understanding of your condition increases, you may want to ask more specific questions.

6. Do I need more information?

If you are not satisfied with the information you have found or been given and still have unanswered questions, you may want to continue to search, or ask for other opinions.

But too much information can be almost as unhelpful as too little. If you are confused, try making a list of questions and discussing it all with your health professional. He or she will be able to help you understand the information you have found and what it means for you.

Part 2: General information about medicines

Some facts and figures about medicines

- There are more than 3,000 prescription medicines available in the UK, all of which have undergone strict testing.
- It takes an average of ten to twelve years and £500 million to bring a medicine from the laboratory to the point where it can be given to patients.
- The great majority of medicines research, to discover and develop new medicines, is done by the pharmaceutical industry. Other organisations that fund research include charities, the Department of Health and the Medical Research Council.
- There are several hundred new medicines being developed in the UK for a range of diseases.
- No company makes medicines for all conditions – most specialise in a number of areas.
- All pharmaceutical companies have doctors working for them who know about the diseases their products are designed to treat. But you should always take any questions to your health professional first.
- Medicines relieve pain and suffering and save many lives, but they are not always the only answer. It's important that you understand the options and tell your health professional what matters to you in your treatment.

How are medicines authorised?

- The first research on a new medicine is done in a laboratory. If the results are promising, it is then studied in animals, under strict ethical and legal controls. This is to investigate effects that computers and test-tubes cannot predict.
- After that, three phases of clinical trials take place, under strict guidelines. This is to find out how the new medicine works in humans, to decide how large a dose is needed, and to check that it does not produce unacceptable side effects.
- Finally, many patients – perhaps several thousand – take the medicine under expert supervision for a specified period. It is tested in comparison with an established treatment and/or a dummy medicine (placebo).
- If the results show that the drug works, is safe and is of high quality, all the evidence is presented to the Government's Medicines and Healthcare Products Regulatory Agency. If they are satisfied by the evidence, they issue a marketing authorisation (licence).
- The authorities then watch the newly licensed medicine carefully in large numbers of patients to confirm that it works and is safe in general use.

Making sure medicines are safe

The Medicines and Healthcare products Regulatory Agency (MHRA) is the government agency responsible for ensuring that medicines, healthcare products and medical equipment work, and are acceptably safe. We keep watch over medicines, and take necessary action to protect the public promptly if there is a problem.

If you think a medicine has caused an unwanted side effect or reaction, you can report the problem to the MHRA through the Yellow Card scheme. Yellow Card reports are completely confidential. We collect them from both healthcare professionals and patients, on all types of medicines. These include prescription medicines, medicines bought over the counter, and herbal and other complementary remedies.

Even if you are unsure whether a side effect was caused by a medicine or combination of medicines, please complete a Yellow Card form. Forms can be found in pharmacies and other outlets across the NHS. They are also available directly from the Yellow Card hotline on freephone 0808 100 3352 or can be completed on the web at **www.yellowcard.gov.uk**

www.mhra.gov.uk



Part 3: Directory of helpful organisations

This part of the booklet is a Directory of websites and phone numbers where you can go to get information about health and medicines.

The Directory can also be found at **www.askaboutmedicines.org**, where you can click on website addresses to go straight to them. You can also download a copy of the whole booklet for printing.

All the information in this Directory was correct in May 2007. But web addresses and phone numbers do change. Whenever we learn of something that needs to be changed we update the online Directory. But we can't usually make the changes to the downloadable booklet immediately. So if you find something in here out of date, go to the online Directory if you can, where you should find the latest information. If necessary, please let us know by emailing info@askaboutmedicines.org.

Organisations listed in the Directory are grouped under headings referring to the area of the body concerned (for example, "hearing and sight", "liver and kidneys", "muscles, bones and joints").

This Directory will provide you with a good starting point but it is not intended to provide all the answers. It would be impossible to list every helpful website. Most of the websites listed will have links to other sites. If you speak to someone from a Helpline who cannot answer your questions, they may be able to tell you how to find someone who can.

Getting started

Basic tips and help with searching the internet:

- A Basic Tutorial on Searching the Web:
www.sc.edu/beaufort/library/pages/bones/bones.shtml
- Ask Bruce at BBC on the internet:
www.bbc.co.uk/webwise/askbruce/articles/search/index.shtml
- Power Searching for Anyone:
www.searchenginewatch.com/facts/article.php/2156031

Health Gateways

A gateway (sometimes called a portal) is a website that provides an easy route to other sites.

You can find links to patient organisations and support groups at:

- Long-term Conditions Alliance: www.ltca.org.uk
(choose “Do you need help with a long-term condition?” on the homepage)
- Patient UK: www.patient.co.uk/selfhelp.asp
- UK Self Help: www.ukselfhelp.info
- Contact a Family (for families with disabled children):
www.cafamily.org.uk/dirworks.html

Good general information about health is available at:

- NHS Direct Online: www.nhsdirect.nhs.uk
- Net Doctor: www.netdoctor.co.uk
- BBC Health: www.bbc.co.uk/health

Judging Website Quality

The guideline available from Judge Health (www.judgehealth.co.uk) will help you make your own way through the large quantity of information on the internet and to judge the quality of the sites you find.

Medicines Information

By law, every licensed medicine must come with a Patient Information Leaflet (PIL). These are produced by the manufacturer and approved by the Government's medicines regulator. The electronic Medicines Compendium (eMC) contains PILs and other information about thousands of UK medicines. It is updated daily and available at **www.emc.medicines.org.uk**.

For blind or partially sighted people, there are PILs in different formats at **www.xpil.medicines.org.uk**, together with information about the RNIB Medicines Information Line. This is free to use and available 24 hours a day, 7 days a week on **0800 198 5000**.

The Medicines Information Project is working to provide people with information about medicines, conditions and the different treatment options available. Please visit the website at **www.medguides.medicines.org.uk** for more information.

Details of companies that make prescription medicines can be found on the ABPI website **www.abpi.org.uk**. Details of companies that make medicines you can buy without prescription are on the PAGB website **www.pagb.co.uk**.

There are codes of practice for the pharmaceutical industry and you can find them on these websites.

Search Engines

Use search engines as part of your internet search if you cannot find what you are looking for from the gateways. Some examples of search engines covering health topics are:

- Google: www.google.co.uk
- Ask: www.ask.co.uk
- AllTheWeb: www.alltheweb.com
- Yahoo: www.yahoo.com
- Windows Live: <http://www.live.com>

Allergy

British Allergy Foundation

Tel: 01322 619 898
www.allergyfoundation.com

The Anaphylaxis Campaign

Tel: 01252 542 029
www.anaphylaxis.org.uk

Allergy in Schools

Tel: 01252 542 029
www.allergyinschools.org.uk

Babies and Small Children

BLISS

(premature baby charity)
 Tel: 0500 61 81 40
www.bliss.org.uk

BDF Newlife

(birth defects)
 Tel: 08700 70 70 20
www.bdfcharity.co.uk

Bladder and Bowel

Continence Foundation

Tel: 0845 345 0165
www.continence-foundation.org.uk

CORE

(digestive disorders)
 Tel: 020 7486 0341
www.corecharity.org.uk

Incontact

(continence problems)
 Tel: 0870 770 3246
www.incontact.org

Irritable Bowel Syndrome Network

Tel: 0114 272 3253
www.ibsnetwork.org.uk

National Association for Colitis and Crohn's Disease

Tel: 0845 130 3344 / 2233
www.nacc.org.uk

Cancer

Breakthrough Breast Cancer

Tel: 08080 100 200
www.breakthrough.org.uk

Breast Cancer Care

Tel: 0808 800 6000
www.breastcancercare.org.uk

Cancerbackup

Tel: 0808 800 1234
www.cancerbackup.org.uk

Cancer Research UK

Tel: 020 7061 8355 / 0800 226 237
www.cancerhelp.org.uk

CLIC Sargent

(for children with cancer)
 Tel: 0800 197 0068
www.clicsargent.org.uk

Bowel Cancer UK

Tel: 08708 50 60 50
www.bowelcanceruk.org.uk

Cancer continued**The Lavender Trust**

(for younger women
with breast cancer)

Tel: 0808 800 6000

www.lavendertrust.org.uk

Leukaemia Research Fund

Tel: 020 7405 0101

www.lrf.org.uk

Lymphoma Association

Tel: 08 08 808 5555

www.lymphoma.org.uk

**Lynn's Bowel Cancer
Campaign**

Tel: 0870 24 24 870

www.bowelcancer.tv

Macmillan Cancer Support

Tel: 0808 808 2020

www.macmillan.org.uk

Macmillan YouthLine

Tel: 0808 808 0800

Orchid

(testicular and prostate cancers)

Tel: 020 7601 7808

www.orchid-cancer.org.uk

Ovacome

(ovarian cancer)

Tel: 020 7380 9589

www.ovacome.org.uk

Prostate Cancer Charity

Tel: 0800 074 8383

www.prostate-cancer.org.uk

Roy Castle Lung Foundation

Tel: 0871 220 5426

www.roycastle.org

Tenovus the Cancer Charity

Tel: 0808 808 10 10

www.tenovus.com

**Contraception, Pregnancy
and Sexual Health****British Pregnancy
Advisory Service**

Tel: 08457 30 40 30

www.bpas.org

Brook

Tel: 0800 018 5023

www.brook.org.uk

fpa

(formerly the Family
Planning Association)

Tel: 0845 122 8690

www.fpa.org.uk

IVF / Infertility

www.ivf-infertility.com

Marie Stopes International

Tel: 020 7574 7400

www.mariestopes.org.uk

**UK Infertility and
Parenting Forum**

www.fertilityzone.co.uk

Child and Teenage Health

Addiss – Attention Deficit Disorder
Tel: 020 8952 2800
www.addiss.co.uk

Child Growth Foundation
www.heightmatters.org.uk

Children First for Health
(general health information for children of all ages)
www.childrenfirst.nhs.uk

Contact A Family
Tel: 0808 808 3555
www.cafamily.org.uk

Great Ormond Street Hospital
(information for children and families about conditions treated at GOSH)
www.goshfamilies.nhs.uk

LifeBytes
www.lifebytes.gov.uk

Teenage Health Freak
www.teenagehealthfreak.org

WellChild
0808 801 0330
www.wellchild.org.uk

Diabetes

Better Under Seven
Tel: 0845 123 2377
www.diabetesa1c.co.uk

Diabetes Insight
www.diabetes-insight.info

Diabetes UK
Tel: 0845 120 2960
www.diabetes.org.uk

Insulin Dependent Diabetes Trust
Tel: 01604 622 837
www.iddtinternational.org

Juvenile Diabetes Research Foundation
Tel: 020 7713 2030
www.jdrf.org.uk

General Health and Medicines Information

Consumer Health Information Centre CHIC
(general advice on everyday healthcare problems)
www.chic.org.uk

CHIC Over-The-Counter
(medicines advice line)
Tel: 020 8742 7042

General Health and Medicines Information continued

Health Supplements Information Service

www.hsis.org

Medicine Chest Online

(info on medicines & food supplements available from pharmacist)
www.medicinchestonline.com

National Institute for Health and Clinical Excellence (NICE)

(national guidance on the promotion of good health and the prevention and treatment of ill health)
Tel: 020 7067 5800
www.nice.org.uk

National Pharmacy Association

www.npa.co.uk

Hearing and Sight

Hearing Concern

Tel: 0845 074 4600
www.hearingconcern.org.uk

International Glaucoma Association

Tel: 0870 609 1870
www.iga.org.uk

National Deaf Children's Society

Tel: 0808 800 8880
www.ndcs.org.uk

Royal National Institute of the Blind

Tel: 0845 766 9999
www.rnib.org.uk

RNID

(for deaf and hard of hearing people)
Tel: 0808 808 0123
textphone 0808 808 9000
www.rnid.org.uk

Sense

(for deaf/blind people)
Tel: 0845 127 0060
textphone 0845 127 0062
www.sense.org.uk

Heart, Blood and Circulation

Anti Coagulation - Europe

Tel: 020 8289 6875
www anticoagulationeurope.org

Arrhythmia Alliance

Tel: 01789 450 787 (24 hours)
www.aral.org.uk

Blood Pressure Association

020 8772 4994
www.bpassoc.org.uk

British Cardiac Patients Association

Tel: 01954 202 022
www.bcpa.co.uk

British Heart Foundation

Tel: 08450 70 80 70
www.bhf.org.uk

Cardiomyopathy Association

Tel: 01494 791 224
www.cardiomyopathy.org

Childrens Heart Foundation

Tel: 0808 808 5000
www.childrens-heart-fed.org.uk

Deep Vein Thrombosis

www.inate.org

Haemophilia Society

0800 018 60 68
www.haemophilia.org.uk

Hearts for Life

www.heartsforlife.co.uk

Heartline

(for children with heart conditions and their families)
Tel: 01276 70 76 36
www.heartline.org.uk

H-E-A-R-T UK

Tel: 01628 628 638
www.heartuk.org.uk

Sickle Cell Society

Tel: 0800 001 5660
www.sicklecellsociety.org

Stroke Association

Tel: 0845 30 33 100
www.stroke.org.uk

HIV and AIDS**National AIDS Trust**

Tel: 020 7814 6767
www.nat.org.uk

Terrence Higgins Trust

Tel: 0845 12 21 200
www.tht.org.uk

UK Coalition of Patients living with HIV and AIDS

Tel: 020 7564 2180
www.ukcoalition.org

You Choose

www.youchoose.org.uk

Infections**British Polio Fellowship**

Tel: 0800 01 80 586
www.britishpolio.org.uk

Encephalitis Information Resource

Tel: 01653 699 599
www.encephalitis.info

Meningitis Research Foundation

24-hour helpline
Tel: 08 08 800 3344 (UK)
Tel: 1800 41 33 44 (IRE)
www.meningitis.org

Meningitis Trust

24-hour helpline
Tel: 0800 028 18 28 (UK)
Tel: 1800 523 196 (IRE)
www.meningitis-trust.org

RAPPID

(Paediatric Pneumococcal Infection)

Tel: 0845 07 07 620

www.rappid.org.uk

The Herpes Viruses Association

Tel: 0845 123 2305

www.herpes.org.uk

Learning Disabilities and medicines information for people with learning difficulties

National Society For Epilepsy
(epilepsy and learning disabilities)

Tel: 01494 601 400

www.epilepsynse.org.uk/pages/info/leaflets/learning.cfm

The Elfrida Society

(accessible health information for people with learning disabilities)

Tel: 020 7359 7443

<http://www.elfrida.com/health2.htm>

SCOPE

(cerebral palsy)

Tel: 0808 800 3333

www.scope.org.uk

MENCAP

Tel: 0808 808 1111

www.mencap.org.uk

Liver and Kidney**British Kidney Patient Association**

Tel: 01420 47 20 21

www.britishkidney-pa.co.uk

British Liver Trust

Tel: 0870 770 8028

www.britishlivertrust.org.uk

Children's Liver Disease Foundation

Tel: 0121 212 3839

www.childliverdisease.org

National Kidney Federation

Tel: 08456 01 02 09

www.kidney.org.uk

National Kidney Research Fund

Tel: 0845 070 7601

www.nkrf.org.uk

Men's Health**Lovelifife Matters**

(for female partners of men with erection problems)

Tel: 0800 068 2204

www.lovelifematters.co.uk

Men's Health Forum

Tel: 020 7388 4449

www.menshealthforum.org.uk

Men's Health on the BBC

www.bbc.co.uk/health/mens

NetDoctor Erectile Dysfunction Community

www.netdoctor.co.uk/erectiledysfunction/index.shtml

Sexual Dysfunction Association

Tel: 0870 774 3571
www.sda.uk.net

Mental Health**Depression Alliance**

Tel: 0845 123 23 20
www.depressionalliance.org

First Steps to Freedom (anxiety disorders)

Tel: 0845 120 2916
www.first-steps.org

Hearing Voices Network

Tel: 0845 122 8642
www.hearing-voices.org

Jewish Association for the Mentally Ill

Tel: 020 8458 2223
www.jamiuk.org

Making Space

Tel: 01925 571 680
www.makingspace.co.uk

MDF The BiPolar Organisation

Tel: 08456 340 540
www.mdf.org.uk

Mental Health Foundation

Tel: 020 7803 1101
www.mentalhealth.org.uk

Mind

Tel: 0845 766 0163
www.mind.org.uk

National Institute For Mental Health in England

Tel: 0113 25 45 127
www.nimhe.org.uk

OCD Action

(for Obsessive Compulsive Disorder)
Tel: 0845 390 6232
www.ocdaction.org.uk

Psychiatric Medication Helpline (South London & Maudsley NHS Trust)

Tel: 020 3228 2999

Rethink

Tel: 020 8974 6814
www.rethink.org

SANE

Tel: 0845 767 8000
www.sane.org.uk

Young Minds

(Parents' Information Service)
Tel: 0800 018 2138
www.youngminds.org.uk

Migrane and Pain

Action On Pain

Tel: 0845 603 1593
www.action-on-pain.co.uk

Migraine Action Association

Tel: 01536 461 333
www.migraine.org.uk

Migraine Trust

Tel: 020 7462 6601
www.migrainetrust.org

Pain Concern

Tel: 01620 822 572
www.painconcern.org.uk

Pain Relief Foundation

Tel: 0151 529 5820
www.painrelieffoundation.org.uk

Muscles, Bones and Joints

Arthritis Care

Tel: 0808 800 40 50
www.arthritiscare.org.uk

Arthritis Research Campaign

Tel: 0870 850 5000
www.arc.org.uk

Back Care

Tel: 0845 130 2704
www.backcare.org.uk

Brittle Bone Society

Tel: 0800 028 2459
www.brittlebone.org

Children's Chronic Arthritis Association

Tel: 01905 745 595
www.ccaa.org.uk

LUPUS UK

Tel: 01708 731 251
www.lupusuk.com

National Ankylosing Spondylitis Society

Tel: 020 8948 9117
www.nass.co.uk

National Osteoporosis Society

Tel: 0845 450 0230
www.nos.org.uk

National Rheumatoid Arthritis Society

Tel: 0800 298 7650
www.rheumatoid.org.uk

UK Gout Society

www.ukgoutsociety.org

Neurological Conditions

Alzheimer's Society

Tel: 0845 300 0336
www.alzheimers.org.uk

Brain and Spine Foundation

Tel: 0808 808 1000
www.brainandspine.org.uk

Epilepsy Action

Tel: 0808 800 5050
www.epilepsy.org.uk

Epilepsy Bereaved

Tel: 01235 772 852 (24 hours)
www.epilepsybereaved.org.uk

Huntingdon's Disease Association

Tel: 020 7223 7000
www.hda.org.uk

National Society for Epilepsy

Tel: 01494 601 400
www.epilepsynse.org.uk

Neurological Alliance

Tel: 020 7566 1540
www.neural.org.uk

Motor Neurone Disease Association

Tel: 08457 62 62 62
www.mndassociation.org

Multiple Sclerosis Resource Centre

Tel: 0800 783 0518
www.msrmc.co.uk

Multiple Sclerosis Society

Tel: 0808 800 8000
www.mssociety.org.uk

Multiple Sclerosis Trust

Tel: 01462 476 700
www.mstrust.org.uk

Muscular Dystrophy Campaign

Tel: 020 7720 8055
www.muscular-dystrophy.org

Parkinson's Disease Society

Tel: 0808 800 0303
www.parkinsons.org.uk

Progressive Supranuclear Palsy Association

Tel: 01939 270 889 (North)
Tel: 020 7676 2128 (South East)
Tel: 01934 316 221 (South West)
www.pspeur.org

NHS Information

Directory of GP websites

www.click-for-health.com

NHS Direct

(England & Wales)
Tel: 08 45 46 47
www.nhsdirect.nhs.uk

NHS 24

(Scotland)
Tel: 08454 24 24 24
www.nhs24.com

NHS England

www.nhs.uk

NHS Northern Ireland

www.healthandcareni.co.uk

NHS Scotland

www.show.scot.nhs.uk

NHS Wales

www.wales.nhs.uk

Obesity & Eating Disorders**beat**

(eating disorders)
Tel: 0846 634 14 14
www.b-eat.co.uk

beat for young people

Tel: 0845 634 76 50
textline: 07786 20 18 20
www.b-eat.co.uk/YoungPeople

National Obesity Forum

Tel: 0115 846 2109
www.nationalobesityforum.org.uk

TOAST

Tel: 01279 866 010
www.toast-uk.org.uk

Weight Wise

www.bdaweightwise.com

Older People's Health**Age Concern**

Tel: 0800 00 99 66
www.ageconcern.org.uk

Alzheimer's Society

Tel: 0845 300 0336
www.alzheimers.org.uk

Help The Aged

Tel: 020 7278 1114
www.helptheaged.org.uk

Oral Health**Dental Health Foundation**

Tel: 0845 063 1188
www.dentalhealth.org.uk

**UK and Ireland Internet
Dental Guide**

www.dentalguide.co.uk

Patients and Carers**Patients Association**

Tel: 0845 608 4455
www.patients-association.com

Carers UK

Tel: 0808 808 7777
www.carersuk.org

Crossroads Caring for Carers

Tel: 0845 450 0350
www.crossroads.org.uk

Princess Royal Trust for Carers

Tel: 020 7480 7788
www.carers.org

Respiratory Conditions**Action Asthma**

www.actionasthma.co.uk

Asthma UK

Tel: 08457 01 02 03
www.asthma.org.uk

British Lung Foundation

Tel: 08458 50 50 20
www.lunguk.org

Cystic Fibrosis Trust

Tel: 0845 859 1000
www.cftrust.org.uk

Skin

Acne Support Group

Tel: 0870 870 2263
www.stopspots.org

LUPUS UK

Tel: 01708 731 251
www.lupusuk.com

National Eczema Society

Tel: 0870 241 3604
www.eczema.org

Psoriasis Association

Tel: 0845 676 0076
www.psoriasis-association.org.uk

Skin Care Campaign

www.skincarecampaign.org

Vitiligo Society

Tel: 0800 0168 2631
www.vitiligosociety.org.uk

Stopping Smoking

ASH

(Action on Smoking
and Health UK)
Tel: 020 7739 5902
www.ash.org.uk

Go Smokefree

(NHS Stop Smoking service)
Tel: 0800 169 0169
www.gosmokefree.co.uk

QUIT

Tel: 0800 00 22 00
www.quit.org.uk

The Time Is Right

www.thetimeisright.co.uk

Travel Medicine and Health

Foreign and Commonwealth Office

www.fco.gov.uk (choose “Travel
Advice” and then “Travel Health”
from menus)

Malaria

www.malariahotspots.co.uk

MASTA

www.masta-travel-health.com

National Travel Health Network and Centre

Tel: 0845 155 5000 ext 5943
www.nathnac.org

Travel Health

www.travelhealth.co.uk

Vaccines

Department of Health

<http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Immunisation/index.htm>

Health Protection Agency

http://www.hpa.org.uk/infections/topics_az/vaccination/vacc_menu.htm

UK Vaccine Industry Group
(information for the public on vaccines)
www.uvig.org

APMSD

(general information about vaccines for children, adults and travel)
www.apmsd.co.uk

Women's Health

Amarant Trust

(menopause info)
Tel: 01293 413 000
www.amarantmenopausetrust.org.uk

Endometriosis SHE Trust (UK)

Tel: 08707 743 664/5
www.shetrust.org.uk

fpa

(formerly the Family Planning Association)
Tel: 0845 122 8690
www.fpa.org.uk

National Association for Premenstrual Syndrome

Tel: 0870 777 2177
www.pms.org.uk

National Childbirth Trust

Tel: 0870 444 8707 (enquiries)
8708 (breastfeeding)
8709 (pregnancy & birth)
www.nct.org.uk

Endometriosis UK

Tel: 0808 808 2227
www.endo.org.uk

Women's Health

www.womenshealthlondon.org.uk

Women's Health Concern

Tel: 0845 123 2319
www.womens-health-concern.org

Women's Health Information

www.womens-health.co.uk

This booklet was originally developed as part of the first Ask About Medicines Week in 2003, under the title Health & Medicines Information Guide & Directory. It proved so popular that we are now on the third edition, with updated information and even more valuable advice to help you make informed decisions about your health and the medicines you may be taking.

Ask About Medicines and its annual campaign Ask About Medicines Week are initiatives of AAMW Ltd, an independent company limited by guarantee. A wide range of organisations including voluntary, health professional, commercial and statutory bodies have come together as partners to support these initiatives.

The Directors of AAMW Ltd are David Dickinson, Melinda Letts and Joanne Shaw (Chair). To find out more about the Directors, visit **www.askaboutmedicines.org** and look under “Background”.

This booklet has been produced in partnership with the Association of the British Pharmaceutical Industry (ABPI), who also covered the costs. The pharmaceutical industry regularly provides non-promotional information about medical conditions and treatment options and regulated information about individual medicines.

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You can find an interactive version of the Directory, with links to all the websites listed, at **www.askaboutmedicines.org**. You can download printable copies from the same address or from **www.abpi.org.uk**. To order hard copies, telephone 01795 427 614 or email **abpi@edist.co.uk**.

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The Association of the
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www.abpi.org.uk



www.askaboutmedicines.org