Chapter 20

Children and M.E.

Children and teenagers can and do develop M.E. Children around the age of puberty seem most vulnerable (it is rarely found in children under the age of 5). Males and females are equally affected. The most serious effect is the cognitive dysfunction, which causes loss of education at a critical age. Even if the child is well enough to attend school, his or her performance in class and at exams falls behind.

The most common, and serious, misdiagnosis is 'school phobia'. A physician who has made a particular study of childhood M.E. is Dr David S. Bell, a paediatrician at Lyndonville, NY, USA, where there was an M.E. outbreak in 1985: '104 patients were identified who retrospectively met criteria (for CFS). 44 patients were in the 6-7 year age group. All were followed up for at least two years, when only four children had made a complete recovery'.

Children can also suffer from having a parent or sibling with M.E. They may feel left out, neglected, or unloved if more attention is given to a sick brother or sister, or if an ill parent has not the energy for good parenting. A child may suffer anguish at seeing a parent devastated by M.E., and may demonstrate this by bad behaviour, depression or sleep disturbance. It is important to remember the silent suffering of a young child where another member of the family has severe M.E., or any other chronic illness.

The onset of M.E. in a young person does not differ from that in an adult, although it is usually more acute, and follows an infection which is frequently present among school classmates. Dr Bell has observed two patterns of onset: those aged 5-12 tend to have a gradual onset, and adolescents are usually acute in onset following a flu-like illness. This makes diagnosis much more difficult in the younger age group. M.E. in children may be misdiagnosed as: migraine, abdominal pain syndrome, atypical epilepsy ('petit mal' -type seizures are more common in childhood M.E. than in adults), juvenile rheumatoid arthritis, and school phobia.

The clinical features and chief symptoms are no different from those experienced by an adult, although some of the nervous system symptoms may not be so obvious because a child is less likely to complain specifically of poor memory, poor concentration, or depression. These symptoms manifest instead as poor school performance.

Children tend to become ill rapidly if they develop an infection, and they will tend to have a higher temperature than would adults, and more severe symptoms. They react more rapidly than adults, but also recover more quickly from most acute infections. So it is noticeable when a youngster who has been laid low with a feverish illness fails to make the expected recovery in a week or two.

Problems of Children with M.E. *Diagnosis*

The agreed criteria for diagnosing M.E./CFS include a length of illness of six months or more. Clearly, parents want to know what is wrong before their child has been ill for six months. Bearing in mind that physical activity makes the condition worse, and that rest early on may allow early recovery, it is obviously very important to get an assessment and provisional diagnosis when the child is not recovering as expected from an infection - this may be a diagnosis of a 'Post-viral Fatigue Syndrome' (PVFS), made on the basis of the child's history and the absence of signs or positive test results for any other disease.

Once this diagnosis has been reached, maybe as early as six or eight weeks after the onset of illness, the child can be allowed to rest as needed, the school is informed, and pressure to go to school or do sports is removed. The diagnosis may become M.E. if the illness continues for many months, with classical symptoms of muscle fatigue and brain disturbance.

Some GPs and school doctors are still reluctant to diagnose PVFS, or M.E. or CFS in a child. They may either still consider that M.E. is psychological, or believe that it is a condition mainly experienced by the over-twenties.

Although M.E. itself is less common under age 20, many children suffer prolonged fatigue after an infection; some of these do continue to be unwell, or even deteriorate, and have the classic M.E. syndrome for a year or more. It is tragic for a child and his or her parents to have to battle with doctors and education authorities for months, while the child may try to attend school and live a normal life but keeps on relapsing and possibly deteriorates.

If your doctor is ignorant about M.E. and other post-viral syndromes, or is simply unhelpful, you can do several things:

a) Contact one of the national M.E. support groups, and obtain information for the doctor about the illness.
b) Change to another doctor.
c) Find out if there is a specialist in your area who understands M.E., and ask for a referral, or arrange for a private consultation.

Because there are often strange psychological symptoms, and the fatigue leads to inability or reluctance to go to school or to do homework, some doctors and education authorities find it easier to diagnose 'school phobia' rather than suspect post-viral fatigue syndrome. They may also try to diagnose some family-behaviour problem to explain the child's change in behaviour.

Factors which help in the diagnosis of PVFS/M.E. are:

- a child who was enjoying school and sports has changed since becoming ill - the psychological problems are new and out of character
- the association of what was obviously an acute infection - in the child, or in the family - with the onset of the illness. The infection may have given few symptoms in the child, but others in the family may have had it more severely
- worsening of the child's symptoms after exercise or after mental exertions - e.g. after sports or an exam

- fluctuating symptoms from week to week or day by day
- aches and pains quite unlike anything the child has had before
- symptoms not improved by going on holiday, or at weekends; in other words, normal family life and exercise out of school are just as bad as school activities. A child with school phobia would be expected to make a dramatic improvement during holidays.

Before the consultation with a GP or specialist, write down the history of the onset of the illness, and any of the above factors if they apply to your child.

Do not be fobbed off by a doctor if you think your child has PVFS/M.E. Insist that adequate tests are done to exclude other physical illnesses, and if there is no diagnosis, ask what is making your child ill.

If the doctor does not know about M.E., and finds no physical signs of illness, and blood tests are normal, the next stage may well be a referral to a child psychologist or psychiatrist. This assessment will be quite exhausting for the child. However, many parents do agree to such an assessment; a properly-trained and skilled psychologist should be able to diagnose that the child has an illness rather than a purely psychological upset. The results of such an assessment may actually strengthen your case.

Management of Children with PVFS and M.E.

Complete physical and mental rest must be encouraged at first. For the first few weeks or months, general nursing care, as would be done for any ill child, is appropriate. The appetite may be poor, there may be nausea, constipation, diarrhoea, tummy pains, or severe headache. Do not use aspirin for pain; rather a small dose of paracetamol, or homoeopathic remedies if your doctor uses them. Constipation seems to make symptoms worse, possibly due to toxins absorbed from the bowel, so encourage plenty of fluids, and as much vegetable and fruit intake as possible - a liquidiser for making vegetable soups is invaluable.

Try and avoid sugar, 'junk food: Coke, and other non-nutritious things favoured by children. The diet guidelines of Chapter 11 apply to children, and adequate protein intake is especially important for weight to be maintained and growth to continue.

Problems arise when the child appears to make some recovery, and wants to do activities with friends, or to go to school and behave normally. You cannot force the child to stay in bed or in the house all the time; yet you cannot stand back and watch uncontrolled behaviour which will inevitably lead to a relapse.

The child's friends may be unsympathetic or even cruel when they see their pal going to school for half a morning, looking quite normal, then having to go home to rest for the remainder of the day. Keeping up with the peer group is very important for children and teenagers, and the loss of friends and activities shared with them can be as damaging psychologically as the pain and other symptoms.

When the child is getting better enough to want to go and do things, then a diary is a good idea, so that he or she can learn for him- or herself what the limits of the illness are at the time.

A frank discussion about the illness, what has caused it, how it affects the body and mind, and the likelihood of getting better, is a good idea at this stage. This will also dispel fears about other diseases such as cancer or heart disease or leukaemia, which may be preying on a young mind. With many TV programmes about illness, youngsters may know a lot about serious disease at an early age.

A plan of rest and activity for the child can be discussed among the whole family, so that he or she is involved to some extent with managing the illness. Brothers and sisters, and friends, should be encouraged to include the child in any discussion of what is going on in school and in their activities.

School, Education

Hopefully, once you have a diagnosis the school authorities will be understanding and co-operative about any restricted ability to attend school. There is a need for flexibility, and in some cases a compromise is needed so that part-time attendance is possible.

Avoiding sports such as gymnastics, team games and athletics is mandatory until it is clear that improvement is virtually permanent. As with adults, children and students who have M.E. will find that the less physical activity undertaken the more energy will be available for the brain. Some mental functioning may be possible so long as there is little physical exercise.

In theory, a home tutor should be a useful solution for children who are well enough to do some learning but cannot cope with the stress and noise of a full classroom. In practice, home tutors are rather scarce, and may not be easy to arrange. Sometimes a parent may be able to supervise some work at home provided by the school, done at a pace the child can manage.

In some areas, there may be enough M.E.-affected families to get together so that affected children and adolescents can meet or receive home tuition together.

It is enormously helpful for an affected youngster to have friends who have the same problems, even if the communication is by post. As with adults with M.E., the knowledge that there are others like you relieves the isolation.

At the moment, no one has come up with any magic cure for young people with M.E. The basic principles of management are no different to those that are advised for adults. Nutritional supplements are beneficial, at a dosage about half those suggested for adults. Multivitamin and mineral preparations for children are available, in chewable or liquid form, at most chemists and health food shops.

The disruption to schooling and social development which results from getting this illness as a child or adolescent is serious. At an age when things move on quickly, to have to drop out of life for a year or more can have long-lasting consequences. The pressures on youngsters to succeed - at sports, with class-work, in national exams and at university are great, reflecting the intense competition for jobs that awaits school-leavers and university graduates.

Perhaps it is not only the viruses that are causing M.E. in children. Perhaps, in those worst affected, the tragedy resulting from the disease is yet another by-product of a society that places so much emphasis on achievement and material success; a society in which the opportunities to attain these things are restricted by high unemployment, and the demand for paper qualifications for virtually every job.

The following is a tragic case history, which will hopefully have a happy ending. Few children are as badly affected as this one, but young children can develop M.E. and remain ill for some years.

John's Story (told by his mother)

'May, 1986 – John fell ill after returning from a school trip; he was then 11 years old. His father and I both developed the same bug - swollen glands and nausea. Then in August we were on holiday by the sea. John was very sick and had diarrhoea for 24 hours, and was in bed for several days, as he began to feel achy and so tired. A trip to the zoo was a disaster, as the walk up the drive from the car park was just too much, he was exhausted and in tears with tiredness. He *never ever* got back to his real self; however he did start his new school and seemed to settle in well.

'Sept. 1986 - He was ill at school, burning up, headache, sore tummy, and his glands were still swollen. Teachers and other pupils were all ill with the same thing. John did not improve, he had bad headaches, sore throats, felt sick all the time, and sweated very heavily. He had very acidy-smelling breath, especially in the mornings, and poor appetite because of the nausea. Tests for glandular fever were negative. Later blood samples showed there had been a huge virus infection.

'Nov. 1986 - We saw a paediatrician for the first time at the hospital. John had been ill now for six months. He had a brain scan, which was normal, and more blood tests. 'Christmas, 1986 - He began to lose his balance and started to drag his right leg. His legs seemed to be getting very weak, he still had nausea, and could not sleep.

'Feb., 1987 - John was no better, and his legs were weaker.

As we live in a remote area, we had to fly down to the hospital, where he'd been referred for a second opinion. We had a wheelchair and lift on and off the plane. He was examined and had blood tests, X-rays, brain scan, EEG, etc. These were all clear, and when we saw the specialist, he said John had Post-viral Fatigue Syndrome, and although this could be worse than the actual virus, he felt sure he would make a good recovery.

'Back home John was prescribed Optimax, (which we found out was for depression, and was not recommended for children), also Motillium for nausea, but he had so many side effects from these two drugs that we stopped them.

'April - John had all the same symptoms, but was getting worse. The paediatrician suggested we see a psychiatrist, to help keep his spirits up. John has never been depressed.

'Our G.P. suggested some very gentle leg exercises to try and keep the muscles going for when he started to feel better. We only went to physiotherapy once, as he found it so exhausting. We carried on with some of the exercises at home, but it made him feel more sick, tired and sore, and the bad breath came back.

'May - We took John to see a psychiatrist. He said that the virus which had affected John could be Coxsackie B, as this can cause disability like polio, but that you do get better from it. He also said that only complete and utter rest could cure it, and that this could take up to two years.

'July - We went to the main hospital again for tests to be repeated. No tests were carried out, only an examination, and one of the staff told him there was "nothing wrong" with him and he would be walking

in two weeks. The neurologist we saw there felt it was a psychiatric problem, and that he would be better in a psychiatric ward, removed from the environment in which he had become ill. However we did not accept the psychiatric treatment offered, and took him home.

'Back at home John was admitted to our local hospital to have the tests we had expected in the main hospital. The admission turned into a three-week Hell. The only test carried out was a lumbar puncture, the result of which was normal.

'They started giving him physiotherapy, which made him feel really ill, the pain brought tears to his eyes, but he was told "not to be a baby". John couldn't grip a spoon or fork any more, and could hardly lift his arms. He was encouraged to feed himself - this would take him ages, and his food would go cold. His voice was now getting weaker and it was often too tiring for him to repeat something. He would tell us he couldn't put up with much more. It seemed other people could not believe how ill he really felt.

'Soon after this, we were given an article from a magazine called "What is this scourge called M.E.?" There in black and white were all the symptoms our son had - mental confusion, headaches, sore throats, sickness, vivid dreams, heightened sensitivity to light and sound. Here at last was the answer; we now felt we had found out what was wrong.

'Aug. 1987 - We went to see a neurology specialist at a famous hospital for Nervous Diseases, where after an hour's consultation and an examination he said John was a severe case of M.E. or Post-viral Fatigue Syndrome. We were pleased to have a diagnosis. He said it could be years before John was really better, that school was out for the foreseeable future, and that physiotherapy was wrong until he started to show an improvement; he said he would write this in his letters to the doctors at home.

'End of Sept. - John needed to have laxatives every fourth night. He also started to cough when he came into contact with smoke, or car fumes, especially diesel from buses and lorries if they passed us on our walks in his wheelchair. Grass-cuttings, perfumes and washing powders would all make him sneeze, and set his body shaking as though his balance had gone. His voice became so weak that it was just too exhausting for him to repeat anything. His fingers were now curled into a fist, and it was too painful to ease them out. We felt that the psychiatrist was trying to get a response to his questions that would show that it was something in John's mind that was making him ill. We have always believed, and still do, that our son is physically ill, it is not in his mind, and we will go on and on fighting for him.

'October - John had huge ulcers on his lips. He got confused if too many questions were asked at once, TV and flashing lights hurt his eyes, he had to wear dark glasses. One day the psychiatrist called, and seemed to be saying he didn't believe John still had M.E.

'We decided to take John privately to see the neurologist again in the Nervous Diseases Hospital, as since August John's voice had gone altogether, and he could no longer open his fingers.

Blood tests, brain scans, X-rays, EEG were carried out, and all were fine. They fitted splints to his fingers to open them. All the doctors there said he had a physical illness, and always said he had M.E.'

The above story illustrates a typical onset and symptoms of a child of 11 who developed severe M.E. It is not the whole story, because the parents were eventually advised that their son needed admission to a psychiatric unit. The family felt this was not right for him, and declined this treatment. This led to the boy being taken into care, on the grounds that he was a seriously ill child and the parents had refused treatment. John's life was never in danger, and no-one had investigated whether his home was uncaring. However, after some months in hospital, where efforts to get him to walk and talk failed (he was thought to have hysterical paralysis), he was allowed home.

Once at home, John had gentle physiotherapy, good diet, evening primrose oil and magnesium supplements. He did eventually recover completely, 5 years after becoming ill. His story highlights the difficulties faced by families with a child who develops severe M.E. Whilst

psychological support, possibly low-dose antidepressants, and very gentle physiotherapy are certainly helpful in many cases, hospital admission is not usually appropriate. People with M.E. are acutely noise-sensitive, and deteriorate in the face of any stress, so a quiet home environment with familiar faces is usually the best place for recovery.

Fortunately, although children may have the illness more severely than adults, their chances of complete recovery are very good.