

Severe M.E.

Zoe's Story

Soon, the long-awaited report of the Government's Working Group on CFS/M.E. will be published. *Zoe Williams* hopes that the needs and experiences of those severely affected by the illness will be taken into account.

Over my ten years of illness I have had a wide range of experiences of NHS professionals. Although I think the majority had good intentions, their desire to help me has not always prevented them from doing exactly the opposite. A common theme is the belief that people with M.E. would get better if they did a little bit more each week. I can't count the number of times that I have had to explain to a professional that this does not fit my experiences. It can be heart-breaking when this is held up as the effective treatment that I would so love it to be.

In my experience when my health is improving it is very natural to do more. It is important to be self-controlled and not to try and rush the improvement, as it is easy to overdo it. When my health is on a plateau or deteriorating, trying to do more can be positively dangerous. At all times I have to weigh up the risks and benefits of particular activities in relation to my symptoms and health status at that time and my priorities for the week. It is very hard that few professionals respect the risk of deterioration, even though I have had both short-term and permanent deteriorations when I have been encouraged to override my sense of risk and do something that I felt I may not be well enough for.

Bad advice made me worse

If I had been encouraged to listen to my body, learning from my experiences, I doubt that I would be as ill as I am. Instead, I was told to do what I knew in my heart was dangerous. It is not merely a case of insensitivity – it is a case of being advised by someone with authority, to do things that predictably make the illness worse. Yet patients expressing concern about possible long-term relapse tend to be treated as if they are over-anxious.

Initially I was treated as if my illness was not at all serious, but at the age of 13 I was already too ill to go into school even for an hour in the library. Now I tend to be treated as if I am unique in having been in bed for nine years, although I know there are many in a similar situation. There seems to be very little expertise in severe and long-term M.E.

'The doctor who helped me the most treated me very gently'

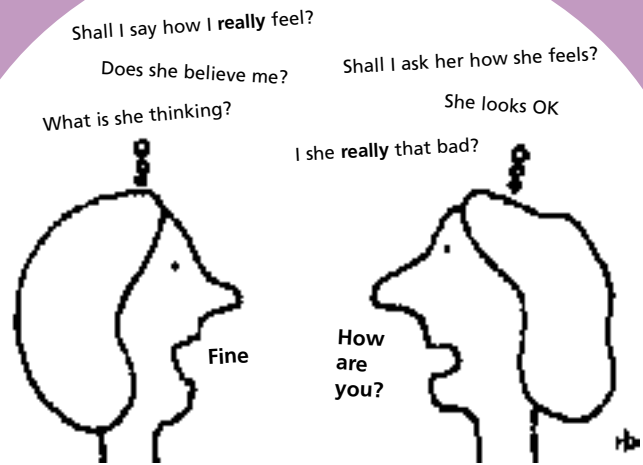
When a person feels that they have been treated badly, this has an effect even if the problem was unintentional and there is no blame attached. Many people with M.E. have had very difficult experiences with the medical profession and so they are often

nervous around doctors. The doctor who helped me the most treated me very gently. She realised that my anxiety was not to do with her, but simply a consequence of my experiences. Although she could not help me physically, she helped to restore my self-respect. One of the hardest things for me has been self-doubt. I didn't really believe my own body because I was continually told things that didn't seem to make sense. It was horribly confusing and it has taken years to build my confidence in the knowledge that it is not my behaviour or attitudes that are keeping me so ill.

Home visits would help

When I was less severely ill I went to out-patients appointments. The combination of the journeys, the consultation and the long period spent in the waiting room sitting up in a chair caused me a lot of physical suffering; I also think that it contributed to the major deterioration I was experiencing, from which I have never recovered. The health impact of appointments on moderately severe M.E. would, I think, be lessened if patients had a comfortable, quiet place to lie down while they waited. Home visits should also be provided where travel may be detrimental to the patient's health.

If I were to die in the near future, I would like to leave my body to research into M.E. It seems to me



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that with any mysterious illness, autopsies would be a good place to start investigating. At present I am not aware of there being anyone willing to carry out such research, and I think this is something that should change.

A personal wish list

I would also like to see:

- more scientific rigour and attention to sub-groups in research
- equality with other comparable disabilities when it comes to service provision and volume of research
- access to services for people who are housebound (using home visits, telephone consultations, mobile clinics, post, e-mail)
- suitable in-patient facilities for assessment, treatment and respite care (with single, quiet rooms)



Zoe Williams is often bedbound

It seems an omission not to call for more training in M.E. for doctors, nurses, physios and occupational therapists, as it is most certainly needed. However, I am concerned about the type of training. I do not want to see 'do-a-bit-more-each-day' training. I would love medical professionals to be told more about the physical abnormalities present in M.E. patients and theories which might explain some of these, and

also to learn about how different sub-groups react to different treatments.

Zoe's views, as outlined here, were submitted to members of the CMO Group and Department of Health as part of the 'Sounding Board' event for M.E. patients held summer 2000.



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