

The Parent Trap

What can you do when your parents don't believe you're as ill as you say – or when they go the other way and become over-protective? 20-year old Alex Bacon asks other young people with M.E. for tips on improving relationships with your mum and dad.

For most teenagers, adolescence is an emotional roller coaster ride of strong emotions; a time when we're starting to carve our own path towards independence from parents in the progression to adulthood. But what happens when you get ill with M.E, and can't storm out of the house to hang out with your best friend like you used to after a row?

Arrested development

Mark writes: 'I got so pissed off with my parents because they no longer treated me like an adult, but an invalid without a mind of my own.... I was going through the typical teen angst of anger and frustration without knowing how to deal with it.' Many of you report a similar conflict between wanting to express your feelings, and fearing upsetting those who you depend on most for care.

Realising it was okay to express himself openly with his parents meant Mark was able to set boundaries so they respected his privacy, allowing him more space to get better at his own pace.

Asserting yourself also requires both physical and emotional energy, making it difficult for a person already drained with M.E. 'I occasionally slammed doors, but I rarely had the energy to shout, let alone slam!' Like Hanna, many of us can relate to the problem of not being able to let off steam and rebel when we're ill.

But Nikki believes it is possible: 'sometimes I'd smoke a fag in my room when my parents were out. It was a small way I could put two fingers up at the illness.' Most of us find that talking to friends about how we feel can also help vent some of the pent-up anger, as Mel explains: 'I cope by texting or calling my mates when I feel like screaming at my parents...they understand how I feel because they have similar problems themselves.'

Going onto 'safe' chatrooms or message boards, such as those run by the Association of Young People with M.E. (AYME), is another great way to meet and chat to others in a similar situation. Mel adds: 'at least I can feel sexy flirting with a bloke in a chatroom, even if it is in cyberspace!'

'They didn't believe I was ill'

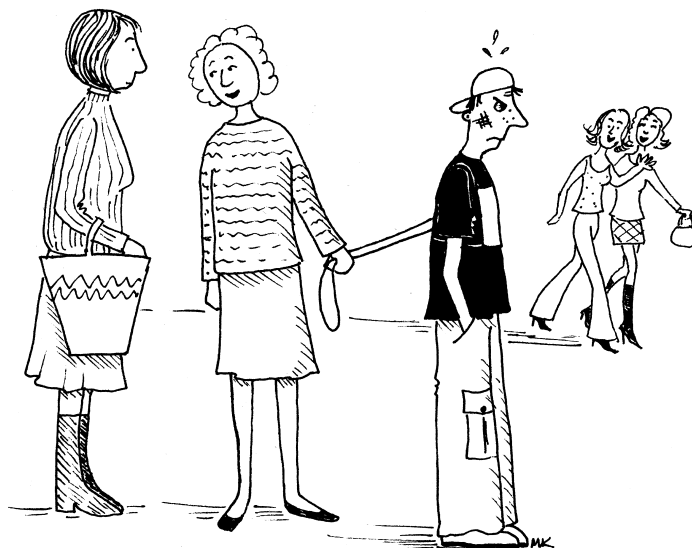
Being hit by M.E. can test even the happiest of parent-child relationships if we're forced to remain at home while our mates head off for uni or a flatshare with friends. The situation can be even harder if your parents are unsupportive.

Andrew explains: 'my parents did not accept I was ill and my father in particular was totally dismissive...being forced out of bed onto the floor confirmed the utter contempt shown.' Lisa also writes: 'I felt depressed and suicidal...not because I couldn't walk but because my parents didn't believe me – this was the most painful part of

my recovery.' Both Andrew and Lisa suffered badly from a lack of medical support which had a huge effect on their parents' attitudes to their illness.

These examples may sound extreme, but in fact most people find M.E. a difficult illness to understand (including those that have it!), particularly as it shows few visual signs to others and can be misrepresented by the media and some doctors as being 'all in the mind'. 'After coming back from the pub with friends my dad asked me: "how come you have the energy to meet up with your friends but not for washing up?"', remembers Janie. 'I felt like smashing a plate 'cause it was so unfair but he really didn't understand how doing something one day could wipe me out for the next.'

Improving communication and, if possible, getting your GP to explain about the illness fluctuating (or waving an AfME booklet under their nose) might help your family to understand better. Andrew also advises getting a written diagnosis from a sympathetic doctor to show parents.



'SINCE HIS ILLNESS WE KEEP A CLOSE EYE ON HIM...YOU CAN'T BE TOO CAREFUL CAN YOU?'



A firm diagnosis helps

Parents who are in denial of their child's illness may try to 'normalise' them through forcing them back into a pace of life that they can no longer cope with. This can inevitably lead to feelings of resentment towards parents, as Fi explains: 'Mine would often pressurise me to "pull myself together"...they thought I was not making enough effort to get back to school.' Following a firm diagnosis three years later, however, she found they became very supportive – so their relationship improved as a result of her finally being taken seriously by doctors.

'Unconditional and continuous support was the key to my recovery'

For some parents, the illness also raises the dilemma between trying to encourage their child's personal growth, while fearing relapse. Due to the unpredictable nature of M.E., it can be easy for parents to fall into the trap of smothering their child. Amanda writes: 'My mum would actively discourage me from pursuing the sort of passions and social interests that most teenagers get to explore...it would have been healthy to sometimes let me push out my limits a bit.'

Maureen, whose son has now recovered from M.E., feels it's important to share fears and frustrations about the illness together. She also believes that compromise is key. Being aware of her son's limitations, but encouraging him to pursue his interests within his capabilities, helped them both to keep positive about the future.

Independence Day

Being reliant on your mum or dad for care can be hard when you're craving independence. Parents may feel the need to take over their child's life if they are unable to do a great deal for themselves, or they might push their kids from doctor to doctor, desperately searching for a cure. This can lead to us feeling out of control of our lives, and you might feel like you're letting your parents down if they spend a fortune

on a treatment and it doesn't work. If your mum is deciding which doctor you see and what you should eat, there's also the danger you'll lose confidence in your ability to make decisions for yourself.

Sometimes, giving yourself enough space from your parents can be the answer. Nikki says: 'In the end, moving into my own flat was the only solution...I gained more independence and we both felt happier as our relationship became less claustrophobic.'

But your feedback shows that there can be a silver lining to the cloud of illness too. Stronger relationships are often built with parents that probably wouldn't have developed had we been well. Hanna explains: 'My folks always wanted what was best for me and supported me in finding my own way through the illness...it has made me even closer to my mum.'

Respect our boundaries!

Although we do need parental support, our personal space and boundaries should be appreciated as much as any 'normal' person's (that means knocking before you come in our rooms!).

If possible, having time away from parents with friends or on holiday can help ease any family tensions, as well as increasing your sense of independence and self-confidence. Doing a college or home study course can also help you to feel like you're moving on mentally.

Even if you aren't lucky enough to receive the kind of support and understanding you need from your mum and dad, don't give up hope. As well as offering a parents' support network, AYME can be contacted in confidence for advice on getting your parents to take you seriously. Finding other people your age who are dealing with similar stuff can make all the difference.

Remember that becoming independent is a gradual process. I'll give the last word to Hanna: 'If you manage to live through the dark times, it can only make you stronger.'

AYME is free to join for under 25s – contact details on page 46.

Action for M.E. has a website for under 18s – check out www.a4me.org.uk