**THE INDEPENDENT**

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# Cyberchondria: The perils of internet self-diagnosis

It's all too easy to consult Dr Google when we're feeling under the weather – and all too easy to convince ourselves we're seriously ill

By Simon Usborne

*Tuesday, 17 February 2009*

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Catherine was worried. For weeks she had been experiencing twitching in muscles all over her body. So, she did what millions of us would do: she Googled "muscle twitching". Do the search yourself to see why Catherine's worry quickly turned to terror. Among the results are a page on a university website about Creutzfeldt-Jakob disease (CJD), the incurable and fatal brain disease (which lists "muscle twitching" as a symptom), and a site about amyotrophic lateral sclerosis (ALS), another rare and fatal brain condition, also known as Lou Gehrig's disease.

Next stop: Catherine's doctor. But just as quickly as she beat a path to his door, he ruled out anything serious – after all, the chances of contracting CJD or ALS are vanishingly small. Instead, he diagnosed benign fasciculation syndrome (BFS), a medical name for a number of non-threatening symptoms that include twitching. But that wasn't enough for Catherine, who Googled "BFS" when the shakes got worse. She ended up on a forum at the site AboutBFS.com.

"New member ... terrified ... mouth/speech problems. PLEASE help", she posted last month. "I have been living life as

if I was going to die in 18 months … I feel like everyone thinks I'm crazy." But Catherine is no more crazy than she is terminally ill. She is, however, a "cyberchondriac", a term that describes a growing number of otherwise rational internet users who, when they present their symptoms to "Dr Google", latch on to the worst "diagnosis" thrown back at them.

*Is the internet making first-year medical students of us all?*

Cyberchondria has been around for almost a decade, but a recent study is the first to systematically investigate it. Eric Horvitz and Ryen White, scientists at Microsoft's research division, analysed the internet behaviour of a million surfers around the world, and carried out a survey of more than 500 Microsoft employees, to discover how the internet is giving many of us an acute case of the heebie-jeebies.

Let's take brain tumours as an example. They are mercifully rare, developing in fewer than one in 50,000 people (0.002 per cent of us). Yet Horvitz and White's research shows that 25 per cent of the documents thrown up by a web search for "headache" points to a brain tumour as a possible cause. ALS, which is the form of motor neurone disease (MND) from which Stephen Hawking suffers, is similarly rare; MND affects fewer than one in every 14,000 people (0.007 per cent of us). But again, as Catherine found, the proportion of websites listing it as a cause of twitching is significantly higher.

"The problem starts with bias," says Horvitz, who also has a medical degree. "Nobody is excited to write about caffeine withdrawal and its role in headaches, but brain tumours – that's much more interesting. Search engines aren't savvy about this bias – they are programmed to generate results relevant to the query, not the person making it." Apparently unaware of the disproportionate level of attention given to scary diseases, people frequently relate search rankings with likelihood; if a search for muscle twitching reveals three results near the top of the page about ALS, then, as Horvitz says: "It's, 'Oh my God, these twitches mean I've got motor neurone disease – get me a wheelchair!'."

Why are so many of us so willing to believe the skewed result of web searches? One problem is laziness. A recent American study by the Pew Internet Project revealed that while eight in 10 of us use the internet to look for information about our health, about the same proportion – 75 per cent – do not check the source of that information or the date it was created. The rest comes down to psychology. Horvitz points to a famous fallacy known as "base rate neglect", where evidence makes people believe something is relatively likely to happen, despite the real chances being very low. "If a healthy person under 35 has chest pain, it is unlikely to be related to the heart, but because there is so much on the web linking the two, they forget the low background probability."

A similar effect playing on the minds of cyberchondriacs is something called "availability bias", which happens when people make predictions of likelihood based largely on what comes to mind. A classic example is the smoker who thinks they're safe "because my granny smoked 20 a day and lived to 96". Likewise, the net surfer who sees 100 results for ALS lets that skew their prediction of their own risk. "The same thing happened before the internet," Horvitz adds. "I remember getting worried when I was studying medicine. According to one study, up to 75 per cent of first- and second-year medical students end up thinking they have one significant yet imaginary disease based on what they're learning – some call it 'medical school-itis'. To some extent, the internet is making first- year medical students of us all. The problem is that often the information isn't as good."

Surely the only cure for cyberchondria is to steer well clear of the internet? Not according to Pauline Brimblecombe, a GP who works near Cambridge. She believes the internet has made patients "more interested in their own health and therefore more likely to look after themselves". She adds: "If my patients Google something and come rushing in with bits of paper, at least I know what they're worried about and can reassure them." Horvitz, too, believes in the power of the web. "It's an extraordinary resource for healthcare information," he says. "We're talking about a stone with a rough edge here, not a fatal flaw."

One man trying to polish that stone is John Voorhis, an IT consultant from New Jersey. When he developed muscle twitches like Catherine's, he was also scared. But,

unlike Catherine, Voorhis was reassured by his doctor, who also diagnosed him with BFS. Then, alarmed by the lack of information about his condition – and the tsunami of online horror stories – he launched AboutBFS.com, the site that allayed Catherine's fears. "A lot of people come to the site thinking they have ALS," Voorhis says. "Now they find a community of people to reassure them. I can't count the number of times I've had emails from people saying the site has saved their marriage or even their life."

Voorhis is helping one group of cyberchondriacs, but a Swiss organisation is trying to reach them all. The Health on the Net Foundation (HON) started life in 1995 with a meeting of 60 scientists in Geneva. "They realised very early on that the internet would be used not only by researchers and scientists but also the general public," says Celia Boyer, HON's executive director. "They also identified that due to the nature of the web – anyone can put information online – it could be a dangerous place to get health information."

HON has set up a code of conduct, which requires the 6,500 sites that have signed up to it to display information responsibly and inform readers about its purpose and source. It also runs Medhunt, a search engine that pools results from trusted sites. "We are also developing the next generation of search engine," Boyer adds. "We want to create a kind of filter you can add to Google or other sites that only presents results from approved websites."

Horvitz goes one step further and prescribes smart search engines that realise when someone is tapping in symptoms, automatically switching to a "diagnostic mode" in which users are asked their age and other information to provide results based on likelihood rather than simply relevance. But until "Dr Google" wises up, Horvitz says the responsibility to reassure the growing number of cyberchondriacs panicking at their keyboards lies with GPs. "Doctors need to work with patients and realise they are going to go to the web before they come in," he says. "They need to provide guidance on good websites and put themselves in patients' shoes so they know what's out there – good or bad."

**Medical sites: Who to trust**

*Medhunt*

Run by the Health on the Net Foundation, this search engine pools results from websites that comply with its strict code of conduct. www.hon.ch/MedHunt

*NHS Direct*

Choose your symptoms from an A-Z list or pick a body part to narrow the search for a possible cause. The site will often direct you to your GP. www.selfhelpguide.nhs.uk

*Patient UK*

Comprehensive source of information run by doctors. Read leaflets, find support or even book appointments and order repeat prescriptions. www.patient.co.uk

*WebMD*

American site with exhaustive content designed to help you manage your health and find help, plus a smart symptom checker. www.webmd.com

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## Request to republish

 **chazknight** wrote:

Tuesday, 17 February 2009 at 12:54 am (UTC)

Hello,

AltSearchEngines.com covers all alternative search engines, particularly medical search engines via our writer of note Hope Leman. I wold love to republish this informative article for my readers; can you let me know your policies?

Thanks,

Charles Knight, editor
AltSearchEngines.com

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## Helps and Hinders

**starsatnight1** wrote:

Tuesday, 17 February 2009 at 01:09 am (UTC)

The interesting thing is I did go online after having some symptoms, and while accounts from blogs of people's own experiences could on the one hand be reassuring, accounts which detailed similar but more extreme versions of my symptoms led to some panic and fear. The possible illnesses/causes I narrowed down my symptoms to were actually suggested by my doctor. So the information I found out wasn't wildly off, I mostly stuck to nhs and websites I thought looked reliable. One potential cause I didn't think of was suggested by the doc, and the doctor discounted one I'd been worried about. But the others in the middle, they were what I had imagined might be wrong. I do think online info and confessions regarding health can lead to exacerbating fear and worry however. I've never been so panicked before going to a first appointment with a GP. I kept thinking of all the things I read and how the Doctor might mention one of those things. I might have been better without it …

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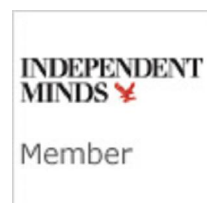
## Medical Expert System for the 3rd World

**alexweir1949** wrote:

Tuesday, 17 February 2009 at 07:42 am (UTC)

The 3rd world needs a medical expert system much much more than the west.
Look at http://cd3wd.com/MedExpSys/index.htm to see what is about to happen…
Mr Alex Weir, Harare, Zimbabwe

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## Webicine

**scot_in_canada** wrote:

Tuesday, 17 February 2009 at 11:17 am (UTC)

I practiced in a city with a large number of computer company employees. The amount of information available to the patient is astounding; most is rubbish. However with the doctor shortage, more patients turned to the internet for advice. I was forced to adapt to this new reality and provided appropriate web sites for medical information. They do exist and should be inquired about at your next doctor visit.

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## Intelligent Computers?

**cadwallon** wrote:

Tuesday, 17 February 2009 at 02:40 pm (UTC)

I have some knowledge of Patient UK, one of the sites listed at the bottom of the article.

I've worked in expert systems, medical diagnostics and high-quality medical information provision since the 1980s - everything from hand held triage calculators for paramedics to use at sea to full blown diagnostic systems for GPs.

Most general purpose Internet search engines (not mentioning any names) don't use any sort of medical filter when indexing content from around the world. They have no underpinning medical model or review process to weigh up what is valuable and what is not. So, you are as likely to get professor Mad's crackpot theory as a balanced up-to-date view, particularly if professor Mad is good at tempting the search engine's automatic indexing spiders with his material. And this is why you might be directed to a piece on brain tumours when you were just looking for a remedy for a mild hang-over.

Taking the 'headache' example and feeding it into Patient UK, you will get a prioritised list of headache related articles followed by articles on some of the causes of headache ->
http://www.patient.co.uk/DisplayConcepts.asp?f=1&maxresults=50&WordId=headache

And the reason this happens is there has been professional medical oversight of index creation and the search engine uses an underlying medical model.

The technology driving this search engine is actually capable of generating formal lists of diagnostic reminders based on a patient's symptoms and signs.
Here's a demo for abdominal pain and guarding (possible appendicitis)
http://www.webmentorlibrary.com/login.asp?user=DEMO&pword=password&target=index&param=destination=conceptsearch.asp?c=abdominal pain and guarding

Although, this facility is available to many GPs as they practice, it's switched off on the general access Patient UK site.

Why is this?
Diagnosis is much more than typing in a few symptoms. It's all to do with interpretation of what people say, the words they choose, how they say them and how they look. It's about following leads, knowing background and putting things in correct context.

Poor old computing devices typically have to take everything on face value, only recognise certain terms, have no common sense and can easily be drawn beyond the limits of their algorithms and databases.

But, website visitors can't see any of this. Indeed, diagnostic system creators might not even know the limitations of their products. So, it can, at best, be misleading or, at worst, downright dangerous to use Internet based search engines for diagnosis.

Medical practitioners, on the other hand, have been trained in terminology and, importantly, can look at lists of suggestions and say "that's rubbish". For them, the machine can provide reminders of valid, but unusual, things they might otherwise overlook.

Quite a different kettle of fish, are Internet sites that turn published research into eg patient friendly risk calculators. Providing the limits of capability and outputs are clearly explained, these can be useful and safe personal assessment tools.

We will see more and more of these as the NHS encourages people to look after themselves.

Anyway, for the moment, my advice is to pick a couple of high quality medical sites and use those.

Good health sites should have:

* an independent editorial and updating process - independent of political, commercial or sales promotion/ selling pressure (eg of its miracle cure)
* a scientific, evidence-based approach to content creation - rather than opinion, pressure group or propaganda
* clear, well written, accessible material
* up-to-date material
* citing of references, funding and people involved

Watch out for differences between UK recommendations and health recommendations for other countries. And remember, some Internet reference sources, eg Wikipedia, can be edited by anyone at any time.

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