

## **An Interview with John – April 2004**

John has lived in the Sheffield area for 15 years, having been born and brought up in the town of Clonmel, Co. Tipperary, and having also lived in London for a large part of his adult life. John is one of the more severely affected of our members, having been virtually housebound since 1999 as well as for long periods before then. John's cheerfulness and sense of humour belie the seriousness of his condition, which is betrayed by, for instance, the weakness of his voice and the many layers of clothing he must wear in order to keep warm. Earlier this year John agreed to talk to Kath, our Information Officer, about some of his experiences.

John is now fifty-five, but he can easily date the onset of his health problems to the year 1957 when he was only eight years old. Whilst in the school yard with the other children, John suddenly felt an excruciating bowel pain which left him unable to do anything but cry out in pain. With no-one to fetch him from school John had to make his own way home, but he has never been able to remember anything else about this incident until the time he awoke in hospital. Double pneumonia was diagnosed, so eight year old John was immediately isolated in a glass walled hospital room, where he stayed for four months.

After this first health crisis, John suffered recurring bowel pains, muscle and joint pains and constant colds in the autumns and winters. Despite this, his childhood and teenage years were very happy. His family - mum, dad and seven children - lived in the town centre, over the town's fire station, within easy reach of John's schools and the local parks, including tennis courts and pitch and put course. He had a kind family and 'wonderful' friends, with whom he honed his skills at golf, first on the pitch and put course and later on bigger courses. Having been an extremely bright child, John was now too ill to undertake extended studies, but he taught himself to 'work round' his illnesses.

He had learned something about the brain's capacity for retaining information, and so he trained himself seriously to 'cram' for exams each year in May and June – his best time of year - whilst taking his necessary rest and coping with his inevitable winter illnesses during the rest of the year.<sup>1</sup> Luckily, summer holidays from school lasted 13 weeks, and John was allowed to rest and sleep when he needed it during most of the year. He is grateful that, though his family was not well-to-do, he was never pressurised into getting a job to earn some pocket money (though he did in fact manage to earn small amounts by betting on his golfing skills against over-confident older people!).

So John's early years passed happily enough, it now seems, despite his want for good health. He was not able to travel, but school was only a five minute

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<sup>1</sup> Ed's note – this is NOT recommended, since it could lead to relapse and/or chronicity. A home tutoring service is now available to children with long term illnesses.

walk away. He did pass all his exams, though not as well as he knew he otherwise might have done.

Then, when John was 18 years old, his father died and John had to become the breadwinner. He got a job with a local Solicitor, which luckily, again, was only a short walk away from his house. John could go home for his mid day meal and, importantly, he need never get wet. For six years he struggled on, with the months between November and April being the worst for him, until at the age of twenty-three he left Co Tipperary for London, with a longer term view to working in Australia.

This was a far cry from John's previous comparatively sheltered life, but before long he secured a job as an Employment Officer in Shepherds Bush. John now describes this job as an 'eye opener'! But despite the difficulties of his work, the other staff members were good to him and, very importantly, the office was warm. But he had ambitions to become a home owner, which was impossible in London, on his salary. So John took an extra job in a night club. The almost predictable result was, of course, a massive health relapse, with the bowel problems coming back with a vengeance. Incredibly, John was subject to seven bowel operations during one year, all at the Charing Cross teaching hospital. He now questions the necessity for these operations, and certainly they took a huge toll on his health.

Even so, in the same decade John went back to work, got married, and had his daughter Emily. John was still working with the Employment Service, and in 1979 he brought his family to South Yorkshire after being promoted to a position working in the new building commissioned by the MSC (as it then was) at the bottom of the Moor. Living in Penistone, though, the climate of the cold valley, and the journey to work, made things very difficult for John. He feels that he was 'only just clinging on' to his job and his lifestyle – a feeling which he now recognises as part of a life-long anxiety. However he performed well at work, partly driven by this very anxiety. In 1987 the family went to Australia but came back after a year at the wish of John's wife.

So John struggled on with his career, now living in Nether Edge, which was, at least, close to his place of work. But in the winter of 1994/5, glandular fever struck, and this is what, as John would say, 'finished him off'. Unfortunately, the glandular fever was not actually diagnosed until April 1995, when John had already been ill for eighteen months. M.E./CFS was diagnosed in 1996 and John was told for the first time, by his consultant, that he should not be working at all. Another struggle came with his employer, who finally gave him his pension in 1998.

This period marks the start of the chronic pain which has been John's worst problem since that time. In fact, coping with severe pain during all of his waking hours is John's chief concern and also his main occupation.

He is beset by other symptoms too, which have developed at different times. For three years he was so sensitive to light that the whole house had to be screened and curtained. Eighteen months ago he developed severe sinusitis

which has caused a vicious circle of pain, tooth grinding and dental problems. Eating is so painful that he has to take mainly liquid foods. John has seen many specialists over the years, he has been prescribed most of the pain control medications available to M.E./CFS patients in the UK, and he has attended pain clinics, but still nothing touches his pain. He has long been asking for morphine but so far no doctor has been willing to prescribe it. John's current hope is that, once the 'grinding kit' which is being made for him at the dental hospital is tried, and if this does not address his jaw and head pains, he will be allowed the morphine which may bring relief.

John has lived alone for several years and he has been his own main carer during this time. John has never found a professional carer with the sensitivity to respect his illness, but finally, after some negative experiences and after trying for eighteen months, he has now been awarded home care by Social Services, and will soon be looking for a carer / carers whom he can employ under the Direct Payments scheme.

His shopping is done by the Council's shopping service, and the housework has been largely ignored, or minimal, for the past eighteen months. John has the Friday and the Sunday papers delivered, mainly so that he 'knows what day it is', because he is unable read at length or to listen to the radio. A hairdresser visits from time to time. John gets from his bed to his couch by means of a lightweight office-type chair, which runs quite smoothly on its castors over the uncarpeted floor, and this is how he opens the door for visitors. A wheelchair by the door is virtually unused.

Though John is isolated, he is clear that he is not lonely. His four sisters and two brothers, and his daughter (none of whom lives in the area), telephone him regularly and thus can give him 'too much support' at times when his need is only for quiet and rest. He says that his full time job is, simply, coping with pain. "I am the only one who can help me", he says. John undertook an ambitious trip to Australia in 1998, at a time when he thought his condition was improving, but unfortunately the trip was a disaster. The long haul made him seriously ill, he had to be hospitalised, and then spent most of his visit immobile.

The reason for John's trip to Australia was to visit his daughter Emily. Asked what keeps him going, John gestures towards photographs of Emily and his six month old grandchild. The 'human spirit' keeps him going, he says. "You can spend fifty years in the gulag and still come out of it". He is sure that by some means he will emerge from the condition he is now in. Moreover, he has a great trust in progress and technology. He is sure that a cure ultimately will be found.

*John is not this member's real name but the story is true, as related to Kath our Information Officer.*