Do you have cyberchondriacia?

By John Costello
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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 is a page 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, and information about 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. Instead, he diagnosed benign fasciculation syndrome (BFS), a medical name for a number of non-threatening symptoms.

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.

TERRIFIED

"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." 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 present their symptoms to Dr Google and then latch on to the worst diagnosis.

Cyberchondria has been around for almost a decade, but a recent study is the first to systematically investigate it. Eric Horvitz and Ryan White, scientists at Microsoft's research division, analysed the internet behaviour of a million net 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. Yet Horvitz and White's research showed that 25pc of the documents thrown up by a web search for "headache" point to a brain tumour as a possible cause.

"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."

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 — 75pc — do not check the source of that information.

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 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 and lets that skew their prediction of their own risk.

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".

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."

A Swiss organisation is trying to smooth those edges. The Health on the Net Foundation (HON) started life in 1995 with a
meeting of 60 scientists in Geneva. “They realised that anyone can put information online and that the web could be a
dangerous place to get health information,” said Celia Boyer, HON's executive director.

HON has set up a code of conduct that requires the 6,500 sites signed up to it to display information responsibly.

But until Dr Google wises up, Horvitz says the responsibility to reassure the growing number of cyberchondriacs lies with GPs.
“Doctors need to realise their patients are going to go to the web before they come in,” he says. “They need to put themselves
in patients' shoes so they know what's out there — good or bad.”

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