

'First hand account of symptoms' Database

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'First hand account of symptoms' Database

I was wondering if anybody out there in internet land with the right skills and attitudes had thought of initiating a website to collect first hand accounts of symptoms and experiences of illnesses, in order to shed light on the more intractible and rare conditions, or come to think of it the whole nature of illnesses themselves.

In my personal life I have been generally interested in information that falls through the cracks, the kind of stuff that gets ignored, forgotten about or dismissed as trivial, irrelevant or bogus. This intellectual pursuit came into sharp and intensely personal focus when I became ill about 6 years ago and I found myself flung upon the mercy of the UK medical profession. My local GP had right from the start treated my condition as basically a fungal irritation of the skin. I was on the strongest drug for fungal conditions, but when I came off this medicine my condition deteriorated so fast I was rushed off to hospital and then into the domain of the consultant who eventually 'diagnosed' my condition and refused any fungal connection whatsoever, despite my GP having witnessed such.

Anyway I don't wish to go on about that. I have heard plenty of similar tales and the reason why I've mentioned all this, is that in terms of our official medical histories, my experiences and others like it have dissappeared of the map, and that this is happening every day all across the world. I find the enormity of that thought truly daunting. What an appalling loss of knowledge! All those personal experiences and symptoms if collated and analysed could have shown unexpected patterns and connections have just been lost and only maybe haphazardly found through personal internet searches,

I find the whole doctor / patient, doctor / consultant relationship deeply unsatisfying from the point of view of a good exchange of information. First of all there is a basic imbalanced power relationship going on here (which becomes more acute the higher you go up the medical hierarchy) and the doctor still won't like the patient challenging his diagnosis Then on a practical level GP's are rushed off their feet and are looking for the ABC's of the illness you might have and when they've got that fixed in their head, other info and symptoms they really don't have time to deal with get lumped into the

convenient dumping ground known as 'Psychological symptoms', remember the denial of M.E. as a 'real condition' by the medical profession. To be fair to the GP, he is not a researcher and even if a GP is aware of some extra information, as in my case, he maybe wary of challenging the authority of his medical superiors.

The key result of this poor doctor / patient relationship is that you, the patient, can become wary of telling the doctor things he doesn't want to hear. So a lot of people faced with this state of affairs stop the open flow of information and look elsewhere and all those experiences of alternative cures or failures just disappears from your official medical history and so does all the statistical analysis of it that might have shed light on it too has gone as well.

I decided to stress the symptoms aspect of the database idea in the news group posting because in the rarer illnesses a lot of diagnoses are very vague in the understanding of why they appear and what the disease actually is. So I thought if we minimalised the role of the medical labels and focused in on all the symptoms reported by people of their illnesses, no matter how subtle or insignificant they might be, it might enable us to see a clearer picture of what is going on.

However I have also come to believe that when we fall ill we all do that in our unique ways. All our experiences before, during and after, all become important to the understanding of the illness. And although we are each unique there are many similarities between us, and our own stories if told properly, might lead us to the clearest understanding into the whole nature of our illness. So a Symptoms / Biography Database would be a more correct title.

Apart from shedding light on the less understood illnesses a database of symptoms combined with a biography might act as a guide when faced with the multitude of treatments out there. Anybody who has found themselves outside the cozy security of official medical practice can find it hard to tell what is bogus or genuine or what is appropriate treatment or not. And we all know personally of, or have heard stories of one person's triumphant success story with one particular alternative treatment only to find that when we try it we blatantly fail. And after trying a good selection of these alternative therapies with all the financial costs and then hopes being dashed it's not hard to get disillusioned and give up. We begin to feel like failures and those success stories only make us feel more so.

I imagine this Symptoms / Biography database would be one of those self evolving sites I've heard of driven by a carefully thought out questionnaire. Am I just dreaming here getting carried away on a flight of fancy or is this a good idea ?

Clive from the UK

To see my own unique resolving of my own illness go to <http://www.geocities.com/clivemcgee/dowsing.html> and I hope that might not put anybody off what I hope is a good idea. I honestly don't believe that nobody else has thought of this and if they have, please E mail me to let me know for I would be glad to recount my experiences to it. Maybe there are practical problems I haven't forseen.

Also if you have some objections to whole crazy notion please

contact me at clivemcgee@yahoo.com because as a dedicated cross poster I simply can't deal with all your different newsgroup responses. Below are some criticisms and my responses to them and if anybody contacts me directly I will add their objections to it with my attempt at an answer.

FHO'S (FREQUENTLY HEARD OBJECTIONS)

Response 1 – There are problems either with my mental faculties or my intellectual capacities, usually delivered in a very short and distinct fashion

My Reply – Don't you just love the security of the one liner retort, dismissing somebody with a simple observation or insult. You don't have to present an argument or anything so no one knows what your actual level of intellectual competence is. Here is my own one line retort which I find quite funny due to its topicality
'This guy is one symptom short of a full disease'.

Response 2 – I'm encouraging Hyperchondriacs to give vent to their warped fantasies

My Reply – Actually the idea of hyperchondriacs getting involved with it did cross my mind though I thought the sheer numbers involved would, statistically speaking, drown out the small number of silly people who might join it. And anyway the overuse of the psychological card by the medical profession (Which I mentioned in the post, citing as a classic example the refusal to accept M.E. as a real condition) to avoid dealing with pieces of jigsaw puzzle that don't fit, has I believe, over inflated the amount of hyperchondriacally invented disease sufferers out there. To reinforce that point my friend who was suffering from epileptic fits throughout his adult life was only diagnosed 15 years later with Epilepsy prior to that period he was basically being accused of being a malingerer or imbalanced.

How many more cases like that are out there ?

Anyway I think people will get the feel for stories and experiences genuinely told and a faker or hyperchondriac won't have the necessary experiences and technical knowledge to sound convincing. And for the small amount of people who for whatever motivation wandered onto such a site would find these experiences of pain and anguish too hard to bear and a real hyperchondriac might die from over anxiety if they started reading them !