

Emma's story

By Sheila Davies, mother and carer

Emma and I entered the doctor's surgery – it was our first visit to our GP since Emma came out of hospital. Our GP gave a welcoming but slightly apprehensive smile. She expressed her pleasure in seeing that Emma was now out of hospital and began to read Emma's hospital discharge letter. I peered over to sneak a look. It said:

'Admitted 18/4/97 – not walking, not talking.
Discharged 12/8/98 – walking, talking.'

That was it, 16 months of her life summed up in ten words. It told the GP nothing about her current condition, or what had happened in those intervening months.

Emma first fell ill in December '96. She was 10 years old at the time. At first we thought it was simply a virus, which seemed to be leaving her incredibly tired. If she tried doing anything she seemed to fade after a short period of time, and had to lie down. Gradually she could do less and less until after only four months she could no longer walk, stand, read, write or barely talk. She was admitted to the local hospital for 'two days observation', and was discharged 16 months later. Our lives changed dramatically during this time.

Before she fell ill, I thought ME was just about feeling very tired, and had not realised that children could get it. When Emma was admitted to hospital, I was told that the doctors wanted to manage her illness using the Royal Colleges' Report as a guide. This alarmed me, as I had read criticisms of it in the ME press*. I read the report three times, and each time it seemed to be saying something different, depending on which bit one concentrated on.

For instance, Chapter 9 – Management, reads:

'Increases in activity need to be planned in a cautious, controlled and mutually agreed manner' and 'the management of CFS involves co-operation, but not collusion'.

Chapter 10, the chapter on children with CFS, states:

'Identify goals for each week with child and family.' Unfortunately this can easily be interpreted as 'tell the child and family the goals for each week'.

Hospitals and ME



With the Duchess of Kent at the Childline awards in 1997

* AfME Chief Executive Chris Clark comments: 'The inclusion of the patients' voice within the Chief Medical Officer's Working Group is a demonstration of partnership and the need for agreement that should be followed in every care setting.'

When Emma was first admitted to hospital, one of the nurses said he'd had experience of nursing children with ME before. This sounded comforting at the time, but in fact most of the nurses appeared to know very little about ME, and we were never confident that the doctors did either.

We were assigned a psychiatrist whom we had met prior to Emma going into hospital. We thought we had gone to see him for help coping with the consequences of the illness, but left with the impression he knew nothing about ME and thought her symptoms due to some mental illness. Our impressions remained unchanged after she was admitted.

When we arrived on the ward Emma was at 0% activity level, and did not want to do anything. Initially targets were set around eating, washing and dressing, and she required assistance from the nurses to manage all of these activities. Decisions to increase these targets were made at weekly hospital meetings of doctors, psychiatrists, nurses, physiotherapists, play leaders and the hospital school teacher – in other words everybody but Emma and ourselves, who were excluded from these meetings.

After this meeting the doctors would then meet myself and my husband, ostensibly to decide how to increase Emma's targets. On occasions we refused to agree to what was being suggested, but generally we felt had little choice in the matter but to go along with what they wanted. The only alternative was to take Emma home or find another hospital. We did not feel we could cope at home with Emma and thought this decision might end up with legal moves being taken to put Emma into care. I rang round and discovered there was no other hospital available to go to.

I would not have survived those first months Emma was in hospital without Jill Moss and AYME (the Association of Young People with ME). Quite often I rang her in a state, faced with some ultimatum from the hospital, and needing information and advice. When the meeting between the hospital doctors, myself and my husband began to get very fraught, she offered to come along and support us, bringing with her a depth of knowledge that we did not have. The situation between ourselves and the doctors eventually broke down completely, when attempts were made by them to severely restrict our rights to visit Emma, and to stop us having any say in what happened to her on the ward.



Emma, aged 11, shortly after admission to hospital

Being in hospital was not all bad. We were very lucky in the support we received from some of the nurses, physiotherapists and play leaders, who befriended both Emma and myself and made us very welcome on the ward. Their general philosophy was to make the ward a happy and friendly place. From being very alone and unsupported with the illness at home, we were surrounded by people who, while not knowing much about ME, most certainly wanted to help in whatever way they could.

When I meet other ME sufferers and their carers, they inevitably end up asking me: 'What made Emma better?' It is impossible for me to pinpoint one particular thing that made the difference. I believe that it is a case of managing the illness to give the body the best opportunity of healing itself, which can involve a variety of strategies and can take a considerable length of time. I also know others who have tried everything that we did and still not got better. However, if Emma relapsed or I myself got ME, these are the strategies that I would take:

- Try and restore sleep pattern – drugs like amitriptyline/structured day/relaxation techniques might help.
- Find a level of activity you can cope with on most days and keep to it.
- Increase activity, only once you are easily maintaining your current level. Make sure that increases in activity are in minute steps, and are achievable. Better to go too slow than too fast.
- Minimise stress as much as possible – it hinders recovery.
- With what energy you have, concentrate on the things you can enjoy.

- Never give up hope about recovering, but accept the fact that it can take a long long time.

I also realise it is very difficult to do all those things alone and unsupported. The support you need is from people who help make you feel good about yourself despite your illness, are sympathetic when things go wrong and who always provide positive encouragement rather than criticism. Being surrounded by friends all wanting to be there for you is good medicine, for everyone.

When Emma finally recovered, I needed time to recover too. I was still very angry inside about some of the problems we had encountered when dealing with the medical profession and kept asking myself: What needs to happen to make this situation change? This led me to write *My Daughter and ME*, to try and make sense of what we went through.

Emma's version of events



Fully recovered, Emma is thrilled to be able to ride again

The first 10 years of my life were very happy and enjoyable. I would play tennis, swim, horse ride and I had many friends. Then I fell ill with a virus which left me incredibly tired. I caught this three times, but by the third time I began gradually to get worse and worse. I would get terrible beating headaches, muscle pains, cramping stomach aches, felt cold all the time and had a hacking cough. I used to watch all the children coming home from school and wonder if I would ever be able to do that again. I remember thinking, 'This is it. I'm going to be like this for the rest of my life.'

I couldn't be bothered to even try to get better. I was annoyed with my mum for trying to make me eat and do things I didn't want to. I just wanted to stay in my little bedroom, lying in bed for the rest of my life. One morning I woke up and

found that I couldn't stand. This was the day that I completely gave up hope. I now stopped eating and couldn't sit up, couldn't read, couldn't write, could hardly talk and sometimes got paralysed legs. But still I wasn't told that I had ME but that I simply was getting all these symptoms from post-viral fatigue syndrome and would get better soon.

This is when I went into hospital for the weekend and ended up staying for 16 months, where I was given targets to achieve each week. I disliked everyone at this point: my family for putting me there, the doctors for making me do certain tasks and the nurses for making me carry out the tasks the doctors had set.

I would hate Tuesdays, as the doctors and my parents would have a meeting about increasing my targets. All day I would be worrying about what targets were set and if I could complete them or not. I thought that I should have a say in what my targets would be, as it was me that would be doing them. Luckily I had people to talk to about this. AYME provide pen pals with ME who you can write to (details below). This was a great help to me as I had others who would understand what I was going through. I would sit in bed and tell my mother what I wanted to say to them and then she would type up the letter and send it off. Sometimes getting better seemed too hard and seemed to take too long, and I would feel like giving up. I used to wish that I could just fall asleep and then wake up the next morning completely normal again.

As I slowly started to get better, life in hospital improved too. I accepted the fact that I had to do my targets and as I got more energy, I found these were easier to do. I was becoming good friends with some of the nurses and started to go to a special school for an hour, a few days a week, in my wheelchair. Eventually I also began attending my normal secondary school one day a week, to have a single lesson on the ground floor.

It was a long time before I could walk. For months I tried, using a pulpit frame, but eventually found I could manage crutches. By the time I left hospital in August 1998, I was again a happy child enjoying life. I don't think that my treatment was what made me better. I think that it helped me a lot, but that my body just had to get better by itself in its own time. I now have a full and active life. I go horse riding three times a week, do jazz dance and drama lessons on a Saturday, and enjoy going out with my friends. I am fully recovered, and aim to stay that way.

Sheila Davies' book *My Daughter and M.E.* is published by the AYME, Association of Young People with M.E. Box 605, Milton Keynes MK2 2XD

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