

A practical guide to on-line health sites

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LET'S say you're feeling unwell and want advice. You contact your doctor and the receptionist says she can fit you in next week. You don't want to wait that long, so what do you do?

Do you go to the local hospital's emergency department and possibly wait for hours, or do you try to find out the information you need some other way?

This is why the Internet is starting to revolutionise medical care in so many ways, because it's easily accessible and readily available 24/7.

It also fills the gap in medical services that exists in some countries less fortunate than Australia such as the United States, where access to health care is restricted to people's ability to pay rather than their need.

Some people prefer online medical advice because they are too embarrassed to see a doctor and feel that their doctor may not understand of their problem.

Others want to know more details about their diagnosis, to check on the latest research or perhaps feel they need a second opinion.

Still others are fine themselves but care for loved ones and need information to help them.

THE MAN BEHIND THIS RESEARCH

This article was inspired by an interview I heard in early 2011 on ABC radio with Andrew Schorr. Schorr is an American medical journalist who was diagnosed with chronic lymphocytic leukaemia in 1996.

Once he had his diagnosis he went searching the Web for more information. He identified the experts in lymphocytic leukaemia treatment and was invited to take part in a clinical trial. That trial led to his lasting remission.

Today he is a leading broadcaster on health matters, founder of the Patient Power website (www.patientpower.info/) and author of *The Web-Savvy Patient: an Insider's Guide to Navigating the Internet When Facing Medical Crisis*, published earlier this year.

I have not read the book but have read glowing reviews. Therefore the information today comes from my own extensive research plus what Andrew Schorr himself has said in various media interviews.

Of course, many of us have been in Andrew Schorr's shoes. We have been told we are suffering from XYZ disease but not much more.

That's when we turn to others apart from our GP for more information.

HOW ATTITUDES CHANGE

Now, just leaving the Web to one side for the moment, where do you think most Australians go for initial medical advice? This reminds me of a short history of Medicine

The patient says: "I have an earache."

This is how the medicine man responded at different eras.

2000 B.C. - *Here, eat this root.*

1000 A.D. - *That root is heathen. Here, say this prayer.*

1850 A.D. - *That prayer is superstition. Here, drink this potion.*

1940 A.D. - *That potion is www. Here, swallow this pill.*

1985 A.D. - *That pill is ineffective. Here, take this antibiotic.*

2013 A.D. - *That antibiotic is artificial. Here, eat this root.*

ROLE OF NBN

As Australia's population ages, the pressure is increasing on health services to support sufferers of chronic illnesses, such as heart conditions.

The National Broadband Network is designed to help alleviate some of these pressures by enabling in-home health solutions such as personal health monitors.

These monitors, about the size of a toaster, can connect to specific medical devices, including blood pressure monitors, glucose meters and weight scales.

Doctors and other health care professionals can remotely review and act on this information using a secure server on the NBN.

MORE DOCTORS TWEETING

As a result, doctors have ongoing access to data so that they can better manage each patient's conditions. Patients benefit from customised care in the comfort of their home and can also monitor their health status and communicate with care teams.

Meanwhile Australian doctors are taking to social media in greater numbers, and new research at the University of Adelaide is looking at what doctors consider to be the main risks of 'consulting' with the public in this way.

Media Studies Masters student, Margarita Flabouris, says there has been increasing encouragement within the Australian medical profession to use social media, but there are minimal guidelines currently available for the profession.

“The main message has been: this is new technology so we should use it. But there's still little understanding among many health professionals about how or why to use it, how to use it well, and what the pitfalls might be,” Ms Flabouris says.

"Most doctors use Twitter for peer to peer communication, but some are using it for health promotion and marketing purposes, providing information about health to the general public.

"This raises a number of questions about how to do this in a way that really engages with the public, how to provide information that is relevant to other social media users, and whether issues such as patient confidentiality and privacy are taken into consideration when discussing medical conditions.”

One frequent tweeter, a professor, supports social media and added "Also, if there are real problems with information out there in social media - such as about a drug or a device, and people are getting the wrong message - it's relatively easy to correct it by using social media.”

WHAT SITES CAN YOU TRUST?

So while doctors sort out what they can do on line, what about us – the patients?

And aside from these future technological solutions to put us in touch remotely with medical specialists, can you trust the Internet generally for medical advice?

The answer is perhaps! As one commentator wrote: “If you want to buy something good, you have to shop around. In the same way, to gain good medical advice, you have to shop around and find those sites that are genuine.”

Millions of Australians search for health information on the web every year. Sometimes the information found is just what was needed.

Other searches end in frustration or retrieval of inaccurate, even dangerous, information.

American critics advise sick people to avoid online doctors. Why? Because of the difficulty of suing them if the diagnosis is wrong!

They also say getting medical information from your computer poses clear dangers for consumers - and some serious implications for doctors. If patients delay seeking medical attention, for example, the burden on doctors to treat them may increase.

EVEN MICROSOFT HAS DOUBTS

Even Microsoft says some health websites have the potential to escalate a Web searcher's medical concerns.

The software giant asked 5,000 of its employees in 2008 about their medical search habits. Nearly 90 per cent said they had searched for the symptoms of a basic medical condition and found information on more serious illnesses.

Eric Horvitz, an artificial intelligence researcher at Microsoft Research, said many people treated search engines as though they could answer questions like a doctor. "People tend to look at just the first couple of results. If they find 'brain tumour' that's their launching point," he said.

In addition to the survey, Microsoft researchers also anonymously analysed health-related searches made using its Live Search website.

They found that roughly two per cent of all web searches were health-related, and said around a third of people "escalated" their follow-up searches to explore serious illnesses.

DON'T DIAGNOSE YOURSELF

A more recent American study said while many of us are tempted to turn to the Internet and look up symptoms at least 20 percent of the time your search will lead you astray.

The study, which focused on sports injuries like tennis elbow and knee ligament tears, points out the widespread dangers of diagnosing yourself on the web for all sorts of medical conditions.

Following bad medical advice can be harmful for patients and a pain for doctors who have to spend time correcting misinformation before settling on the best treatment plan.

For example doctors at the Carolinas Medical Centre in Charlotte, North Carolina noticed that many of their patients were coming in with misinformed ideas they had found on the Internet about how best to treat their problems.

To gauge the problem's prevalence, researchers searched Yahoo and Google for 10 common sports medicine diagnoses.

Results, published in the *US Journal of Bone and Joint Surgery*, revealed a huge amount of variability in the quality of sites that turned up, especially among academic and commercial sites. Nearly half of the top 10 sites were commercial.

Some of the commercial sites were surprisingly good. More often, though, commercial sites were sponsored by companies trying to sell products for diagnosing or treating the condition.

Those were less trustworthy -- usually promoting their products as the best option without any evidence to support their claims. Some 20 percent of all results fell into this category.

IS THE SITE UP TO DATE?

In general, the sites of non-profit and educational organizations scored the highest. But even then, it can be hard to tell whether a site is inaccurate, incomplete or outdated, said Gary Schwitzer, publisher of [HealthNewsReview](http://healthnewsreview.org/), (<http://healthnewsreview.org/>) a site that monitors the media for inaccurate health information.

In the fast-paced world of health care, following guidelines that are even just five years old can be dangerous.

"The democratization and access to information that the web allows is viewed as a good thing, but there is, on the other hand, so much disease-mongering," Gary Schwitzer said.

"So, the spectrum is very clearly one of strong benefits at one end and strong potential harms at the other."

WHERE TO GET ACCURATE INFORMATION

This guide is based principally on the collective wisdom the US Medical Library Association (MLA), whose primary purpose is promoting quality information.

(While it is aimed at mainly finding reliable information on conditions and diseases, you can also use the same techniques to find out more about drugs your doctor may prescribe, including their possible side effects).

As you may have discovered, clicking on a favourite search engine and entering a disease or medical condition can often result in hundreds, even thousands, of "hits." This can be discouraging.

Here are a few ideas for filtering the available web pages to a manageable number:

Search by diagnosis

Andrew Schorr, the patient who inspired this report, insists that you get a medical diagnosis before you going searching the Web.

Otherwise, if you just search for symptoms, you'll be inundated with hundreds, perhaps thousands, of results.

Use advanced search tools

If you are using a search engine such as Google, learn how to use the advanced searching features so that you can combine terms to make your retrieval more precise. For example, entering the term "cancer" and "chemotherapy" linked together is more precise than trying to read through all the links found by entering the general term "cancer."

Even better is to use the full medical name for your condition – if in doubt about spelling, ask your doctor to print it out for you.

WHO DO WE ASK FIRST FOR SPECIALIST RECOMMENDATIONS?

According to a Roy Morgan research report, many of us rely in the first instance on “trusted advisors.”

These ‘trusted advisers’ help family and friends with recommendations on health and nutrition. Overall, 64% of trusted advisers are women, 28% were aged 35-49, and 45% had a diploma or a degree.

As of 2010, the proportion of ‘trusted advisers’ who bought herbal products in the last six months was almost double that of the general Australian population.

Trusted advisers were also more likely to have purchased numerous other health products in the last six months compared with the general Australian population.

They also appear more willing to spend money on health services, including doctor visits, than the general population.

Nick Williams, Healthcare Consultant at Roy Morgan Research, said: “Word of mouth can be a trusted and powerful source of information.

“Just over one-in-five of us are asked for advice on health and nutrition information by family and friends, and the same proportion seek out health and nutrition information among family and friends. This equates to large amounts of health related information being communicated within family and social circles.

“Trusted advisers on health and nutrition have a clear preference for the internet when sourcing information, with 35% nominating it as the most useful media for finding health related information.

FIND THE EXPERTS IN YOUR CONDITON

Let's get personal for a moment – in other words, who is going to treat you? Recent American research showed that 42% of Americans spend 10 times longer searching for a new car than they did researching the right doctor.

It's a startling contrast, given choosing the wrong health care provider can be more devastating (both physically and financially) than being stuck with a car that's a lemon.

Start your search for an expert by getting local opinions. Ask friends and family.

Do they have a doctor that they would recommend? Have they been (or do they know someone who was) hospitalized for a similar condition or procedure, with positive results?

Is the doctor easy to talk to? Having a good rapport with a medical professional is critical to receiving quality care. Make sure that you are comfortable communicating openly and honestly with a doctor or specialist.

TAKE YOUR SEARCH TO THE WEB

Then widen your investigation by doing a Web search.

Search for **at least three sources of information**. You will usually find some of the same names – of doctors and researchers – coming up as specialising in specific diseases or treatments or research.

The more different sites that mention a particular doctor the more certain you can be you are identifying the real specialists.

Using this triangulation technique then lets you move on to finding out, via the Web, more about each of those specialists such as where they are based, their background and research achievements.

Identifying the leading specialists in your area of medical interest is of obvious value to you. These men and women are, by definition, up to date with the latest research.

Once you know who are the real experts you can contact them direct and perhaps say you are interested in participating in clinical trials for new drugs or treatments.

Check to see if there have been any recent medical conferences on your diseases. Perhaps a new form of treatment was discussed or unveiled at a conference. You may be able to track down the papers. Who wrote the papers? That again will help you identify doctors on the leading edge of research

MORE STEPS TO TAKE

Find the best hospitals

Your on-line research may also help you identify the hospitals and research centres where patients with your particular condition appear to be having the best outcomes.

Link up with patient mentors

Use the Web to find what Schorr calls “patient mentors” – that is, other people who have the same disease and may have already been through a course of treatment. Patients are willing to share their knowledge and help you along the road.

Connecting with a community of patients often results in getting better information to support your situation than you could get if you just relied on your doctor or did blind Internet searches.

One Web site that I only recently discovered is **The Experience Project** (<http://www.experienceproject.com/>).

The Experience Project is a free social networking website of online communities devoted to connecting people through shared life experiences. It has an interactive, user-submitted network of personal stories, confessions, blogs, groups, photos, and videos, on a huge range of topics, including coping with specific health problems.

The site has collected more than seven million real-life experiences. You can join communities organized around experiences and interests, and view shared experiences to connect and interact with people.

GOOGLE ALERT

Another way of keeping up to date with developments in your ailment is to set a **Google alert**.

Go to <http://www.google.com.au/alerts> and type in your search query - say Parkinson's disease – and your email details.

TRUSTWORTHY SITES

Get to know trustworthy medical sites

Become familiar with the general health information finding tools such as the Federal government's *HealthInsite* (www.healthinsite.gov.au/index.cfm) or the American equivalent, *Healthfinder* (<http://www.healthfinder.gov>) run by the US Department of Health and Human Services,

When you have found sites that look relevant, use the guidelines below to help you decide whether the information is as credible, timely, and useful as it looks.

Try to remove the emotion from your search.

You may find it difficult to separate the objectivity of what you need to know from the fear of what you might find. Andrew Schorr suggests that if you can't remove the emotion from your searches and information gathering that **you should ask someone else to help you.**

HOW TO EVALUTE CONTENT

Use the wisdom of crowds

If 9 out of 10 Web sites say rubbing your stomach with raw onion doesn't cure cancer, tend to believe them, especially if the odd one out is claiming a world-wide medical conspiracy against onions.

Who is the site sponsor?

Can you easily identify the site sponsor? Sponsorship is important because it helps establish the site as respected and dependable. Does the site list advisory board members or consultants? This may give you further insights on the credibility of information published on the site.

The web address itself can provide additional information about the nature of the site and the sponsor's intent.

A government agency has **.gov** in the address.

An educational institution is indicated by **.edu** in the address.

A professional organization such as a scientific or research society will be identified as **.org**.

Commercial sites identified by **.com** will most often identify the sponsor as a company, for example Merck & Co., the pharmaceutical firm.

What should you know about **.com** health sites? Commercial sites may represent a specific company or be sponsored by a company using the web for commercial reasons—to sell products.

At the same time, many commercial websites have valuable and credible information. Some hospitals have **.com** in their address. The site should fully disclose the sponsor of the site, including the identities of commercial and non-commercial organizations that have contributed funding, services, or material to the site.

Is the information up to date?

As we said earlier, health information changes constantly as new information is learned about diseases and treatments through research and patient care. Web sites should reflect the most up-to-date information.

The website should be consistently available, with the date of the latest revision clearly given. This usually appears at the bottom of the page.

Is it fact or fiction?

Information should be presented in a clear manner. It should be factual (not opinion) and capable of being verified from a primary information source such as the professional literature, abstracts, or links to other web pages.

Information represented as an opinion should be clearly stated and the source should be identified as a qualified professional or organization.

Be on your guard if the author rants against the medical establishment or quotes untraceable or unbelievable testimonials of miracle cures.

Look up medical terms you don't fully understand

Much of the health-related information that you find may seem to be written in a foreign language because of the highly technical terminology used in the health professions.

One Web site which is useful in understanding medical terminology is the US Medical Library Association's "[DecipheringMedspeak](#)".

Go to http://www.mlanet.org/resources/medspeak/medspeaka_d.html

Otherwise do a Web search to find medical dictionaries.

TRUSTWORTHY (X FINGERS) CONSUMER HEALTH SITES

This is just my list. Do your own research and narrow the list down to a few favourites

And keep checking that the sites are kept current so you can keep abreast of any breakthroughs

HEALTHY AUSTRALIA

Obviously being active can reduce your chances of cancer and heart disease, and it can improve your quality of life tenfold.

HealthyActive has all the information on the Australian Government's active-lifestyle initiatives, including finding out how you measure up and tips for young children. Go to www.healthyactive.gov.au.

HEALTH INSITE

HealthInsite (www.healthinsite.gov.au/index.cfm), a site I mentioned earlier, is run by the Australian Government. It was designed as a single entry point to quality on-line information from leading health information providers, including peak health organisations, government agencies and educational and research institutions.

It covers a lot of information on all sorts of health topics plus detailed information on conditions and diseases.

MY DR

My Doctor (www.mydr.com.au/) is a site run by MIMS Australia, a leading supplier of independent medical information to Australian healthcare professionals. *MyDr* is the patient page and offers free membership in return for some of your personal details.

Is you become a member you will get enewsletters, offers and "other exciting features" and access to *myDr Plus* health information, including animations and other interactive health content.

You can also take part in online Forums where you can post your health concerns and seek support from other members.

DEPT OF HEALTH

The Federal Department of Health and Ageing (www.health.gov.au/) offers a wide range of government-style advice. For most of us the most useful info is found under the "For consumers" tab.

You will find advice on a range of ailments plus links covering such topics as sun screens, weight loss programmes, hearing services and mental health issues.

BETTER HEALTH

Victoria's Better Health Channel (www.betterhealth.vic.gov.au/) is an award-winning Australian web site, again with lots of advice and links, through a few are obviously only useful if you live in Victoria.

The Health Report on ABC Radio National covers a range of health topics. You can search their past programmes at <http://www.abc.net.au/radionational/programs/healthreport/>

DAISI

The well regarded Disability and Aged Information Service (DAISI) is based in Lismore. The website at www.daisi.asn.au has lots of helpful information including a "Latest News" section and links to more than 500 services and programmes on the Far North Coast of NSW.

MY AGED CARE

If you are looking for support for yourself or for a carer, one place to start is the support groups' page with the Department of Health (<http://www.myagedcare.gov.au/>)

GOOGLE GROUPS

Another way of communicating directly with perhaps fellow sufferers is to use Google Groups. Go to <http://groups.google.com/>

If you have some idea of what you're looking for, the easiest way to find related groups about this topic is to search all of Google Groups by using the search box at the top of most pages. The search results will show both groups and posts that match your search terms.

JEAN HAILES

Jean Hailes for Women's Health aims to provide information to help improve the health and wellbeing of Australian women. You can find out about menopause, bone health and ageing well, or get involved with a research project at www.jeanhailes.org.au

BEYOND BLUE

Of course, not all sickness is physical. Feeling sad for a long time can be as debilitating as any chronic disease, and it's harder to diagnose. beyondblue provides information on depression, anxiety and substance misuse without the social stigma. Go to www.beyondblue.org.au

But remember that groups and on-line chat rooms about health can attract their share of misinformed people and the occasional huckster.

OVERSEAS SITES WORTH CHECKING

[Cancer.gov](http://www.cancer.gov/) (<http://www.cancer.gov/>) is the official website for The American National Cancer Institute (NCI). It is the US Federal Government's main agency for cancer research and training and has many useful links

[Centers for Disease Control and Prevention](http://www.cdc.gov/) (<http://www.cdc.gov/>) is dedicated to promoting "health and quality of life by preventing and controlling disease, injury, and disability."

familydoctor.org (<http://familydoctor.org/>) is operated by the American Academy of Family Physicians (AAFP), a national medical organization representing more than 93,700 family doctors. It is more general but easy to follow.

[Healthfinder®](http://www.healthfinder.gov/) (<http://www.healthfinder.gov/>) is a gateway to US consumer health information website. Menu lists on its home page provide links to online journals, medical dictionaries and prevention and self-care.

[MayoClinic](http://www.mayoclinic.com/) (<http://www.mayoclinic.com/>) is an excellent resource to the latest treatment and research into medical conditions.

Contributors include more than 2,000 doctors, scientists, and educators at the Mayo Clinic, a non-profit institution with more than 100 years of history in patient care, medical research, and education.

[MedlinePlus](http://medlineplus.gov/) (<http://medlineplus.gov/>) is the US National Library of Medicine's website for consumer health information. The site offers authoritative, up-to-date health information. Its explanatory videos on how the body works are especially good.

And finally, check the inspiration for this report at www.patientpower.info/

BACK TO THE START – CHECK WITH YOUR GP

Keep your GP advised of what you are doing. Increasingly, doctors expect their patients to do on-line research.

Tell him/her you are actively searching for alternatives to what he or she recommends (if you intend to).

And remember that when you walk into your doctor's office you need to be able to ask intelligent questions.

Andrew Schorr suggests you approach your doctor's appointment as if it was a business meeting. You don't want to waste their time or yours.

Say "Here are three questions that I'd like answers to" NOT "I'd like to read from these 20 pages of my research."

And don't downgrade your GP because he or she doesn't know all the esoteric details of your pet illness.

He's a generalist – you're the specialist.