The informed patient: friend or foe?

Like the use of the internet, the informed patient is a growing phenomenon. In this article, Marjorie Weiss looks at how pharmacists can deal with them.

Although GPs remain a common source of health information for patients, people also use a range of other sources, such as the internet, leaflets, books, newspapers and magazines, nurses, pharmacists, family and friends. The changing attitude towards patients within the UK health care system — illustrated by Government initiatives, such as the Expert Patients Programme — and the increased access to information (eg, on the world wide web) have made it easier for patients to take more responsibility for their health and have prompted them to ask more questions.

It is estimated that 32 per cent of Europeans and 53 per cent of Americans search the internet for health information, with websites becoming as important as non-internet sources for health information. This knowledgeable patient-consumer, the “informed patient”, has become a fact of modern life and, given that younger people are more likely to access the internet than older people, this phenomenon is unlikely to diminish in the coming decades. Health care professionals need to recognise that patients want more information and are prepared to search for it.

Health care professionals need to recognise that patients want more information

Motivations and perceptions

Patients seek health information for a variety of reasons, including a desire to find out what is wrong, wanting to learn more about a specific clinical condition or treatment, to help with self-care or to decide when it would be appropriate to consult a health care professional.

After seeing a health professional, people can also search for information as a way of reassuring themselves that they know all that is available: to ascertain the veracity of what they have been told or to find out about treatment options that may not have been covered in the consultation. This checking on information may be more likely if a patient is dissatisfied with a consultation. Research suggests that when accessing information on the internet, patients seek out websites aimed at health care professionals because they want to have access to more complex information.

Health care professionals may not always view a patient coming to see them, loaded with information from family, friends or the internet, with complete equanimity. Some may feel threatened by an informed patient, perceiving that their professional knowledge is being challenged by someone who, for whatever reason, has felt the need to access information traditionally kept within the domain.
Panel 1: Tips for dealing with an informed patient

(1) Be honest if you do not know the answer
If the question or topic is something you do not have a clue about, be honest about it. However, you could read through the material with the patient and make a professional judgement.

(2) Listen to the patient
Let patients tell their story as to what information they feel they need and why they need it. For example, were they worrying about something specific? Had they tried to get this information from any other sources? What difficulties had they had in getting the information they needed? Ask them what is concerning them and from what they found out, what they think the answers are. In truth, their perceived answers are probably what is concerning them.

(3) Manage your time
You might not be able to give advice immediately. If you are short of time, ask the patient to come back when you are less busy. You might also need time to look at the information property. If the information is conflicting between different sources, you will need to identify the more accurate one and this can also take time.

(4) Help the patient to identify good internet sources
Ask patients to show you where they have sourced their information and indicate which of these sources are reliable and which are not.

(5) Be wary of everything that is available on the internet
Explain that some information is published on the web can be one-sided. Just as we are advised not to purchase goods from sites without the “padlock”, the recognised symbol for trusted sites where money is exchanged for goods, not all health-related websites are trustworthy.

Panel 1: Tips for dealing with an informed patient

A discussion of how to handle such an interaction using a specific clinical example follows. Although this article chief focuses on information accessed from the internet, the overall strategy for dealing with an informed patient and many of the principles for judging the quality of health information can be applied to many situations regardless of the source of health information.

The interaction
A regular customer, Samantha Jones, comes into your pharmacy clutching a sheaf of papers which, she says, is all about Femodene — the new GP in the local surgery has prescribed it for her. From searching on the internet, she has found that Femodene can cause blood clotting. You dispensed the pills to her a few days ago but she is thinking “maybe I should stop taking them”. There are two basic steps to the consultation:

- Gather information
- Provide additional information or reassure as appropriate

Gather information The first stage in dealing with an informed patient is to listen fully and find out what prompted him or her to look up the information. Was Ms Jones worried about something in particular? Was she dissatisfied with her consultation with the new GP? Her answers to such questions should reveal why she thinks she is particularly at risk of a blood clot (ie, what her additional risk factors are) and what she knows about why she was prescribed Femodene.

You find out that Ms Jones’s work involves considerable travelling and she is concerned that her frequent air travel, in conjunction with the Femodene, puts her at increased risk of getting a blood clot. Ms Jones does not know why she was prescribed Femodene on this occasion; she has used other oral contraceptives in the past.

Treat concerns or ideas seriously Ms Jones is clearly concerned about her risk of having a blood clot. Looking at the information she has collected will to help you understand her concerns. A frequent cause of failure in communication between a health care professional and a patient is when a patient feels that his or her views have been devalued or dismissed, or that the health professional has failed to understand his or her perspective.

In this case, Ms Jones’s anxiety about having a blood clot, even though the risk is small, is a legitimate issue for an individual taking an oral contraceptive to be concerned about. However, even if the concern was completely irrational from a pharmacological perspective, it would be important to uncover it and acknowledge the patient’s viewpoint.

Inform or reassure as appropriate From your own knowledge, or after consulting your own internet sources (see Panel 2), you can reassure Ms Jones as to the relative risks of thromboembolism when taking
Femodene compared with traditional second generation oral contraceptives (25 v 15 cases per 100,000 women per year of use) and compared with the risk of thromboembolism in pregnancy (60 cases per 100,000 pregnancies).

Information about the risks of third generation oral contraceptives can be found in the British National Formulary and the Bandolier website. The NHS Direct website provides useful advice on the risks of thromboembolism associated with long-haul air travel, as well as useful strategies for prevention. This website discusses the uncertainty regarding our current state of knowledge concerning long-haul air travel and thromboembolism (eg, that it is not known whether the flight itself causes the thrombosis or whether people who have a thrombosis after air travel were at risk for other reasons). This uncertainty should be conveyed to the patient underlying an inherent feature of much clinical information: not all of it provides definitive black and white answers and medical knowledge is always evolving. The uncertainty around current evidence needs to be communicated to the patient.

This may also be a good opportunity to make Ms Jones aware of the variation in quality of information on the internet so she can develop her own skills as a critical user of health information websites. The Health on the Net (HON) Foundation has developed a code of conduct which describes eight key ethical principles that website producers should abide by when presenting health care information:4

- Authority — the website indicates the qualifications of authors
- Complementariness — the information presented should support, not replace the doctor-patient relationship
- Privacy — the website owner should respect the privacy and confidentiality of personal data submitted to the site by the visitor
- Attribution — the website should cite the source(s) of published information, date and medical and health pages
- Justifiability — the website must back up claims relating to benefit and performance
- Transparency — the website should include identities of editor and webmaster, and the editor should be accessible (eg, an accurate e-mail contact is provided)
- Financial disclosure — the website should identify funding sources
- Sponsorship — the website should clearly differentiate between advertising and editorial content

Health-related websites are under no obligation to incorporate these key principles but may display the HONcode logo which, when accessed, will indicate whether the site is still endorsed by the HON. Taking this one stage further, a recent UK project called Judge Health provides detailed advice for consumers on how to search the internet for health information, how to judge the quality of a website and how to manage information in partnership with health care professionals.3 This site was developed by the Information Research Management Research Institute at Northumbria University in partnership with the charity Contact a Family. The Judge Health project’s consumer guidelines were developed to help consumers make informed decisions about websites (see Panel 3, p146).

**Acting as an internet guide**

When dealing with an informed patient, there are several options for how to provide infor-
mation. It can be presented verbally to the patient from the pharmacist’s own knowledge, or it may be possible for the pharmacist and patient to access the sites together in the pharmacy. A third possibility is for the pharmacist to access the internet first and present the information to the patient at a later time.

Finding appropriate, high quality information which is of relevance to the patient’s concerns does take time. As noted by one pharmacist (Panel 1), do not be afraid to arrange a appointment with the patient at a future time so you can read the information properly. Another option is for the pharmacist to be the patient’s “internet guide” by making him or her aware of the quality issues in internet health information and suggesting useful websites that can be accessed alone. Whatever approach is taken, it is important for pharmacists to identify the pharmacy profession as a useful resource for health information.

This role of internet guide may be particularly appropriate if you are approached by a friend or family member in an informal or social situation for advice about medicines or a condition. One strategy for managing such situations is to empower patients to access appropriate information themselves before seeing their doctor.

These situations can be particularly problematic because you are unlikely to have access to all the medical or pharmaceutical information about the patient and, in situations where there may have been poor communication between the patient and a professional colleague, you would not wish to judge another professional without having full information.

The situation may mean that the individual needs to be referred to his or her GP. As an internet guide, the pharmacist could encourage the person to prepare a list of questions to ask the GP at the appointment.

Panel 3: How to judge the quality of a website

Issues that should be considered in order to judge the quality of a health-related website include:

- Trust and reputation Is the website reputable and trustworthy?
- Identity Who or what organisation produced the site?
- Purpose What are the website’s aims and who is its audience?
- Funding sources Who funds the site?
- Date When was the site last updated or reviewed?
- Bias How is the information written — is a balanced view provided?
- Accuracy Who wrote descriptions of conditions and treatments and what sources did they use?
- Medical research How is complex medical research explained?
- Personal experiences Are personal experiences clearly marked as personal?
- Foreign sites Different health systems may have different terms or health care practices
- Communication Can the website owner be contacted easily?
- Links Why and how have links been chosen?
- Disclaimers What are the site’s terms and conditions and are issues, such as privacy, copyright and accuracy of information, covered?
- Kitemarks Is the site endorsed by another organisation?
- Design Is personal information private and secure? Are advertisements clearly marked? Is the website it easy to use?
- Interactive facilities Are there e-mail lists, bulletin boards, chat rooms? If so, what are the required rules for polite, supportive behaviour?

References
5. The Judge project for judging the quality of health information on websites. Available at: www.judgehealth.org.uk/consumer_guidelines.htm (accessed 1 December 2006).

Action: practice points

Reading is only one way to undertake CPD and the Society will expect to see various approaches in a pharmacist’s CPD portfolio.

1. Visit some of the websites in Panel 2 and judge for yourself how useful these websites are to your practice.
2. Use the criteria in Panel 3 to evaluate the quality of your favourite health-related website.
3. Try incorporating some of the techniques suggested in this article (eg, focusing on the patient’s perspective) the next time an informed patient visits your pharmacy.

Evaluate

For your work to be presented as CPD, you need to evaluate your reading and any other activities. Answer the following questions: What have you learnt? How has it added value to your practice? (Have you applied this learning or had any feedback?) What will you do now and how will this be achieved?