

# A Patient's View of Modern Medicine

Chapter 8 by James Ashdown

What does it mean to be a patient? I suffer from a number of chronic conditions which have meant that I have had many experiences of being a 'patient'. By and large they have not been good experiences. Occasionally I have learnt something useful but I am more likely to have left the surgery or hospital feeling frustrated and patronised. Others have more positive experiences but generally it is probably fair to say that being a patient is not a pleasant experience. Maybe it is because in being a patient we become an object rather than feeling the empowered subject of our own lives. I want to go on to explore this experience of being a patient and suggest some ways for modern medicine to become a more humane experience for patients.

It seems to me that I'm a patient in three different ways. Firstly I am a patient because I am constructed in that way by doctors and other medical people. Secondly I am a patient in terms of my relationships with other people and the way they see me. And finally I am a patient because I myself am suffering from a condition which is causing me pain and difficulty. Let us examine these three different ways of being a patient.

## *The patient and the doctor*

Doctors have gradually acquired social status over the past 200 years. In the novels of Jane Austen the sons of the wealthy could enter the army, the church or perhaps the law. There doesn't seem to be any possibility of them becoming doctors. But now doctors are one of the recognised pillars of the establishment. As we can see from the way TS Eliot uses the image of the surgeon in *East Coker*, first published in 1944:

The wounded surgeon plies the steel  
That questions the distempered part;  
Beneath the bleeding hands we feel  
The sharp compassion of the healer's art

Science and technology have enabled doctors to affect successful cures even by doing violence to our bodies -- the sharp compassion. The transformation of doctors -- especially surgeons from low status, marginal people has been remarkable. But suspicion of them seems to be growing as the glister of technological success has worn off and we question what doctors are really up to. I myself have suffered ongoing and apparently permanent discomfort from an operation on a pilonidal sinus which was probably not necessary but done 'just to be on the safe side'. My wife's brother-in-law is presently unable to open his mouth eight weeks after the extraction of a wisdom tooth which had unforeseen side-effects. In both cases incompetent nursing care has contributed to the problems. You no doubt are able to add your own 'horror stories'. It is easier to accept these mistakes when doctors are humble and good listeners but this seems to be unusual rather than normal -- as my father was told by a London specialist 'I normally find that when people have something particular to tell me it is of no account'. Of course the doctors have their successes -- my father is looking very sprightly now with his hip socket replaced by the some high-tech metal and plastic, and you will be able to add your own 'success stories'.

Personally I struggle to add any success stories to the library of medical advance but this is, perhaps, because my main problems have been associated with that condition most widely known as ME. This condition is very poorly understood by doctors and the encounter of many sufferers with their doctors has been difficult and unsatisfactory. Often they are simply not believed or told they are suffering from depression or some other 'psychosomatic' condition. Just as common is for them to be believed but then told that there is nothing that can be done. With persistence patients are able to get to see a specialist who may be of benefit to them but seems to be just as likely to offer them a treatment which has little or no success. And then some sufferers just get better over time, perhaps through a change in lifestyle or perhaps for no very clear reason. Modern technological medicine doesn't seem to have much to offer sufferers from ME. A bit of CBT<sup>1</sup>, perhaps, nutritional advice and some drugs to manage symptoms but basically doctors are thrown back on more traditional resources of empathy and (dare I say it) love

Once, I was having a really bad time with ME, I remember Andrew saying “Daphne, this illness is crucifying you because of your personality; your character. You are so gregarious, so giving, so outgoing and at this moment in time you are imprisoned,” and he just sat and looked at me with such compassion and empathy—I could have hugged him.

People with ME often want to be part of the medical system -- they want to have a diagnosis, they want to be accepted as being ill but the irony of this is that medically speaking it rarely does them any good. But that perhaps is not the point for although a medical diagnosis might not get you anywhere nearer a cure it will almost certainly help you negotiate your role as a chronically ill person in society.

### ***The patient in community***

Medicine tends to treat the patient simply as an individual. But the patient does not experience their illness this way. For the patient an illness is often most significant in the way it affects their relationship with other people. They are not able to do what they used to do, they have difficulty performing the roles which people expect of them -- either in their family or at work. This is often what really counts and it is much easier to negotiate a new role for yourself if you can say to your employer 'my doctor says that I have myofascitic neuralgia and if I don't reduce my hours to two days a week I'll probably die ... or sue you under the disability discrimination act' rather than 'my doctor hasn't got any idea of what's going on but I feel really tired and could do with reducing my hours'. Patient's relationships need to be renegotiated with friends and family as well. They will often put enormous pressure on the patient to explore all possible avenues of diagnosis and cure. Exactly why this is the case can vary but modern medicine certainly creates the expectation that diagnosis and cure is possible. This desire of friends and family may arise out of genuine concern and care but, unfortunately, it is just as likely to come from a judgment that the patient is malingering and workshy.

Under these kind of pressures the patient will often look for some kind of alternative therapy. In conditions such as ME these are very often resorted to, sometimes these are effective but more often, perhaps, they are of marginal or no real medical benefit. Perhaps what is more useful is that they often provide a listening ear and someone who will validate

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<sup>1</sup> Cognitive behavioural therapy

the sufferer's experience, although personally I think this side of alternative medicine is overdone. Although you might get more time with your alternative therapist they are not necessarily any better at really listening to you. Sometimes their heads are just too full of their own theories and therapies. Although alternative therapies often operate with a very different theory of illness and cure they are still embedded in our society dominated as it is by the medical model and its emphasis and expectation of quick cure. Actually doctors are sometimes more sceptical about modern medicine than are the general populace, GPs, in particular, are often only too well aware of what little they can do in many situations of chronic illness.

Someone suffering from chronic illness often needs to become a recognised patient in order to access government support in their time of crisis. For many ME sufferers the appointment with a doctor to certify that they are still unwell enough to continue receiving support are times of dreadful anxiety. This recurring anxiety almost certainly contributes to their continuing ill-health. Being a patient gives one a certain status in our society which can help you negotiate your way through a life afflicted with pain and disability, but it can also trap and dis-empower in very unhelpful ways.

### ***A patient's story***

Modern medicine puts pressure on a patient to be 'compliant'. And this is reinforced by the surrounding culture which is as, if not more, medicalised than doctors. This compliance can often be of medical benefit to a patient -- I think of a friend who recently told me of how wonderful she feels now the doctors have got the cocktails of drugs right for her chronic condition. But this is not always the case -- iatrogenic illness is disturbingly common. Ivan Illich, who introduced me to the term iatrogenic (meaning *caused by doctors*) suggests that the problem with medicine goes much deeper than this. Our medicalised culture has caused us to forget that coping with illness is fundamental to what it means to be a human being. Yet so powerful is the medicalisation of our lives and society that Illich came later to regret the use of the word coping -- for he felt that this had been co-opted into the medical establishment and turned into yet another avoidance of the art of living!

I have a lot of time for Illich's analysis. It was the first time that I read something that truly resonated with my experience and deep convictions, although I find myself unable to practise as radical a rejection of medicine as Illich himself practised. I find myself wanting to tread a more moderate path. And this is important. What has become clear to me, especially in my engagement with ME and related conditions, is that everyone has to find their own path through their illness: a path which relates to our own experience, convictions and the relationships we have with those around us. It is all too easy for us to be bullied by medics, alternative practitioners and friends and families who think they know what we should do. I find my Christian faith crucial in giving me some bearings in the confusing and contested realm which is my experience of ill-health. I have found the perspective of the early Church Fathers, especially mediated through Jean-Claude Larchet's book *The Theology of Illness* particularly helpful

To consider illness strictly as a phenomenon unto itself is almost inevitably to see it in a negative, sterile light; and this only increases the physical suffering and moral pain which result from a sense of its absurdity. The consequence of such an attitude is... to develop in the soul troubling passions, such as fear, anxiety, anger, weariness, revolt and despair...

It is because of this very danger that the Fathers stress the point that "it is not in vain, nor without reason, that we are subject to illnesses." This is why they encourage us to be vigilant when illness strikes, and not to trouble ourselves first of all with their natural causes and means to cure them".

Medicine fixes us first of all on the natural causes and the successes of modern medicine have caused us to expect that we should be cured. This inevitably causes sufferers from conditions of uncertain diagnosis such as ME distress and anger, and therefore spiritual anguish. Why does God cause us to suffer from this condition which many people don't believe in and causes us to be labelled as depressed or malingering? But if we can liberate ourselves from our patient status and rather see ourselves as ordinary people suffering from particular symptoms then perhaps we can be attentive to what God, or our bodies, if you prefer, are saying to us. From this perspective conditions can become times of spiritual opportunity rather than merely of spiritual anguish. Not that this is easy but at least our lives are in our own hands rather than those of technologies which may or may not be able to help us. It seems to me that this is a position from which we can decide which medical interventions we wish to engage with -- rather than desperately searching for anything that might help. In this way we can make the technologies compliant to the needs of the patient, rather than seeking to manipulate patients into compliance with medical technology. I believe this attitude actually improves relationships between patients and doctors. Doctors are no longer little gods who are worshipped so long as they effect a cure, but a source of skill and knowledge who can help us better navigate the tempests of life.

### ***The recovery of stories***

A key stage in the story of modern medicine was the shift from symptoms to signs. That is the change from listening to the stories that patients told about their bodies to an examination of those bodies using scientific tests. This has brought considerable benefits and enabled us to learn much more about our bodies and the ways they work. But it is unfortunate that the success of using tests has often caused listening to patient stories to be undervalued. This is, actually, bad science for knowledge is more secure when it is achieved through triangulation -- the same data viewed from different perspectives. In recent years there has been more of an emphasis on listening to illness narratives. This seems to me a positive step for it will help scientific medicine become more compliant to patients needs.

This is well illustrated by an article *Exploring Patients' Experiences as a Primary Source of Meaning* by Marsha Vanderford, Elaine B. Jenks and Barbara F. Sharf. I will use it to suggest some ways in which a holistic medicine can be patient rather than technology centred.

Rather than conceiving of patients as recipients of and reactors to the messages of others, we propose a focus on patients as active interpreters, managers, and creators of the meaning of their health and illness

Patients experience matters because they need to be involved in their own health. In a cack-handed and paternalistic manner this is what the language of patient compliance means. If the complexities of patient's stories are not brought into the treatment of their ill-health then it is likely to be ineffective for patients must be the agents of their own healing -- whether that means taking the drugs regularly or resolutely refusing treatments that are

counter-productive. For a patient their identity is central but illness and medical treatment often strip them of key elements of that identity:

Little reference [is paid] to their home environment, religion, social relationships, moral status, or the meaning they give to their ill-health. ... [They are] stripped of many of the props of social identity and individuality, and clothed in a uniform. ... There is a loss of control over one's body, and over personal space, privacy, behavior, diet and use of time.

This does not encourage health. On the other hand, as I have previously discussed, patients with ME are often looking for a diagnosis in order to be help construct an identity which makes sense of the symptoms they are experiencing. Patients need to be able to create an identity for themselves which makes sense of what they are experiencing in their bodies. But this is not something just created by the patients, in partnership with their doctors -- all their relationships will come into play, particularly those with their families whose attitudes and opinions will be central to making sense of what is going on for them and finding some kind of healing.

What is critical are the stories which patients create and tell. Stories which create an identity will help them cope and heal. Stories which enable patients to avoid despair and hear what God is saying to them in the midst of their pain. As Arthur Frank demonstrates in his book *The Wounded Storyteller* there are positive and destructive ways of telling these stories. Patients need to be assisted in telling these stories, given opportunities to express what they are feeling, to be listened to and taken seriously and to try to triangulate their experiences with medical data and doctor's experience. Otherwise they will be swamped by chaotic stories which overwhelm and add to their illness.

I believe modern scientific medicine has much to offer us -- even those of us suffering from perplexing conditions such as ME which do not seem to respond very well to what it has to offer. But when scientific medicine is able to integrate itself with the well told stories of patient's illnesses and struggles I believe it will become much more powerful, as it becomes more compliant to patient's real needs.

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**Article reference:** <http://www.wphtrust.com/handbook08.html> "A Patient's view of modern medicine" by James Ashdown, first written 10 March 2007, this version updated on January 25, 2008 , © WPH Trust