

Growing pains of educating M.E.

Lacking support from school but with his mum behind him, Damien Valentine survived a rough ride through his teens to achieve his dreams...

I'm 19 now and despite having severe M.E. since I was 11, I wanted to let other readers know that you can achieve your dreams despite this illness.

When I was first sick, mum kept taking me back to the doctors but no-one knew what was wrong until one morning I fell down five stairs and couldn't get up. My father had to carry me to see a consultant and we were told after tests for just about everything that I had M.E.

I did my best to make it to school, but when I tried to get up to change classrooms my legs wouldn't hold me, and in trying to help me my friends would also be late for class. My parents were asked politely not to send me back until I was well, so I left school at 12 years old.

'Mum kept telling me to use the little energy I had in a positive way'

That year, my father just left. He didn't say goodbye to me or mum. We had been a happy family before, but my mum kept telling me not to blame myself, that none of this was my fault – he just couldn't cope. She also said she wouldn't leave me and we wouldn't give up. She has never let me down.

Mum fought to get me a home tutor and in the meantime read to me or was just there by my side, reading to herself. I had to start using a wheelchair, which mum customised for me by painting aliens on the side.

My new tutor was very kind but mum's attempt to get me 'statemented' (as a child with special learning needs) was unsuccessful. We were told I had no learning difficulties; having had no education for two years didn't mean anything.

Determined to take GCSEs

When I had one year left of compulsory education, we were told it was a waste of time taking GCSEs because the course was two years. I asked to be given a chance, and my mum insisted; she was very angry! So for a year I had an English tutor and a Maths tutor for two hours a week – and passed both exams.

Then we asked about A levels. This time, though, as I was over 16, we were turned down for a home tutor. Having moved house, we contacted the local school to ask about distance learning for their computer course. I've always had a computer and after taking a test to show what I could do, I was in.

During the two-year course, I went in when I was well enough to pick up work and use the internet. Meanwhile, we had to pay for a private home tutor so I could also take A level English Literature. Despite being so ill that I had to take my exams in bed (with my doctor's support), I'm dead pleased to say that I passed both this summer. Although I still have M.E. and lots of black days, I am now doing a foundation course part-time for my degree in computing.



How I'd like to be:
Damien's self-portrait

I want to tell any kids reading this who have M.E. and feel as scared as I was: don't give up. But don't let well-meaning people pile too much on you either – go at your own pace. Mum kept telling me to use the little energy I had in a positive way, so I dropped all subjects except the ones I really needed to get me where I wanted to go. My doctor is brilliant, and so is my mum.

My father died two years ago so I know that life is not to be wasted.

When I got my A level certificates my mum was trying not to cry. She has always told me to believe in myself and it's worked for me. Each person has different needs. Find yours and don't give up hope.

For a free young people's information pack, contact our Wells office. Readers under 25, their parents, and schools can also get information on M.E. and education by contacting AYME (the Association of Young People with M.E.) or the National Association for Education of Sick Children – details on page 47.