

TO WHOM IT MAY CONCERN

In November 1991, at the age of 14, my daughter Lynn became ill after a BCG vaccination. Previously lively and extremely healthy, she contracted one infection after another and needed several courses of antibiotics. Lynn did not improve despite every effort by our GP to turn things around.

A referral to a paediatric consultant resulted in a diagnosis of Myalgic Encephalomyelitis in February 1992. Lynn was put on a course of graded exercise. Her condition steadily worsened as she strived to stick to the programme. She tried to explain that the more she pushed the worse she felt, but no one listened. By May that year she was totally bedridden and tube-fed with many severe and debilitating symptoms.

Desperately seeking help, we were referred to a psychiatric consultant who told us he believed in M.E. as a physical illness and had cured a number of patients in the past. He felt sure his *team* could help Lynn if she was admitted as an in-patient. We agreed.

Lynn stayed two and a half weeks on that psychiatric ward with devastating consequences. She deteriorated rapidly as pressure was put on her to do things she was unable to do. We watched as our daughter, under the care of those who said they could cure her, lost the ability to do almost anything. We wanted to believe what they said so much that we held on, even when we saw her deterioration, but sixteen days after her admission, we knew we had to take her home.

With the help and support of our GP we took our daughter home - she was in a pitiful state. She could do nothing for herself and needed 24 hour total care. She slept almost constantly as her exhausted body struggled to cope with the most fundamental of tasks.

We found an M.E. specialist who did domiciliary visits. He supported and advised us and prescribed medication to ease some of Lynn's awful symptoms, such as muscle spasms, nausea and pain. After many months Lynn began to show signs of improvement and we knew that we had done the right thing in taking her home and looked forward to better times ahead.

Lynn never recovered - too much damage had been done in the early months of her illness when she was forced to do what she knew her body was not able to do. I wish with all my heart that I knew at the start of Lynn's illness that graded exercise at this acute stage causes further damage. She could have been spared seventeen long years of unimaginable suffering if we had done the right thing at the beginning and listened to what she told us.

Lynn is not alone. Many M.E. patients have been made worse by the false belief that graded exercise is the answer. It is not. People need to be supported and cared for and given time to rest their sick bodies. The time for rehabilitation and exercise is when they reach the recovery stage and are no longer ravaged by an illness that steals every vestige of energy.

The last thing anyone - especially a child - needs, is to be removed from the safety of their home, into a strange and frightening environment. The havoc the illness causes is terrifying enough without being taken away from your loved ones and all that is familiar. Such actions only serve to make a bad situation far worse.

My purpose in writing this is to ask that Lynn's case is taken into account when considering the best way to treat severely affected M.E. patients. I don't want anyone else to suffer the way Lynn did through inappropriate treatment. I appeal to those who are in the profession of caring, to listen to the patient, support and guide them, but don't force upon them what they and their families are telling you is wrong.

Sincerely,

Kay Gilderdale

