

'Don't say nothing if it ain't worthwhile'

Stacy Hart has wanted to make it in the music business since she was 13 years old. While a decade with M.E. has limited her options, she gave up waiting for better times and resolved to record her first CD. The result, 'Mama Chill', includes a powerful track about the problems she's had getting support from the medical profession. This is her story.

Music is all I know; it's in my blood. As a kid I used to enter talent contests with my electric guitar. I found as a teenager that my rock chick look either went down a storm or was too – shall we say 'different' from the sweet and wholesome singers I was up against. I won some, lost others, but it gave me good experience.

Now it takes all my energy just to leave the house. When I got sick in my early 20s I struggled to hold down my day job in a newsagents', just holding on by my fingertips. Too weak to walk, I'd be driven there and back by my mum. She also collected me at lunchtime so I could lie down for an hour on the sofa before dragging myself back to work where I'd lean on the counter trying to remain upright.

Creative misdiagnoses

My GP kept saying there was nothing physically wrong with me and we needed the money so on I pushed. But the last six months as my vision became blurred and my words more slurred, I became really frightened about what was wrong with me.

Finally my sister took me to hospital where the doctor took one look at my punky hair and slurred speech and said I had all the symptoms of a drug addict! He refused to accept that I didn't take drugs and said if I wouldn't come clean about my 'habit' he couldn't help me.

I went back to my GP who eventually referred me to a neurologist in London. I really got my hopes up during the year-long wait for my appointment so was surprised when, after checking my reflexes, the doctor asked me to breathe very quickly. I did as he requested but soon felt quite ill so

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asked if I could stop. His diagnosis for all my exhaustion and pain was hyperventilation.

I went back to my GP whose words were: 'When are you going to accept that there is nothing wrong with you?' I couldn't, because I knew he was wrong. During a week's admittance to another hospital for investigations, I went for days without food, awaiting an exploratory procedure that kept being delayed. By the fourth day I had episodes of paralysis and failed to respond to stimulation of my foot reflexes. My mum was incredibly worried about me but despite neither running tests, or talking to me about my symptoms, the ward sister told her I had depression. 'But she's never depressed!' fell on deaf ears.

Fourth time lucky

Finally I happened to see a different GP who asked if I'd been referred to an M.E. consultant yet. Well...no. It was worth another long wait for the appointment to hear the words: 'I believe you' from the consultant at Coppetts Wood hospital. He diagnosed



M.E./CFS, and having little in the way of treatment to offer, recommended I try meditation.

Six years after becoming ill, at least I had a firm diagnosis: not depression, drug addiction or hyperventilation, but M.E. The GPs at my practice have grudgingly accepted this diagnosis but my doctor recently said: 'It's been scientifically proven that M.E. is a psychological illness – there's no physical basis for it.' My passing out in the waiting room obviously didn't count for much.

I now avoid going to the GP's surgery unless an episode of stomach pain and fever forces me there. There's nothing they can do for me.

I have had real help from some unlikely quarters though. After five years on an antidepressant called Motival, I was worried about dependency and wanted to come off it. To help the transition, I was put on Prozac in addition to the original drug but within 24 hours felt suicidal.

Medics at the psychiatric unit my mum and dad took me to couldn't believe I'd had M.E. for so many years without being offered any help, and reassured me that my sudden suicidal feelings were due to an ill-advised drug combination. They wanted to help, but seeing no signs of mental illness, there wasn't much they could do.

Help – off the record

Unofficially, however, the psychologist there did help me get a place on the waiting list for an M.E. clinic that St Albans' hospital were hoping to set up. While the clinic sadly died a death due to lack of funding, I am now part of a

small group of people with M.E. being supported by a team there including a physiotherapist and occupational therapist. Their plan is to put me on a structured programme of rest and activity which I hope will help.

I've always believed I could get better but it has been hard to live with my wings clipped, my social life so limited and my confidence deeply dented by everything that's happened.

Then one day I realised: If this is how it's going to be, I need to do something now or I'll be drawing my pension and still waiting to get well enough to sing again. I've always wanted to record my own rap demo and after saving up for a year, I managed to find a recording studio I could afford.

When the producer heard my stuff he offered to record three tracks for the price of one, letting me spend two hours in the studio at a time with days off to rest in-between.

It doesn't matter about my dream of a record deal anymore; achievement and success mean different things to me now.

Doing the three tracks and getting the CD off to DJs and radio stations provoked a relapse that left me housebound for a time but it was worth it.

Just doing something that gives me so much pleasure has been fantastic. If the magic recording contract never comes along at least I can look back and know that I gave it my best shot.

I'd like to thank everyone at AfME for your struggles on our behalf, especially as many of you are battling the illness yourselves. It's you that drive us, offering hope and making us realise that better times are on their way.

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Stacy – AKA Mama Chill – has achieved her dream of recording a rap demo

Reader giveaway

We have ten copies of Stacy's three-track CD *Mama Chill* to give away. 'Mr Maniac', which takes the mick out of rapper Eminem, is followed by 'Escapism' and then the catchy rap 'Don't say nothing' with lyrics many of us can relate to:

It's like a magnet under the ground/pulling ya down til ya on ya knees/fighting this disease, can't breathe, muscles cease/the pain is a pain that you would not believe/and you have the audacity to say I look fine/and whatever's going on is going on in my mind/yeah well come tell me that when I'm flat/laying on my back like a knick-knack-paddy-whack/no energy... yeah – come see/then ya pray ya never get M.E...

We want to dance again/have the chance again – to live/oh give us normality/dance again/have the chance again to be free/so look beyond the smile...And don't say nothing if it ain't worthwhile!

For your chance to win a copy of *Mama Chill*, please send a postcard to our Wells office marked 'CD giveaway' to arrive by December 10. If you'd like to buy a copy of the CD from Stacy (with half the proceeds being donated back to AfME) it costs £3 plus a padded envelope and two first class stamps. Contact Stacy Hart c/o our Wells office at Box No. 3981.

