



Experiences

Speech to the Royal Society of Medicine

Part of the 2009 conference 'Medicine and me : ME and CFS - Hearing the patient's voice'

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Young Advocate

The Young ME Sufferers Trust

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'Medicine and me : ME and CFS - Hearing the patient's voice'

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My name is Shannen and I have had ME for 6 years. I found it difficult at first coping with the illness and other people's reaction to it. I turned so quickly from a lively, popular girl into someone who couldn't walk far, found standing impossible, couldn't abide the smell of food cooking, bright lights or watching TV and I soon needed a wheelchair. I achieved many small goals thanks to it. After the first summer I gave it back. By winter I needed it again. I was heart-broken when it was delivered - and to think I'd been almost excited with relief to see it first time around!

I have had some amazing highlights along the road to where I am now - living with the illness. The most life-changing ones have happened at home and I often couldn't even have a hug as a reward since my muscles hurt so much.

The hardest thing to maintain during my illness has been friendships. When you are 8 or 9 your parents still arrange your get-togethers. They drop kids over and you go around for tea. I could only stand 20 minutes' company before my head would be splitting, I'd become confused by words, have 'brain fog', become dizzy and need to sleep. My mum couldn't leave me alone and take the friend home and parents, no matter how well my mum explained things, couldn't be hassled to come over for such a short stay. Soon visitors trailed off. Before we'd often have a house full of kids. I got the feeling they thought they'd catch what I had! People didn't really understand and I hated having to explain it, or say how I was feeling. I wanted everything to go back to how it was. I started to get really low as I wanted it all to stop. I wasn't really living any more. I had to be carried everywhere, I couldn't even be alone on the toilet any more once I started to have fits. I used to enjoy being top of the class, going to athletics, being in the swimming club and riding horses. I couldn't imagine ever being well again. Now that I am older things are a bit easier as I can text my friends and they'll make their own arrangements to see me.

Some friends I had to lose as they turned out to be fair-weather friends. You'd be surprised how many there were. The friends I kept surprised me too. They weren't

the people whom I'd have said were my best friends. I now have really understanding friends, well, most of the time - they are teenagers after all!

Mum had bother with the school from day one who refused to send newsletters, homework, cards or even invite me in for the school photo. It was like they'd written me off. I wanted to show them that I still mattered and was still exceptional but in a different way. They wouldn't reward me in any way for my work - wouldn't even mark it. They didn't really want me any more. The Head said that I was one of their brightest pupils and me being sick had messed up all their predictions.

The school wouldn't tell us from one term to the next what they'd be studying to allow me to prepare or for Mum to stock up at the library. Everything was a state secret and only those with good attendance were let in. Friends were told NOT to lend me their homework sheets or newsletters in case I copied up what I'd missed! They were deliberately sabotaging my education. They'd make out they knew what was best for me and would try to overpower me. I knew they were wrong. They'd have me carrying the classes' heavy books and were supposed to let me go if I held up a red card. They'd stall, 'after 5 minutes Shannen', 'after break Shannen', 'when your Mum gets here Shannen'. I knew they were being dishonest. I was nervous of them as I knew they didn't believe how ill I was. They'd make me get up and down for prayers and people coming in and my head was swirling. It was torture. I'm sure they treated me badly just because they didn't believe me.

Soon after this I found the doctors had missed a serious heart condition. The teachers treated me even worse as if I'd got it just to make them look bad! The special needs teacher didn't bother to look up any of my ME complications on the internet. My class teacher was asked if she understood the problems associated with ME and the other staff said that they refused for her to answer that question! Yet I was under her care! I was effectively excluded for a while after this. The teachers wouldn't let me in until the doctors said what exactly was wrong with me, meanwhile the doctors wouldn't

agree. The ME specialist said it was ‘all the ME but complicated’ and the cardiologist said that although I was an enigma he’d treated 100s of children with ‘my condition and not one of them had ME’. So I suffered as a consequence. The doctors were giving me all sorts of ‘cures’ which were disproportionate to the seriousness of my symptoms. I was told to consume more eggs, then coffee, then chocolate! One suggested ½ an hour exercise a day would cure me - in other words, being well again! My parents were keeping everyone informed as no one spoke to anyone else. Eventually they complained to the School Governors, Council, local MP and put in for a Disability Discrimination tribunal. Changes were made to school procedure so that certain mistakes in child-care and pastoral support would never be made again. Shortly after, one of my friends was hit by a car and, like me, put in intensive care. They had cards, phone calls, work and newsletters sent home. I’m proud that things will be better for others because it would all have been for nothing otherwise.

My body was still weak but I started to feel that my brain was awakening. I started writing to Blue Peter again. I already had badges for raising money and taking part in races. Now I told them what had happened and gave them suggestions for doing a show on it. It also made me more aware of energy use in general and so I wrote down some ideas and got a green conservation badge - one of the hardest to earn (except for the lifesaver one). They gave me the affirmation that my teachers would not.

Any achievements my mum would stick on my wall so I could cheer myself up. She’d change my wall quite regularly or move the bed around to give me a different view. I had lots of memories surrounding me - happy times to remember of people who cared. I glued googly eyes on the people I wasn’t keen on any more. I’d learnt to enjoy myself with some of my energy and this stopped me getting low. Before, my energy was allocated so precisely that there was no room for fun, it was claustrophobic.

The next most valuable thing I’ve learned is to listen to myself. I used to hear this when I was young and not really understand. ME made me understand.

The effects of the ME were so huge that I had no choice but to listen to my body. My muscles and head were shouting so loudly. I soon learnt to trust my own judgement. I was fed up suffering when adults wouldn’t listen to me. I’m patient but I’d had enough of it. I got to the stage where I’d rather face a confrontation with a teacher than the pain after doing something unsuitable. I could understand how my Mum got a reputation for being fiery. I thought she was just irritable from the pain

[Shannen’s mother also has ME] and didn’t like people wasting the little time she has.

People say now that I don’t suffer fools gladly and I’m really proud that I’ve changed and am described in this way. Eventually I grew more confident and assertive. I started to take control. I knew by now I was in for a long ride and I wanted to take the driving seat!

I look back at things now and get angry thinking, ‘I was so worried about not upsetting so-and-so that I made myself ill!’ I knew it was stupid and they could take the pain better than me. I knew my judgement was right as if I went off course my bones would shout again. I listen to my body now. I get instant feedback. Plus adults have been wrong about so many things during all of this that I no longer have blind faith in them. They have to prove they are good at their job and earn my respect. I don’t have to prove I am ill. I’m the same with teachers. I know I’m bright. I know I can do well. I might do it differently, take a different road but I’ll get to the same destination. I no longer have absolute trust in any of the ‘caring’ professions. I don’t truly think most of them care - it’s just a job.

Before I got ill I’d always been gifted at maths and would help others at lunchtime with the teacher. So now my mum started to teach me - often in the middle of the night as that was my most awake time. We just did a little every couple of days to stop me getting rusty. I found this quite easy as I never had to write things down and if I had ‘brain fog’ we didn’t do any. There was no pressure and we didn’t waste energy going over and over topics that I understood already.

At the end of Primary I had something like 0.5% attendance but I achieved all Level 5s - the top in my year group. The teacher was seething as it went against her revised predictions and showed that pupils were better off going it alone. Several parents asked my mum to tutor their kids to get them ready for secondary school!

Around this time I also concentrated on dictating letters to magazines and nice people would send me things. I did competitions too as it’s nice to get something unexpected in the post. Putting an address sticker on a postcard is minimum effort and can have brilliant results. Now I wanted to give something back as I was feeling better than some of my friends. Although I was by no means physically strong or ‘better’ I had improved and reached a level that I could not improve on.

Next I became the Young Advocate of the Tymes Trust which made me very proud. It also gave me confidence. I must have been doing something right to have been chosen.

About this time I decided to take my GCSE in Maths. I was going to work to my strengths. There was no point killing myself trying to keep up with subjects I was not going to study further. I was 11 and had just started Secondary school. The teachers wouldn't send me any maths work until I had a tutor and that would be almost a year away. They'd have been better off giving the funding to my mum to find one.

I lost my place in the top set of all subjects despite doing the SATs, as no one would mark them. I know I did well but I lost my place which is supposed to be awarded on merit. I was told my attendance was too poor.

My parents had asked the school if they'd put me in for a GCSE but they said no - I was only 11. Schools don't seem to realise that my age or disability isn't everything there is about me. I am a fighter. I am an achiever. I am determined. Being ill at a young age has only magnified this. I've had to fight for everything. I've learnt to work smarter NOT harder. Unfortunately, two months before the GCSE I was ill with thyrotoxicosis and had to pull out. However, I persevered and passed my Maths and Religious Studies the next year. This year I've taken four more: Statistics, Geography, General Studies and Humanities. I study for a maximum of one hour in the afternoon, often not getting out of bed. You'd be amazed what can be achieved one-to-one.

My mum teaches me and reads when I'm unable to. She knows me so well that if I don't understand a word or a concept she'll draw on an experience I can relate to or an emotion I've felt and I know exactly what that word means. It's probably far quicker than at school. I don't write a lot of things down or discuss things endlessly. Once I've understood a point, that's it. It just goes on the list for revision to ensure I recall it for the exam. I miss out on the drama and nerves of the test build-up too. My SATs are more nerve-wracking. I sit the exam with calm adults in surroundings and with people I never need see again. It's anonymous. For me there is little emotion. They are kind and caring but I know no one is that bothered if I exceed expectations or fail. I just pay my money and have a try. I prefer it this way. There's no pressure. I didn't even have concessions as although my disability led me to this I wanted to do it despite the ME.

Being involved in the Tymes Trust has added an element of importance to my life. I feel I have a job. I've met people who are in Parliament, who are related to the Queen and a man who climbed Mount Kilimanjaro. I've met an athlete who runs marathons for children like me even though none of her family are affected. I've met girls who have almost made a complete recovery. It's been an experience and has started to restore my faith in human nature. Don't get me wrong, having a disability

didn't take away my hope - it was eaten away watching 'carers' at work. They passed over the opportunity to make a difference. I only had one person in the medical profession who gave me hope and she had ME and cancer. She treated me like a person and not a heart-sink case. She didn't write me off but made me feel like a star.

In school I am currently in the bottom set for everything and have been told that I won't be allowed to sit my English Literature GCSE because my attendance isn't good enough. If I can take a GCSE maths aged 12 why can't I at least try Shakespeare? I might not like it or I may decide it is not my strength. Surely, like everyone else, I'm entitled to give it a go? My parents say I'll take it - the school just don't know it yet! It's this attitude that spurs me on to prove them all wrong. They should be offering me more support not less. Last year none of my maths books were marked! All that effort for nothing! Teachers hear I have ME and think I'm lazy or school-phobic. They think I can't be bothered to go to lessons where I have to climb stairs. They amaze me with their ignorance. I used to try to get through to them but some are too set in their ways and won't change.

My friend at school was diagnosed too. She does far more school hours than me but then relapses. She gets fed up with no one listening to her. She's struggling to please everyone else and making herself miserable and ill in the process. She has no control over what she does.

I think doctors could have supported me more with my school. They could have sat me down and realised that I had a good idea of what I wanted to achieve and they could have helped me. They didn't want to get involved in the details. Attendance was everything. The only measure that counted. They didn't want me to take any other route apart from the one everyone else took. They lacked imagination. People who are ill or disabled have to be innovative. They have to be imaginative to get themselves out of tight spots. Why should this stop for something as important as education?

At my age and with my history most people would think in my shoes they'd have a lot of belief in doctors and a close relationship with them. I don't. I hardly go to the GP. Then I have to tell him what I want as he won't offer it. If I need painkillers, a recommendation for home tutoring, a wheelchair or physiotherapy. I know he'll argue against it. Doctors have always seen their role as monitoring my illness rather than intervening and helping to prevent problems. I needed them to be willing to represent me more and fight for my rights. I needed an individual education and for the school to meet my needs. I found this hard to communicate without medical support. My family found it best just to go it alone. We

were the only ones we could rely on.

Doctors need to be aware that not all the achievements patients make will be dynamic compared to usual standards but they will make difficult days easier. I can cope with an awful lot more now than I ever thought.

If at the beginning I'd been told I'd be diagnosed with ME, multi-focal atrial tachycardia, IBS, thyrotoxicosis, possible fibromyalgia, hyper mobility and scoliosis I'd probably have thought 'shoot me now'! Now I know I can deal with it. I am mentally very strong. I'm used to pain. I'm used to rejection. I expect nothing from the professionals. I know I have to live with this at the end of the day. No one can take it all away. I have to live a life with some friends, some enjoyment and some hope.

If I'd have gone the conventional route I may not now feel so optimistic and in control of my own life. I would not have the good friends and role models. I would not have my qualifications - 6 GCSEs. Instead, I may just have short spells of school attendance between relapses!