

# School Daze

*School days are often fondly remembered as the best of your life, but what about when you're juggling the pressures of friends and homework with managing a chronic illness? 18-year-old **Emma West** talks to young people about their experiences of education and M.E.*

In a society where "education, education, education" is supposed to be a teenager's top priority, the pressure on young people to excel is higher than ever. Exams, all of which are reputedly so important that your very life depends on them, occur nearly every year in secondary school. So how can young people with M.E. reconcile the conflicting desires of getting an education and maintaining a social life, with the physical and mental restrictions of chronic illness?

## Teachers on my side

Talking to other young people with M.E., I've realised just how lucky I've been with my experience of education. I became ill with M.E. when I was nine after being unable to recover from flu. It took a year for me to be diagnosed and during this time I wasn't well enough to attend school, a local state primary, very often. However, staff were very supportive and I began to improve, managing two to three days a week.

I found the move up to the state comprehensive hard at first, especially the walking between lessons, but I had a lovely tutor who was always ready to help. My teachers had been informed about my condition and were understanding. However, this didn't stop me from pushing myself too much. I can remember crying because I wanted to go to school but my Mum wouldn't let me because I was too ill.

The only real problem area was P.E. When I was too tired I was made to copy from sports textbooks with the people who had forgotten their kit. It felt like a punishment.

## Assembly on M.E.

My classmates were also a concern to me. I was worried that not doing P.E. and having lots of time off might cause resentment. Shortly after joining secondary school, I decided to do a short talk in assembly to explain what M.E. was and how it affected me. Although it was a daunting experience,

it was so worthwhile. I've never been bullied about my condition. My boyfriend, who was in my year, says he can remember thinking how brave I was.

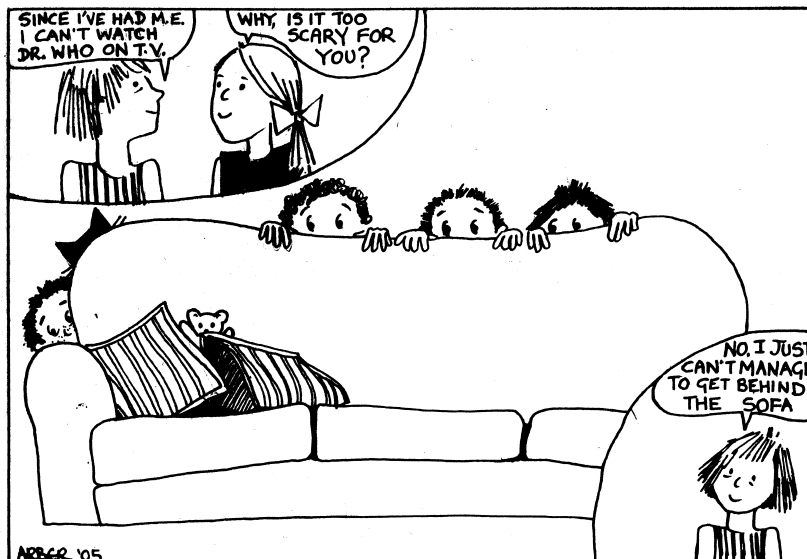
When it came to A levels, the opportunity for home study suited me a lot more. My teachers, again, helped me manage the workload. At one parents' evening they said that as long as I didn't tell any of my classmates (otherwise they'd all want the same treatment), it didn't matter if I didn't hand in one piece of work all year, as long as I did my coursework. This level of understanding meant I could pace myself more effectively; allowing myself nights off from schoolwork to do other things, including finding myself a lovely boyfriend!

Despite this, in the summer I overdid it on revision. I think that this is something many people with M.E. can relate to; the desperate determination not to let their condition get the better of them. Since then I've had a slight relapse, but I think I'm finally learning that I won't get better if I fight against M.E. all the time. Hopefully I'll be able to put this into practice next year, when I go to university.

## "They didn't believe I was ill"

Unfortunately, many young people with M.E. have not had such a good experience of education as I've had. For Alex, it was the combination of school-related stress and becoming ill with flu that led to her becoming ill at 16. Refused a home tutor, she tried to attend mornings at her local state school until the exams.

"As none of my classes were on the ground floor, I had to sit outside reception with all the other people that couldn't get to lessons due to injuries





**'Listen Up':**  
Emma West gave a school assembly on what it was like to have M.E.

For people with M.E., an exam rarely gives an accurate portrayal of their ability; all it really shows is how well they were feeling that day.

Beth initially became ill at 12 after catching glandular fever. Despite trying to attend school as much as possible, her health declined rapidly and as her school was over an hour away, her mother pulled her out.

"Some of the boys thought I was putting it on – you know how disgusting twelve-year-old boys can be – but the teachers were really supportive. They sent me a nice letter when I left," she explains. "It was hard though, I really missed my friends."

Beth's mother moved her to the local convent school nearer to home. As it was all girls, it was "more chilled", and the headteacher understood the condition. It was arranged that she should attend alternate mornings and afternoons, but her health was still getting worse. She was advised to go as much as she could, something she now thinks was a mistake: "I wish I'd been taken out of school, but back then it just wasn't an option."

### **Set those P.E. teachers straight!**

Despite her school's supportive attitude, Beth still managed to come up against some "very thick" P.E. teachers! Instead of being allowed to sit or lie down, she was made to referee the netball matches.

The balance between academic studies and your social life is one of the hardest aspects of life in education to deal with. Teachers have to remember this when dealing with students with M.E: it's not just how much work you can physically do; your other commitments have to be taken into account too. Beth recalls: "I remember hearing a story about a friend who studied so hard that when she got her results, she had no-one to celebrate with." She made a conscious decision not to just concentrate on the academic side, but to also spend time with friends. In her third year she became notorious for not handing in essays!

Unlike Alex, Beth found that seeing less of her schoolmates was in some ways quite a positive experience. "I managed to stay out of the cliques, which meant I was exempt from bitching!" she laughs, "I had a kind of mysterious aura about me!"

and illness," Alex explains. "I didn't really get that much teaching at all."

It took two years for Alex to finally receive a diagnosis of post-viral fatigue syndrome, which led to problems with her teachers in the interim.

"People weren't very sympathetic; even my Head of Year didn't believe that I was ill."

Like me, she also had a bad experience with P.E. teachers.

"They said I was lazy," she recalls. "In my report they wrote that I had 'a negative attitude to a healthy lifestyle!'"

Alex laughs about it now, but at the time the lack of support was degrading. Most painfully of all, she drifted away from her classmates. "My long-term friends were initially supportive, but we lost touch as I only ever saw them at break times," she explains.

Just months after becoming ill, Alex was expected to sit her GCSEs. Luckily, she found out through a friend that she was eligible for extended writing time to allow for the restraints of M.E. Her school didn't tell her this was possible. Throughout the exams, Alex experienced severe headaches and had to rely on painkillers to get her through.

Shortly afterwards, her family moved to a quieter area, and her health began to improve. She enrolled at the local college to do A levels, attending two mornings a week. Sadly, she relapsed shortly after and became house bound, but now she's feeling well enough to take up education again. This time she's studying to be a counsellor.

### **Exam system too inflexible**

Alex wasn't the only person I spoke to who found the pressures of A levels too much. Beth took one AS level exam in 2003, but since then she's relapsed and spent the last two years pacing. Her situation highlights the frustrating inflexibility of the examination system.

At age 16, studying at home became the best option for Beth, and in this way, she gained three GCSEs. However, two attempts to return to school for sixth form both led to relapse. "It was so disheartening," she recalls. "I was very low."

Beth has since made getting better her top priority, and is now managing some days without painkillers. Despite the severity of her condition, she remains positive and believes you have to see the funny side of life with M.E.

### **Putting on a brave face**

Ruth, who has now recovered, urges other young people not to overdo it but to put their health and happiness first. At the age of 15 she contracted severe M.E. following acute stomach pain. Despite appearing to get better, after only a week back at her local state school she collapsed.

"The first time I knew something was wrong with me was when I almost got run over by a car," she writes. "I'd just walked out in front of it, but I didn't realise what had happened until my mum asked me what I was doing. I remember crying and screaming because I didn't know what was happening to my body."

*"I worried that if I moaned too much about my illness, my friends wouldn't phone me"*

At the beginning, Ruth pushed herself to go into school. Despite the fact that she didn't have a diagnosis, the teachers were supportive. Apart from the lessons themselves, maintaining friendships whilst struggling with severe pain was a huge challenge.

"I'd put on a brave face and try to smile. My friends would be talking about boys and stuff, but I couldn't care less what they were saying to me; I was in too much pain to be interested. I never let them know how I felt because I didn't want to upset them. I worried that if I moaned too much about my illness, they wouldn't phone me."

## Supportive school makes all the difference

Fortunately Ruth had a strong family to support her. She also had the medium of art to express herself: "Painting helped me get the anger out."

After gaining a diagnosis, Ruth's health began to gradually improve, until she was well enough to start at art college. A tutor came to her house and dropped off work.

Four years on, Ruth's health has steadily improved through lots of rest and not pushing herself. She is now working in her family's business, and still painting when she gets a chance.

The main theme that emerged from conversations I had with Beth, Alex, Ruth and other young people was how much easier life is if your school or home tutor is supportive. It just isn't productive to try and continue as you

were before you were ill, and yet the Association of Young People with M.E. (AYME) still finds that some schools are offering inadequate support or refusing home tuition to young people struggling to stay in school.

Released in 2002, The Chief Medical Officer's Working Group Report on CFS/M.E. should help to make sure that young people with M.E. are helped to receive education that is suitable for them: "Specifically, a young person with CFS/M.E. should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed."

It is important to remember that your health matters more than any certificate. Beth sums up the sentiment echoed by all the young people I spoke to: "Qualifications can be gained at any time. Just don't push yourself – and most importantly – don't panic!"

## Useful resources

**The Association of Young People with M.E. (AYME)** has produced a DVD pack for teachers about educating young people with M.E. and offers information on education legislation and accessing home tuition. Visit [www.ayme.org.uk](http://www.ayme.org.uk) or call 0845 123 2389

**The Young M.E. Sufferers' (TYMES) Trust** has also published some useful reports such as *Ten Points on the Education of Children with M.E.*, and *Implications for Schools of the CMO's Report*. Visit [www.tymestrust.org](http://www.tymestrust.org) or call the charity on 01245 401 080

**Your Child and M.E.** is an AfME booklet aimed at parents of under-18s (£2 to members; £3 to non-members)

*Our guide to the CMO's Report on CFS/M.E. in children and young people is available free – see page 47.*

## Friendships and dating – experiences wanted

*For my next article, I'd like to hear about younger readers' (teens and twenties) experiences of friendships, socialising and dating, good and bad. I'll look at how you maintain relationships (through home visits, the telephone, internet, going out), how you meet new people (support groups, chat rooms, through friends), and how difficult it is to keep up a social or love life. I'd especially like to hear from young men, as none got in touch last time!*

*Write to Emma at Box no 4270 c/o our Bristol office or e-mail [emma\\_weste@hotmail.com](mailto:emma_weste@hotmail.com)*

## Reader giveaways

### Verity Red's Diary: 10 copies up for grabs

"Ever felt annoyed because no number is stored on 1471 when you were too tired to answer the phone, but you'd like to know who you were ignoring?"

"Ever had to stay at home whilst your boyfriend goes to your friend's party and secretly wished he'd come home early (and he doesn't)?"

"I have. And so has Verity Red. This book will provide you with a few giggles even when there isn't much to laugh about." So writes Lucy Gardener at [www.amazon.com](http://www.amazon.com).

Reviewed last issue, *Verity Red's Diary* by Maria Mann (Janus Publishing, £14.95 see [www.inter-netti.com](http://www.inter-netti.com) for extracts) is a beautifully illustrated, lighthearted account of a year in the life of a woman with M.E., and too many bad hair days to count. The text is broken up by a variety of silly poems:

"Yesterday/Life was such an easy game to play/Now I need my bed to hide away/Oh I wish it was yesterday..."

For your chance to win a copy, send your name and address on a postcard marked 'Verity Red giveaway' to our Bristol office before May 2nd.



### Clean skin without cleansers: 10 sets to win

Cleansers, toiletries and soaps can be harsh on sensitive skins and cause problems for people with chemical sensitivity and allergies. The Healthy House is a friendly mail-order business offering a one-stop shop for people with allergies and chemical sensitivities.

Their recently-launched E-body range offers a new way of cleaning the skin, with three clever cloths that remove make-up and dirt without using anything other than water.

One satisfied customer writes: "This range is just perfect. Now I can be sure that my face is clean without worrying about whether I will react to cleansers."

For your chance to win one of ten sets of cloths containing an eye pad, face glove and body glove worth a total of £22.97, send a postcard marked 'InterAction giveaway' before May 2nd to the Healthy House Ltd, The Old Co-op, Lower Street, Ruscombe, Stroud, GL6 6BU or e-mail your details to [maxima@healthy-house.co.uk](mailto:maxima@healthy-house.co.uk) with 'InterAction giveaway' in the subject line.

*All entrants will be sent a Healthy House catalogue; alternatively telephone 01453 752216 to request one, or visit [www.healthy-house.co.uk](http://www.healthy-house.co.uk).*

