

## Voices of ME

voices from the membership, Morecambe Bay ME Group

The following pages contain three case studies of people with ME. It also includes responses and comments made by members of Morecambe Bay ME Group (MBMEG).

The case study respondents, as with so many people with ME, have lived very active and busy lives prior to contracting the illness. These lives have had to be put on hold: it is likely that they may never return to the previous levels of energy and commitments in their work, social and personal lives. This is a difficult change in circumstances to come to terms with, and the work of MBMEG has been of great value to many in preventing them from becoming marginalised and feeling out of touch with everyday life.

Many members have struggled with the lack of awareness and understanding of the illness from health professionals, employers and sometimes even friends and family. One of the aims of MBMEG is to provide information, support and a network of contacts to help people with ME to feel that they are not facing their illness alone.

MBMEG publishes a newsletter, organises social events, and holds regular meetings where people can find out more about treatments and other issues of relevance to people with ME/Chronic Fatigue Syndrome. The group has recently teamed up with Lancaster Citizens' Advice Bureau in employing a benefits caseworker to support people with ME in the Bay area to access benefits, work related pensions and more.

## case study—**Furness Peninsula**

“Coping with blindness is relatively easy in comparison to coping with ME.

Blindness is an inconvenience; ME is significantly more disabling. It’s only when I tell people this that they begin to get some understanding of how life-shattering ME is.”

SEVENTEEN YEARS ago Ulverston man William Caygill was a remarkably fit, active single man in his early 20s. His great love was rock climbing.

“I lived for rock climbing. I spent every spare moment, when I wasn’t working as a teacher, adventure climbing in England, Scotland and the Alps.”

By 1989 William had reached a very high level in the sport and was so fit that he could run a half-marathon with one day’s notice.

Then on Friday 13 October 1989 William contracted a flu-like virus. His life has never been the same.

At 42 William is struggling with the severe limitations of chronic ME *and* dealing with increasing blindness, a genetic condition unrelated to the disease.

“I suddenly started feeling shivery. Unusually for me I spent the weekend in bed but struggled back to work on the Monday.”

However, William’s flu-like symptoms did not abate. “I became increasingly ill over the next four months. I couldn’t work and I truly felt like I was dying. I consulted two GPs but neither was helpful, saying it was just post-viral fatigue and it would pass.”

William continued to deteriorate so did as much research as he could.

“I came across a leaflet on ME. As soon as I read the description

of ME symptoms I knew this was what I had.”

The debilitating array of physical problems William suffered, as he does to this day, comprise the classic core of ME symptoms: unrelenting exhaustion, unlike anything the sufferer has experienced before, which is little relieved by sleep; severe muscle pain, especially after minor exertion; loss of concentration; dramatic sleep problems; and a fluctuation from day to day, even from hour to hour, in the severity of these symptoms.

By this time William could barely walk. “I had to crawl upstairs on my hands and knees. I consulted another doctor, nearer to home, and I struck lucky. He knew a little about ME and diagnosed it which meant I could start planning for recovery. I started a strict pacing regime and learned to take each day as it came. Many days I was bed-bound, while on others I could move around the house. I was living with friends, who were hugely supportive, as were my parents and neighbours.”

After four years William’s health improved somewhat. “I was still ill but well enough to undertake a part-time degree in Law at Leeds University.”

In 1996 he went back to teaching. However, William became overconfident and pushed beyond the limits the illness was still exerting on him. In 2000 he relapsed severely, lost his job and was also going blind.

“Coping with blindness is easy in comparison to coping with ME. To me blindness is an inconvenience; ME is significantly more disabling.”

Now jobless, William needed to claim benefits. “Tackling the benefits forms is a nightmare. It’s been much easier to get benefits for my sight problems than for my ME because the disease is seen as a greyer area - but I lost my job through ME not blindness.”

William has now entered the chronic phase of the illness. “I

long for a cure. One may come, but not for decades. My hope is that all the medical profession comes to accept the enormity of this illness and the different ranges of disability within it. I think the Chief Medical Officer's report on ME will help in achieving this goal."

He adds: "Morecambe Bay ME Group has been a fabulous source of support. Having access to Robin Serjeant, the Rights for ME worker – is vital. He is able to achieve so much on our behalf - because he doesn't have ME!"

### case study—**Lancaster**

**"I felt sick all the time, had horrendous sleep problems and my body was pumping adrenalin out at a remarkable rate. My heart was beating madly, erratically, and I ended up in the cardiology unit."**

BEFORE ME hit Lynn Marshall in 2001 she led an extremely active life. Her work as a vegetation scientist for Lancaster University's Centre for Ecology and Hydrology, at that time based in Grange-over-Sands, meant that she spent most of her days out 'in the field', collecting plants and other specimens, while her free time was spent fell running, climbing and travelling abroad.

It was after a trip to South America that things began to fall apart for the then 31-year-old.

"I got a bad stomach bug and this was quickly followed by a severe kidney infection which made me very ill," Lynn recalls. "I was rushed into Westmorland General Hospital, as I lived in Kendal then, and I received intravenous antibiotics for a week. I assumed I would soon bounce back and return to work but I just became more ill."

"The fatigue was crippling. I thought the kidney infection hadn't been eradicated so I went back to my Kendal GP's



surgery. I was so exhausted when I got there that I just had to lie on the examination table, unable to move. The duty doctor was a student who didn't have a clue what to do with me. I was sent home in a taxi."

Lynn spent the next week in bed. "No one seemed able to help. Because of the South American trip I asked to be referred to the Hospital for Tropical Medicine in Liverpool but they found nothing. I was also tested for HIV – and was negative."

Meanwhile she was living alone with no back up (her mother was also ill).

"I felt sick all the time, had horrendous sleep problems and my body was pumping adrenalin out at a remarkable rate. My heart was beating madly, erratically, and I ended up in the cardiology unit."

Lynn also saw a psychiatrist who concluded that she definitely didn't have mental problems.

"Throughout these months ME had been mentioned as a possibility but doctors had to eliminate all other possibilities first. After six months I was officially diagnosed with ME. Knowing there was a term for this terrifying collection of symptoms was a relief. At least I could begin to look at ways towards recovery, which basically meant rest."

She continues: "My employer was fantastic. I took paid leave for six months after which I returned to work on a very part-time basis. I did just four hours a week until eventually, slowly, I was back to full-time hours."

However, the nature of her life and her job has had to change dramatically to accommodate the disease. The department moved to the Lancaster University campus in 2003 and Lynn moved to Carnforth to cut down on travelling time. Field work is out of the question so she is now desk bound.



“I don’t have muscle problems as badly as some other sufferers, which can affect the ability to work at the computer, but I still have relapses and succumb to every bug going around. I also have a lot of digestive problems, brain fog and fatigue but I can work flexible hours and also work from home at times too, which helps with pacing.”

Despite the fact that she can earn a living Lynn has had to sacrifice much. “Sadly, social life is extremely minimal.”

Lynn has been lucky enough to escape the benefits system and says, “I don’t know how other sufferers deal with rigid questionnaires and disbelief on top of the illness. I dread the prospect of getting worse and having to depend on benefits. If that happens I will definitely turn to the new benefits worker for help as I just wouldn’t know where to start.”

Meanwhile, Lynn’s dream is to be so well that she never has to think about ME again.

### case study—**South Lakeland**

**I was shocked at the term ME; I knew that a girl at school who was in a wheelchair had had it. This doctor said I wasn’t exercising enough, yet in truth I had increased my amount of exercise because I thought to feel so ill must mean I was unfit.”**

FALLING ILL with ME is a disaster at any age, but being hit by this devastating condition in your teens is especially cruel. This should be a time of dreaming, ambition, finding your own voice, and a busy social life.

Jo, from Kendal, suffered her first bout of ME in 1997 when she was just 17.

“I was studying for A levels at Queen Katherine School, Kendal, and kept getting tonsillitis and became run down. Then I



got a flu-like virus and literally collapsed,” Laura recalls.

“I was diagnosed by a locum GP. I was shocked at the term ME; I knew that a girl at school who was in a wheelchair had had it. This doctor said I wasn’t exercising enough, yet in truth I had increased my amount of exercise because I thought to feel so ill must mean I was unfit.”

This was the worst advice Jo could have received and it began to dawn on her that the more she pushed herself the worse her symptoms became.

The ME diagnosis was confirmed by a consultant at Westmorland General Hospital, but he could offer no cure or specific treatment.

By this time Jo had become bed-bound and remained that way for the first year with her parents caring for her.

“During the second year I built up my strength to the point where I could potter around the house. Eventually I was able to go back to school part-time. The school’s attitude was fantastic. They understood the constraints of the illness and let me come and go as necessary. By balancing rest and activity I was able to pass some A levels and I got into university.”

Leaving the physical support she had at home was a big step but her Communications Studies course at Nottingham Trent University required only six hours a week of formal contact. “I could organise my study time and rest accordingly.” Even so she still had relapses.

After graduation Jo worked, travelled extensively and completed intensive teacher training at St Martin’s College, Lancaster. “I was lucky enough to get a job at my old school as an English teacher.”

But by February half-term, 2005, her old ME symptoms began to threaten. At Easter she suffered the relapse from hell. The condition was back with a vengeance and she had to leave work.



“My muscle problems are particularly severe. I’ve had times when I can’t even brush my hair. I can’t read a book nor can I drive because of the exhaustion and concentration problems.”

From holding down a demanding and well-paid job, Jo, at 26, is now dependent on benefits.

“I don’t have enough National Insurance credits to qualify for Incapacity Benefit but I receive Income Support, Housing Benefit and Disability Living Allowance. I live in a shared house with friends, who are extremely supportive, as are my parents.”

The benefits people were understanding but Jo found filling in all the claim forms a nightmare.

“They’re confusing, ambiguous and draining. You can’t say what you are like on average as it varies such a lot within the spectrum of the illness. You have to focus so much on what you can’t do and this is a very disheartening exercise. I turned to Kendal Citizens Advice Bureau whose help was invaluable.

“I couldn’t survive without Disability Living Allowance and I will use Morecambe Bay ME Group’s benefits worker because my current housing situation isn’t really suitable. I need a ground floor flat but don’t know how leaving here would affect my benefits.”

She adds: “When the benefits system does work it’s great because you can shed that worry and put all your efforts into getting well. I hope by next year I’ll be able to take up voluntary or part-time work. I’m not going to agonise over returning to full-time work because this last relapse has taught me that I must put my health first.”

*The names of those featured in these case studies have been changed to maintain confidentiality.*

## Morecambe Bay ME Group

Imagine suffering from an illness that gives you truly appalling symptoms – deep, bone-aching exhaustion; throbbing muscle pain that won't go away with painkillers, massage or resting; patchy sleep that doesn't refresh you; constant 'flu-type feelings; and a brain that is so fatigued it seems to barely function.

Imagine going to your doctor with these chronic symptoms, and, after the blood tests have come back clear, being told – at worst – that you're just depressed, imagining things, or – at best – that you probably have ME and your doctor doesn't really know how to help, but if you can find somewhere for him to refer you, he gladly will. Except there is nowhere.

Now imagine that these symptoms are invisible, and unpredictable, and that people can't understand that when you've put on your best clothes and dragged yourself to their summer barbecue for two hours, where you *look* fine, that you're in bed for two days afterwards.

One of our members, a young woman with a small child, described her ME as a bereavement. Last year she wrote:

'At the moment I have a strong sense that I have died, especially because I feel I am getting worse and not better despite being off work for so long, and like any bereavement I am struggling with coming to terms with it.

'How does ME affect my daily life? I don't have a daily life any more. I do not get up in the morning knowing that what I plan to do I will do. I take each day at a time trying to gauge what energy I have, how my body feels, with what I would like to do, and what I have to do. It severely curtails what I can do – my mind still wants to do so much, but my body won't allow it. Some days are worse than others; the aches in my arms and legs when I try to prepare meals or take a shower makes me want to stop, but I make myself keep going. On bad days, I can do very little, not only do my arms and legs ache, I feel so drained and



tired, I feel like I have been drugged.'

ME is an illness which affects every system in the body. A couple of decades ago, it was derided as 'yuppie flu', and only recently was acknowledged by the medical profession as a debilitating physical condition. People with ME have suffered from years of negligence combined with a general lack of services for adults with chronic illness, and it has taken its toll: our group has many members who have been ill for more than fifteen years and are now unlikely ever to recover.

Our support group performs the vital role that all support groups for chronically ill people play: information, meetings, socials, newsletters, networking and sharing. But ME patients are a long way from enjoying equality with other long-term illness groups. They need a group that will campaign to raise awareness and to accelerate the painfully slow progress that is being made towards full recognition and provision of appropriate services. Our role, as an independent voice for hundreds of very sick people, cannot be replicated by any other organisation. We are passionate about making positive changes and we must not lose the opportunity to work alongside others to build on those changes.

### What people say about Morecambe Bay ME Group

*'At last I feel like I'm not alone.'* member, Lancaster, email, winter 2003

**'People like you keep people like me going.'** member, Walney, on phone, August 2004

'Thanks for getting information to GPs, by the way. My GP has totally changed his attitude to me – he certainly seemed more knowledgeable and treated me with respect and consideration.'



... Contact with the outside world is virtually nil for me, and to know the group is working on my and everyone else's behalf is comforting, reassuring, and brings hope.' *member, Kendal, letter, August 2004*

**'Thanks for the help and information you provide. I feel it's like a little "hook-up" when the newsletter arrives!'** *member, on subscription form, August 2004*

'Many thanks for emails sent from enquirers, which I've replied to, plus the super newsletter which really is brill... many thanks for all you're doing.' *member, Kendal, email, August 2004*

**'When I first got your leaflets I was in tears...I'd had no support before.'** *new member, Carnforth, at members' meeting, September 2004*

'I just love our newsletter, it manages to impart serious and/or important news in ways that make me laugh! There's not enough laughter in most people's lives, certainly not in mine, and laughter really is a healing process – keep up the good work.' *older member, rural Carnforth, letter, September 2004*

**'Sometimes my faith in the ME group is all that keeps me going.'** *comment by member from Barrow added to group survey form, January 2005*

'I find the group very, very helpful as only fellow sufferers have any comprehension of how very difficult our life is!' *comment added to group survey form, January 2005*

**'Thank you for your kindness, it really makes such a difference knowing the ME group is fighting our corner.'** *member, Kendal, February 2005*

'It is wonderful to now have something to look forward to and to



take part in, where before I felt, at times, hopeless and stigmatised...I now feel I am moving forward.' *young member, Lancaster, September 2005*

**'My life has just opened up since I joined the ME group.'** *new member, Lancaster, May 2005*

'Making this contact has immediately made me feel less isolated – thank you, thank you.' *new member, Sawrey, June 2005*

**'Thank you...you've made me feel human again.'** *member from Barrow, June 2005*

'I do appreciate all your work on our behalf. Not only do you give help to patients but your communications educate other people who are not sympathetic or understanding of the condition.' *longstanding member, Ambleside, July 2005*

**CONTACT:**  
Further information about Morecambe Bay ME Group and the Rights for ME caseworker is available by telephoning 01524 65842, or email: [info@bayme.org](mailto:info@bayme.org)

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