

THE MOTHER OF EAN PROCTER SPEAKS

From the Alison Hunter Memorial Foundation

<http://www.ahmf.org/ww-ean.html>

Ean's Story

Barbara Proctor, Ean's mother

In September 1986, when Ean was 11, Ean's school phoned me to say that he was ill. He was feverish, with a headache, a sore tummy, swollen glands, and was feeling sick. Ean took a week off school, and then - despite still feeling ill, he returned to school because he didn't want to miss any more lessons. Ean didn't improve - he had bad headaches, sore throats, and felt sick all the time. He would sweat very heavily, so we had to keep changing his pyjamas and even his bed linen. His appetite was poor, because of his constant nausea. He had extensive medical tests over the next couple of months, all of which proved inconclusive.

In November 1986 we saw a paediatrician - Dr B at the local hospital for the first time, and found his manner very rude. When I tried to make a point, Dr B glared at me and said "I didn't ask you that, in future only answer what I ask you...". Over Christmas 1986 Ean began to lose his balance and started to drag his right leg. His legs seemed to be getting very weak. 1987 dawned and Dr B suggested that we take Ean to Alder Hey hospital in Liverpool for a second opinion. At Alder Hey, we were told that Ean had Post-Viral Fatigue Syndrome, and should make a good recovery.

Back in the Isle of Man, Ean was prescribed a drug called 'Optimax' by Dr B ("to ease the constant sick feeling"), and a drug called 'Motillum' by our GP, who said that 'Optimax' was for depression 'Motillum' for the sick feeling. Three days after being on both drugs, Ean had the most awful pains in his tummy. When the pain hit him, he would go bright pink, and very hot. We have since discovered that 'Optimax' is not recommended for children, and that 'Motillum' is only to be given to children after chemotherapy cancer treatment.

In July 1987 we flew to Liverpool again. After the physiotherapists had taken Ean for assessment, we returned to him to find him very distressed and crying. The Sister had shaken him and told him there was "nothing wrong with him" and he would be walking in two weeks. Ean said to Rob and myself, "do I have to die to prove how ill I feel?" A Dr R at Alder Hey spoke to Rob and I on our own, and said he felt Ean had a psychiatric problem. We refused to allow Ean to be placed in a psychiatric ward, and took him home.

Back in the Isle of Man, Dr B, and Dr C, a psychiatrist, seemed very supportive, and asked if they could have Ean in the hospital for a few days for tests. We agreed. The 'few days' turned out to be a living hell for Ean. The only test carried out was a lumbar puncture. To do this, the nurses held Ean down, and the Sister told Ean not to move, as if anything went wrong, "it wouldn't be the nurses' fault". They gave Ean physiotherapy which made him feel really ill, and the pain in his back from the lumbar puncture brought tears to his eyes. The physiotherapists would shout at Ean and tell him "not to be a baby". The first time we visited, we were told by the Sister "Not to ask Ean how he was, and if he felt sick, or had a headache or anything - ignore it and change the subject". After about a week I was told I was not allowed to feed Ean his meals. Ean couldn't hold a spoon or fork, and could hardly lift his arms up, let alone feed himself. He was taken to another ward at mealtimes and forced to feed himself. This would take him ages, and his food would go stone cold. His plate would be piled high with food, and he would be told to hurry up, because if he didn't eat it, he "wouldn't see his parents when they next came".

Soon afterwards, we were given an article from a magazine about M.E.. There, in black and white, were all the symptoms our son had - mental confusion, headaches, sore throats, sickness, vivid dreams, sensitivity to light and sound etc.

On August 12th 1987 we took Ean to see Dr M at the National Hospital in London, who said that Ean was a severe case of M.E. or Post-Viral Fatigue Syndrome. He said it could be years before Ean was completely better, and that school was out for the foreseeable future.

Towards the end of September 1987, Ean needed to have laxatives every fourth day. He also became very sensitive to smoke, exhaust fumes, grass-cuttings, perfumes, washing powders etc. His voice became so weak, that we couldn't hear what he said. His fingers were now in a permanent fist, and it was too painful to ease them out. He was wearing dark glasses because of his sensitivity to light.

On the 21st March 1988 we took Ean to the National Hospital again, where he had a whole battery of tests, all inconclusive. All the doctors at the National said that Ean had a "physical and organic illness". Then one day, Rob and I were asked to speak to a psychiatrist "who was doing research into M.E.". This psychiatrist, Dr W, told us that "children did not get M.E." and that he had asked a top child psychiatrist from Great Ormond St Hospital (next door) to see Ean. This was Dr L, who said (without examining Ean), that he saw many children like Ean, and that he could have Ean back to his old self in 3 to 6 months, with a combination of medical and psychiatric treatment.

Ean was admitted to Great Ormond St, and everything seemed fine until we discovered that Ean was in fact going to be admitted to a psychiatric ward, and that it would be necessary for myself, my husband Robin, and Ean's brother Gary to come down to Great Ormond Street from the Isle of Man for weekly family diagnostic sessions. We

said that would be impossible, but were told that without these family sessions, Ean would "never get better", and that as a family, we would not "be able to cope with Ean getting better". It was suggested that I "wouldn't know what to do with myself" as Ean improved and became more independent (as if I was keeping him ill).

Ean and I had our first "diagnostic session", even though Robin and Gary could not be there. We were taken into a room with two microphones hanging from the ceiling, video cameras in two corners, and a one-way mirror the whole length of one wall, and interviewed.

We were eventually allowed to see the children's psychiatric ward that Ean was to be moved to. The door of the ward had a combination lock on it. One girl in the ward was literally ripping her room apart. She had both beds overturned, and things strewn all over the room. She was cowering in a corner screaming and swearing at the nurse. This scared the life out of us, and Rob and I knew immediately that this was no place for a child so ill with M.E., and were certain that they could not have treated children with M.E. in a ward like this.

We wrote a letter to Dr L saying that we would only consider Ean being admitted, if it could be agreed in writing that Ean would not be given drugs without our consent; that he would be allowed unlimited visiting by us; and that his diet would be suitable for an M.E. sufferer. Dr L could not agree to our demands, so we took Ean back to the Isle of Man.

On Monday 23rd May, two social workers arrived on our doorstep and took Ean away under a "Place of Safety Order". We were not even allowed to go with Ean in the ambulance. Ean was to be in the joint care of Dr C, a psychiatrist, and Dr B, a paediatrician, at the local hospital.

During the whole time Ean was in care, we were allowed to see him for only half an hour a day. He was alone in a ward, could not move, could not speak, and had no way of getting help if he needed it. He had been told that he had been taken away from us because he was dying. Ean had to endure the most horrific mental torture. One day the psychiatrist told him "There is nothing wrong with you.... if you don't talk next week, you will be better off in Ballamona [the mental home]". Ean was so scared, he wet himself as he sat in his wheelchair. The Staff nurse would say to him that if he didn't speak or walk "He would grow old in his wheelchair, stay in the hospital for ever, and never go home again". One night, Rob and I found him very distressed in his wheelchair, all alone. He had wet himself, as no-one had asked him if he wanted to go to the toilet, at lunchtime... It was now 7.40 pm. Friday was the day Ean lived in dread of. This was the day the physiotherapists would take him off to the remedial pool. On one occasion they just dropped Ean into the pool, hoping that he would use his arms to save himself. Ean couldn't, and just sank underwater. The swimming sessions went on. After just one week in the hospital, Ean's condition deteriorated; he looked exhausted each evening after physiotherapy; his mouth was full

of ulcers again; his permanent headaches returned; his feeling of constant nausea was worse than ever; and his eyes hurt because his dark glasses had been confiscated. Dr C said that Ean had never had M.E. - just "school phobia" and an "over-protective mother".

Ean was in care in the local hospital for nearly six months. Finally, after further confirmation of the diagnosis of M.E. - from Consultant paediatrician Dr David Lewis, and Professor EJ Field, and a lengthy battle in the courts, Ean was allowed to go home. Although still a Ward of Court, he is now under the care of a Homeopath, and Dr David Lewis, and is slowly improving. The Proctors have recently received a letter from the Queen (reproduced below) sympathising with their plight.

BUCKINGHAM PALACE
12th May, 1989

Dear Mrs Proctor,

I am commanded by The Queen to thank you for your letter of 1st May and to say that Her Majesty can, of course, sympathise with your distress at the problems you and your family have encountered following the diagnosis of your son's illness as myalgic encephalomyelitis.

The Queen has read the enclosures which accompanied your letter and, although it would not be appropriate for Her Majesty to comment publicly on the views you express, I have been directed to forward your letter to the Secretary of State for Health so that he may know of your approach to her.

The Queen was so sorry to hear of Ean's illness, but hopes that he will, in due course, make a complete recovery from this debilitating disease. Her Majesty sends her best wishes to Ean and to you and all your family.

Yours sincerely,

Robert Fellowes

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