

# Doctor, Doctor!

*This May, members of the M.E. Alliance are campaigning for earlier diagnosis of the condition. Crucial to this is finding a GP who believes M.E./CFS is a real illness and takes your symptoms seriously. Dave Lamont looks at ways to improve the doctor-patient relationship and tips to help get your GP on your side*

GPs are often viewed as the 'gatekeepers to the NHS,' as the system requires a doctor's referral to access most services. In addition, GPs are usually the main providers of continuing support for those with long-term illness. An understanding doctor is especially important for people with M.E., who not only need help in alleviating the myriad of symptoms, but also medical back-up to support applications for welfare benefits or social care.

While not everyone with M.E. has this level of support, we share some ideas to help get your GP in your corner, and failing that, tips on making a complaint, or as a last resort, changing doctors.

## Some GPs are a great help...

Many people are keen to sing the praises of their GP. Emma White struck lucky with hers. 'My doctor was very patient with me', she recalls. 'I don't think I'd be in the situation I am today without her help. I had regular appointments and was also referred to a consultant before eventually being diagnosed.' She adds, 'It was hard and frustrating at times but my doctor was very supportive and always seemed to understand my concerns.'

Robin Westwood, who has had M.E. for a number of years, has a similar view: 'My GP doesn't have any magic answers to get me well again but he is open to considering new drugs I may have read about, and treats me respectfully, as an "expert patient" who, he concedes, probably knows more about M.E. than he does.' Robin talks about the benefit of having a good relationship with his GP saying, 'It does help me, at least psychologically, to feel listened to and taken seriously,

and I'm so relieved he understands my need for medication to aid sleep, and for pain relief.'

## ...but not all

While medics' understanding of the illness is growing all the time, unfortunately, some doctors continue to remain either sceptical or ignorant of M.E., often resulting in substandard patient care.

Kim Bickley was left severely disappointed by the response she received from her GP when her son Tom became ill several years ago. At the age of nine he was diagnosed with Glandular Fever but after showing little sign of improvement 18 months later, Kim began to suspect Tom may have M.E. 'We took him to the doctors on numerous occasions only to be told it's the Glandular Fever, it can take a long time to get over,' she explains.

By the age of 11, Tom's health was declining fast and he was practically bedridden. Kim decided to plead with her doctor for further help. 'When I suggested that we thought it was M.E., the doctor said not to be ridiculous. "I agree he does look ill, but I do not know what is wrong with him and I cannot help,"' she says.

Jane-Marie Harrison also struggled with her GP. After being ill for five years he referred her to a heart specialist saying, 'it seemed a good place to start.' Nearly two years later she decided to ask her GP whether he thought she might have M.E. She says that she was shocked when he replied, 'M.E. is for people who are swinging the lead and I don't think you fall into that category.'

Jane-Marie was next referred to a neurologist with her doctor believing she was suffering from MS. The neurologist later told her that there was

nothing neurologically wrong and suggested that she may have CFS, or M.E. She says that when she discussed her GP's earlier comments, the neurologist labelled him as 'very naughty.'

*A report published last year suggests that a GP's personal attitude and beliefs about M.E. can block patients from getting the best care*

## Challenging

A survey carried out by Action for M.E. in 2001 ('Severely Neglected: M.E. in the UK') showed that 65% of respondents had received no advice from their GP on managing their illness. Furthermore, a report published in the *British Medical Journal* last year suggests that a GP's personal attitude and beliefs about M.E. can block patients from getting the best care.

Some of the GPs were found to view patients with M.E. as having a 'low symptom threshold' and 'lacking in stoicism.' Others reportedly felt that M.E. patients have a 'personality trait that is chronic fatigue syndrome waiting to happen.' Little wonder that up to a third of sufferers have opted to change their doctor following unsatisfactory support.

*Positive body language, preparing what you are planning to say beforehand and maintaining constant eye contact are all important*

There is also the fundamental issue of belief. While many more doctors now share the government's view that CFS/M.E. is a 'real and debilitating' condition, Action for M.E.'s recent website survey shows that more than half of respondents waited over a year to be diagnosed.

A number of AfME members have commented that tackling this problem head-on by providing their GP with literature on the condition has led to an improved relationship and better quality of care in the longer term. In this respect AfME's publications such as 'Guidance on the management of CFS/M.E.' (based on CMO Report findings and recommended by the Department of Health) and the guide to symptom control may prove useful.

### Improving the relationship with your GP

Psychologist Jacqueline Siner highlights the side effects of having a bad relationship with your doctor. She says that a breakdown in trust and communication between doctor and patient can lead to a period of confusion, stress and low self-esteem because a patient begins to doubt themselves when confronted by a doctor who is perceived as knowing more than them.

Jacqueline provides a number of tips for patients visiting their doctor. She says that positive body language, preparing what you are planning to say beforehand and maintaining constant eye contact are all important. She adds that developing mutual understanding and respect are key to establishing a strong doctor-patient relationship.

Regular visits to your GP can help your doctor build up a picture of how your illness affects you, making it easier for them to provide supportive documentation in the case of sick leave

or benefits claims. Your doctor may also be able to suggest ways to alleviate individual symptoms such as muscle pain, poor sleep or secondary mood problems.

While some GPs find it hard to relate to M.E. and the problems people with the condition experience, keeping a diary of symptoms or taking a relative or carer with you to an appointment to give an additional perspective on the situation can be helpful. Jackie Fenwick did this with her husband as she felt that her GP initially failed to understand the severity of her illness. However, after hearing a carer's point of view about its effects on their daily life, her doctor's perception of her condition changed, leading to a dramatic improvement in the level of care received.

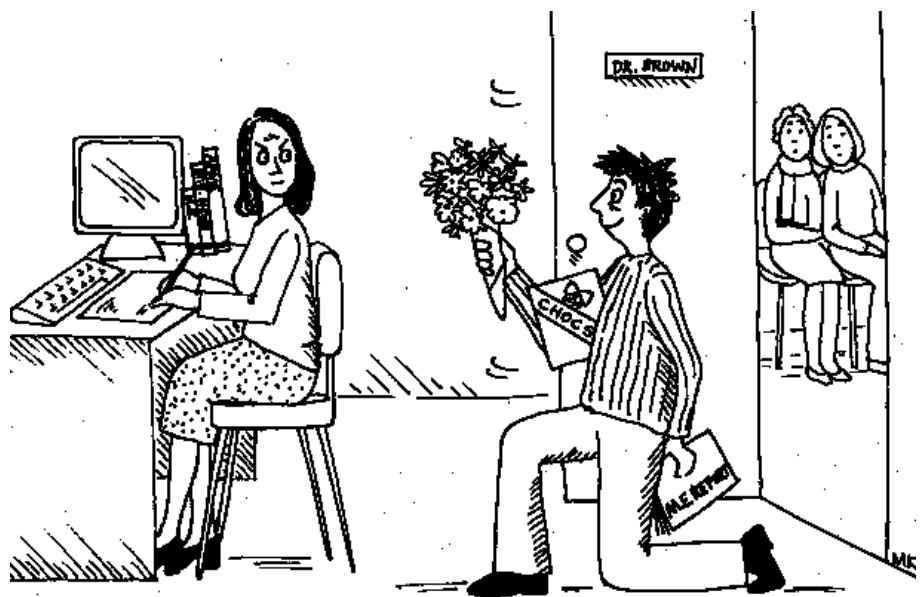
'A Guide to Getting the Best out of your Doctor', an information booklet produced by the Association of Young People with M.E. (AYME), explains how people with M.E. can benefit from a good relationship with their GP and regular visits. The booklet also reminds patients to be aware of their doctor's limitations. 'It is unlikely that your doctor was taught anything about M.E. at medical school. Therefore he/she will learn a great deal from you and probably won't like this any more than you do,' it explains.

### Making a complaint

For patients wishing to make a complaint about their doctor, the first step is to approach them directly in case the problem can be sorted out easily. Failing that, AfME's *Guide to NHS healthcare for people with M.E.* explains that: 'each GP surgery has a complaints procedure and you can speak or write to the person who deals with complaints [usually the Practice Manager]. Sometimes you might want to talk to someone who is not directly involved in your care. The new Patient Advocacy Liaison Service (PALS) that is available in all NHS and Primary Care Trusts should be able to help you.' If you're still not happy once the NHS complaints procedure has been exhausted, you can contact the independent Health Service Ombudsman and ask them to investigate your case.

Debbie Wide felt that her rights were being ignored by her doctor. 'I found he didn't take the M.E. seriously so I asked to change doctor to another in the practice, but the head of the practice wouldn't let me,' she explains.

Unhappy with the level of care afforded to her, Debbie took her concerns to the Practice Manager, who after a series of discussions set up a meeting with herself, Debbie and the GP in question.



SOMETHING TOLD MIKE'S G.P. THAT HE WANTED HER TO READ EVEN MORE INFORMATION ON M.E.

'It was really productive, and I feel has fundamentally changed the relationship I have with my GP,' Debbie says. She adds, 'My doctor had thought he understood M.E. but admitted that after he read the information I gave him and listened to my point of view, he saw it rather differently.'

### Changing your GP

Changing doctors is an important decision and should not be taken lightly, but patients unsatisfied with the care they receive have the right to request an alternative doctor or indeed to move to another practice entirely.

However, a survey carried out last year by consumer watchdog Which? found that nearly half of all surgeries in England were being forced to turn away new patients due to a staffing shortage. These findings again reinforce the need to talk through and try to resolve matters with your existing GP if a problem arises.

Changing practice is in principle a simple process, though patients must live within a catchment area and may be subject to a waiting list if the practice is full. You simply visit the new

GP and ask to be registered, if possible taking your medical card with you. A list of local surgeries can be obtained by calling NHS Direct or visiting their website.

One way to find a GP who understands M.E. is to contact your local support group as some hold lists of members' feedback on doctors in the area, or will let you place a notice in their newsletter requesting recommendations. Alternatively, you can obtain the contact list for your group and call those in your postcode to ask them if they have a supportive GP. It can also be useful to speak to the Practice Manager (e.g. by phone) before joining a new practice, and asking him or her if their surgery treats many patients with M.E./CFS.

### Things can only get better

The *BMJ* study mentioned earlier revealed a feeling of 'hopelessness' among medics about how best to help patients with M.E./CFS. The good news is that funds have now been invested, at least in England, to ensure that healthcare workers start to receive proper training on the diagnosis and



Maintaining eye contact and trying to see your GP's point of view could improve your relationship with your doctor

management of the illness.

Chris Clark, chief executive of Action for M.E. outlines his hopes for the near future saying, 'Patients need caring, understanding and above all well-informed doctors.'

### Getting the most out of your doctor: Useful tips

- Make a list of what you hope to achieve from your appointment and the points you would like to make
- Request a double appointment if there is a lot to discuss
- Try and see your doctor's point of view and always remain civil
- Take a friend or family member along to appointments to back you up and provide an additional perspective
- Use names. Say 'Doctor Smith' not 'Doctor' to encourage a more personal rapport
- Don't be afraid to ask questions or raise any concerns you may have
- Be co-operative; the label they give your illness is less important than the partnership itself. Ask: 'What would you do in my situation?'
- If you're too ill to get to the surgery, you can request a home visit, although this is at the GP's discretion. Other options include requesting a telephone appointment or sending a carer to speak to the doctor on your behalf

### Further information

To find details of GP surgeries in your area, call NHS Direct on 0845 4647 or type in your postcode at [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk), which also contains information for doctors on 'CFS'

To order AfME publications such as *NHS healthcare for people with M.E.*, *Guidance for GPs*, or *A guide to symptom control*, see page 47

To obtain a copy of the AYME booklet *A Guide to Getting the Best out of your Doctor* send £1.50 plus an A5-sized SAE with a 42p stamp to: AYME, PO BOX 605, Milton Keynes, MK2 2XD

*InterAction* featured an article on how to complain about the NHS in issue 37, or e-mail [interaction@afme.org.uk](mailto:interaction@afme.org.uk) to request a copy

POPAN (Prevention of Professional Abuse Network) offers support and advocacy to people who feel they are being abused by health or social care professionals. Tel. 0845 4500 300, or visit [www.popan.org.uk](http://www.popan.org.uk)

To find your nearest M.E. support group, call AfME on 0845 123 2380 or e-mail [admin@afme.org.uk](mailto:admin@afme.org.uk)