

# Learning through shared experience

***My enthusiasm for groups like the PAA is inherited. My father was a GP in a Yorkshire village and watching him as a child, and later working as his assistant, I realised that he'd acquired much of his understanding of medicine from his patients. True, he picked up useful knowledge from books and journals but he screened everything he read through the filter of his own and his patients' experience.***

I later met lots of doctors who behaved in the same way and I came to the conclusion that the empathy they had with their patients – their ability to think themselves into the minds of others – was one of the elusive qualities that go to make a good “healer”, a doctor whom patients feel better for seeing regardless of any treatment that's prescribed.

Today, of course, everyone is supporter of the notion that patients should be involved in their own care: cabinet ministers, the General Medical Council (GMC), the BMA, medical schools, and all those medical politicians who can spot a bandwagon when they see one. But it wasn't always so.

## **“The Good Old Days”**

Some 30 years ago when I was a member of the GMC – albeit a rebel one – and suggested that medical schools should use patients not as specimens to be put on show but as actual teachers who could give talks and lectures to students I was accused of being “a traitor to my profession”. And when I took part in this country's first medical phone-in, offering I might say rather pathetically generalised advice, I was reported to the GMC accused of “serious professional misconduct”.

Twenty years ago I met an American woman who had suffered from diabetes since she was a child. She'd recently been admitted to a London diabetic ward and had taken with her the new American electronic device with which she monitored her blood sugar. The other patients in the ward

were fascinated by it so she showed them how to use it. When the doctors and nurses discovered what had happened she was dismissed from the hospital for “unacceptable behaviour”. Her crime it seemed, was not that she'd let others use the device but that she'd told them what their blood sugar levels were.

## **Doctors' Orders**

So things have improved a lot but we mustn't be complacent. Some old medical attitudes linger on. Doctors still describe patients who dutifully follow their treatments as “showing a high level of compliance” as if doctors were born to issue Doctors' Orders which patients were born to obey. And patients who reject their doctor's treatment or advice are described as “non-compliant” as if it were a failure by the patient rather than the doctor.

Another word doctors still take in their unthinking stride, is “consent.” I dislike it because, when doctors use it, it sounds as if patients have been given a choice when all they've been offered is the chance to acquiesce to what the doctors have chosen for them.

A third C word is “cooperation,” use to describe the commendable behaviour of patients who make changes in their lives just to please their doctors. This treacherous trio of Cs is, of course, linked by definition: a co-operative patient is one who first consents and then complies.

Any doctor fool enough to think that seemingly co-operative patients are passively obedient should recall the memorable clinical trial in which the subjects broke the code by discovering that when they threw their tablets down the lavatory, the drug floated but the placebo sank.

To be positive, however, it's encouraging that so many doctors now accept that patients, particularly those living with a long term illness develop expertise and wisdom about their condition and want to play a part in making decisions about their own health care.



**by Dr. Michael O'Donnell**

Yet those of us who are keen to enable patients to be involved in their own care need to accept that there are problems we need to resolve. Here are just a few.

## **Interpreting risk**

Decisions about treatment often involve our attitude to risk. Doctors' perception of risk, fostered by the evidence presented in scientific journals, is mathematical; most other people's perception is non-mathematical

Imagine, for instance, the public reaction if a fully-laden jumbo jet were to crash at Heathrow Airport on four successive days killing all the passengers. There would certainly be an outcry, panic among intending passengers, and aircraft would be grounded. Yet that is the weekly British death toll attributable to cigarettes, a toll that British people accept with resignation and the British government with apparent equanimity.

Reason can play little part in our notion of risk – people will worry, for instance, about a risk with a drug that is 1,000th the risk they run every time they get into their cars. And our perception of risk also includes a political quality. I once heard the distinguished mathematician, Sir Hermann Bondi, describe a Swedish plan to study the Aurora Borealis by firing instrument-carrying rockets into it. When the rockets had done their job, the burnt-out remnants were due to fall over an area of Lapland so sparsely populated that the mathematical risk of anyone being hit was minute. Even so, the Swedish government felt it should offer protection to the isolated reindeer herders so it lifted them out by helicopter and lifted them back when the experiment was over.

Sir Hermann calculated that the mathematical likelihood of one of them being hit by a piece of rocket was less than one per cent of that of a helicopter accident. But let's look at the political implications. If someone had been hit – or even had had just “a bad fright” – the Interior Minister would have faced the angry accusation that he had done nothing to protect people for whom he was responsible. If, on the other hand, there had been a helicopter crash, people would have happily accepted a ministerial statement that said: “We deeply sympathise with the relatives of the victims of this tragedy. We used a well tried helicopter, flown by a well trained and experienced crew. We are appalled at what has happened but there is no other precaution we could have taken.”

### **Not all patients want to take responsibility**

Doctors soon learn there are about differences in people's attitude towards taking responsibility for decisions about their health. These differences have been measured. A recent survey of over 1,000 American women suffering from breast cancer revealed that 22 per cent wanted to select their own treatment, 44 per cent wanted to collaborate with their doctors in the decision, and 34 per cent wanted to delegate this responsibility to their doctors. As the author of a British Medical Journal editorial put it: “Most patients want to see the road map, including alternative routes, even if they don't want to take over the wheel.”

### **Medical specialities**

The narrow interests of medical specialities don't coincide with the interests of patients. Indeed the patient is sometimes the only person in a position to get specialists together. The American woman with diabetes whom I've already mentioned told me: “I spend a lot of my time as a patient trying to get one specialist to know what the other specialist is saying”.

And an acquaintance of mine who suffers from psoriatic arthropathy told me recently that he is thinking of writing a survival guide on “how to get your GP and your general physician to think in harmony with your dermatologist, your rheumatologist, your orthopaedic surgeon, your physiotherapist, your district nurse and your carer.”

### **Difficulties doctors face in encouraging patients to make choices**

Not surprisingly GPs and specialists who have spent a minimum of ten years in training feel that the knowledge and experience they have acquired in that training should not be discounted

They find it hard not to intervene if patients at times select treatments that are less effective or less cost effective than the medically recommended approach. Patients with moderately raised blood pressure, for instance, value the benefits of drug treatment less than their doctors and not surprisingly are less tolerant of side effects. So encouraging patients to make choices about treatment would probably result in fewer drugs being taken which doctors know would increase the number of strokes and heart attacks in the population.

It's also been estimated that only 50 to 65 per cent of patients with chronic conditions stick to their treatment. By not taking their drugs the other patients are, of course, expressing a choice. Many doctors find it difficult to accept – not to mention encourage – such explicit disagreement with their recommendations. Hence their use of that weasel word “compliance”.

The doctors' difficulty diminishes, however, when they accept that they have to treat an illness rather than a disease. The two are not synonymous. Diseases can be defined, their causes sought, organisms or mechanical defects identified; an illness is an individual event, the possession of one person whose physical condition and emotional state determine the way the disease affects that individual life.

Even with diseases where we have compelling evidence about their nature and treatment, doctors have to weigh the generality of the evidence against the particular needs of the individual and seek to understand the feelings of regret, betrayal, fear, loneliness – indeed all the perplexing emotions – that can turn the same disease into a different illness in different people. And, of course, patients are experts on their own illnesses because they are experts on their own values and priorities, their obligations, their attitude to risk, their preferences and so on.

If doctors are to treat illness as successfully as they treat disease they need to enhance their medical experience with the experience of their patients who contribute to our understanding of the world in which we all struggle to survive.

### **Time.**

Shortage of time is the modern doctor's greatest enemy. Time not just to examine, investigate, and treat but time to explain, to listen, to understand. For some 30 years I've tried, with little success, to convince doctors that if they want patients to recall, and indeed understand, explanations and advice they deliver in consulting rooms they should give the patient a recorded tape cassette of the consultation or send a letter spelling out what they said or meant to say.

The difficulty people have in understanding what they hear is not confined to medicine. It is well-explained by the American author Sue Grafton in one of her highly successful detective novels where her private eye Kinsey Millhone explains why she always writes out her reports: “With verbal reports, much of the data gets lost in translation. Most people aren't trained to listen. Given the complexity of our mental processes, the recipient tunes out, blocks, forgets, or misinterprets eighty per cent of what's been said. Take any fifteen minutes' worth of conversation and try to reconstruct it later and you'll see what I mean. If the communication has any emotional content whatever, the quality of the information retained degrades even further.”

### **Lessons of experience**

These problems should not deter doctors from seeking to improve the ways in which they involve their patients nor patients from becoming involved, if they wish, in their own care. And organisations like the PAA have big role to play in helping to solve those problems. At meetings for instance, patients, nurses, doctors, and carers get a chance to share their experience. Indeed a day such as the PAA conference is a large scale model of the ideal medical consultation in which the doctor learns through the experience of the patient and the patient learns through the experience of the doctor.