ME and the Professionals: parent and child voices

ME (myalgic encephalopathy, also often known as chronic fatigue syndrome)[i] is a complex and poorly understood illness. The most severely affected experience chronic weakness and pain. They are often unable to walk, speak or feed themselves and can experience severe cognitive impairment. Yet the more mildly affected may be able, with careful management and support, to lead relatively normal lives. There is growing evidence that ME is likely to be part of, and perhaps itself encompass, a range of conditions with differing underlying causes. There are no accepted diagnostic tests for the condition. For children, diagnosis is made where symptoms (including weakness/chronic fatigue) have persisted for at least 3 months and other possibly diagnoses have been ruled out.[ii] It is likely that children of any age may develop ME although the condition is most often reported in children age 11 or older. Accurate data has not been collected for Scotland but ME is thought to affect as many as 25,000 children and young people across the UK. Numbers appear to be rising. ME is cited as the biggest cause of long-term illness absence from school.[iii]

Preconceptions about ME are widespread. These have been fuelled by controversy within the medical profession about the causes of ME and appropriate treatments. The crux of the controversy centres on the divide between those who treat ME as a primarily psychological/psychosomatic condition and those who perceive ME to be a biomedical condition. Patient groups are concerned that the ME label has been used by some professionals to lump together patients who experience chronic fatigue that is clearly associated with depression/psychosomatic illness, with the large number of ME patients for whom there is absolutely no positive evidence of depression or psychosomatic illness as a causal factor. In the absence of any other established medical cause for the symptoms of ME, the assumption that these symptoms must have a psychological root has become a default position for some professionals, applied to all ME patients, regardless of their circumstances and medical history. Within the patient community, there is mounting frustration and suspicion about the drivers for the continued assertion of the psychological model in the absence of sound research evidence supporting its practice and outcomes.

Certainly, the balance is shifting towards biomedical models of ME, driven by emerging international research, the experiences of patients and empirical evidence. The World Health Organisation categorises ME as a neurological condition. In line with the Chief Medical Officers (CMO) Working Group Report in 2002, in Scotland, the Health Care Needs Assessment of Services for People with ME-CFS[iv] unambiguously calls for strengthened research and reporting on the biomedical side. The document highlights the "*need to end the culture of disbelief in ME-CFS that pervades primary care*". A sentiment echoed in the Scottish Good Practice Statement for GPs that is currently in the pipeline, as well as in the recently published *Believe in ME* report based on patients' experiences of services in Lothian.

Children and young people with the condition, as well as their parents, have been caught in the cross-fire. To an extent, so also have health and non-health professionals such as teachers, who do not subscribe to a specific view of ME. Patients often find themselves being passed between health professionals who contradict each other; they can feel like hot potatoes whose care nobody is qualified (or wishes) to take long-term responsibility for.

Where the psychological model dominates a patient's care, the onus is upon that patient to make themselves better, through rigid graded exercise and/or cognitive behavioural therapies. This approach is underpinned by an assumption that patients cannot damage themselves through exercise as they are not physically ill. It is assumed that they must be psychologically resistant to treatment and recovery.[v] Limited successes have been claimed for these approaches by practitioners. In contrast, patient surveys report little or no benefit for the majority and actual harm for a substantial minority. Patient experiences are supported by the CMO Report and by a number of practitioners:
"*If ME/CFS was a basically psychological disease then in the case of a severely affected bed-bound young person there would have to be such concrete evidence of severe psycho-pathology to cause such disability that it would be blindingly obvious. However, such evidence is almost invariably lacking*".[vi]

Blanket application of graded exercise and cognitive behavioural therapies has caused substantial distress to many ME patients and their families and is fuelling wide-spread distrust of health professionals. Patients and parents desperately want to see greater support for biomedical research into the causes, treatment and management of ME in children.

Leanne and Lorraine's story

Leanne was in her 1st year of secondary school when she developed a viral infection which she never recovered from. Both Leanne's mother, Lorraine, and two other family members also suffer from ME.

Impact of ME on school, friendships and family life
Before the onset of ME, Leanne was a "*normal, happy child*" who "*loved*" school, with many friends and a passion for Irish dancing. Leanne had been dancing since the age of 5 and attended 3 dancing classes a week. In the months before she became ill, Leanne danced in shows in Ireland, London and Oban. On leaving Primary 7, Leanne received a school award.

Leanne has been too ill to attend school for almost 3 years. Lorraine is very aware of Leanne's entitlements under the ASL (Scotland) Act however, gaining access to the required support in practice, has been difficult: "*our experience has been that the provision of home tuition is dependant on the willingness of teachers… to carry out tuition – if no teacher is willing…then no tuition is provided in that subject*".

Leanne has lost contact with her dancing and school friends: "*it is very difficult to maintain friendships when you are unable to go out or are too ill and exhausted to even have friends round to visit"*. Family life continues as normally as possible: "*we take and deal with every day as it comes and don't look too far into the future. We remain positive that Leanne will be well again*".

Experiences of health services
Leanne's experiences of treatment by health professionals have been at times traumatic, with huge variations in the approach adopted. Leanne's GP has, they are keen to stress, been "*very supportive*", as was the first consultant that Leanne was referred to, who: "*listened to Leanne's feelings regarding management and she accepted that Leanne… had the right to decide on management options.*" However, Leanne's next consultant insisted on the need for Leanne to attend more physiotherapy, as well as for psychological and psychiatric treatment. Leanne and Lorraine found this approach distressing: "*in spite of every guideline stating that you have to have respect for patient autonomy and also stating that a parent/patient choosing their own management option is <u>not</u> evidence of abuse and is <u>not</u> grounds for constituting child protection, a letter was sent to Leanne's GP suggesting that if we remained resistant to his approach then we should be spoken to by child protection!*" Leanne did attend physiotherapy, where she was given exercises which included sit-ups and press-ups. Leanne and Lorraine feel strongly that this treatment was damaging, causing Leanne to relapse and worsening her long-term symptoms.

In the end, this impasse was resolved by taking Leanne to Durham for a second opinion. There, Leanne was seen by a paediatrician with extensive experience of ME. This doctor confirmed that Leanne had severe ME with seriously disabling physical symptoms. Crucially, he supported Leanne and Lorraine's preference for managing the condition using pacing techniques.

The impact of these experiences on the family has been substantial: "*instead of concentrating on caring for Leanne we have had to deal with the threat of child protection and the ongoing stress of accessing education provision. My own ME has relapsed*". Leanne was left feeling that she "*wasn't believed*".

Sandra, Jamie and Christine's story

(Names have been changed to protect privacy)

Sandra is a mother whose two children (now in their early 20s) have both suffered from ME. Her son, Jamie, was the first to become ill and has made a full recovery. Her daughter, Christine, later developed ME and remains very ill.

Impact of ME on school, friendships and family life

Jamie became ill when he was 12. It took around 6 months before ME was diagnosed. Jamie began to recover at the age of 17 and was fully recovered at 19.

For a brief period, Jamie received lessons from the Hospital and Outreach Teaching Service (HOTS). However, these were difficult to obtain and inflexible due to staff shortages and funding constraints. His parents felt under pressure to make him attend school even though he was clearly very ill: "*there was a threat of being referred to the Reporter, to the Children's Panel for non-attendance – this was by a doctor who had never once met any of us*". At the same time, the family felt abandoned by Jamie's school. They had little contact with his Guidance teacher (their main point of contact) and for the two years before he officially left school at age 18, there was no attempt at all by the school to contact the family: "*once he was 16 nobody was interested*".

Jamie became very isolated. Contact with his friends gradually tailed off. Sandra gave up work to care for Jamie. Family outings were restricted as Jamie could neither participate nor be left on his own for long. Christine had to keep quiet around the house to avoid disturbing him.

Happily, despite missing 5 years of schooling through illness Jamie eventually became well enough to attend college and attain his Highers. Since then, he has gained an Honours degree and now has a fulfilling job.

Christine became ill when she was 16, shortly before sitting her Highers. Despite being very unwell, she sat 4 out of 5 of her exams. She missed all of her 6th year at school through illness and had no contact apart from a call asking if she could be taken off the register: "*there seemed to be no understanding that for morale's sake alone she should stay on roll until the end of 6th year*". Before she developed ME, Christine had hoped to go to university. She has been unable to study at all for the last 3 years.

Some of Christine's friends have drifted away, but others "*have been fantastic, popping round for short visits when she's able*". Mobile phones have helped Christine to stay in touch.

Experiences of health services

Jamie's GP was "*moderately interested but didn't know a lot about ME*". The paediatricians made it clear that they thought this was a psychosomatic condition or that he was a 'school refuser'. Antidepressants were prescribed though there was no evidence of depression. When Sandra challenged a paediatric psychiatrist about his advice, he raised the suspicion that she may have Munchhausen's Syndrome by Proxy. At the age of 14, an adult consultant Jamie was referred to "*pushed*" him into Graded Exercise Therapy: "*when this made him worse it was either mother holding him back or he wasn't trying hard enough*". These episodes were extremely traumatic for Jamie and Sandra.

The community paediatrician pushed for Jamie to attend school for a long time before visiting him and realising that he was too ill. Mother and son summed up their experiences thus: "*multi-disciplinary meetings held without our knowledge… General lack of knowledge about the condition and an obsession with schooling, whatever the consequences*".

Christine's experiences with health services have been better. She has mostly seen her GP: "*Very caring, admits that she doesn't know much about ME, but willing to try anything she can to help*". Recently, Christine has received an additional diagnosis related to heart rate abnormalities, following a hard-won out-of-area referral to a consultant in Newcastle. This has opened up new options for treatment and the family are cautiously optimistic for the future.

How can we better support children and young people with ME?

Professional viewpoint

Dr Nigel Speight[vii] is a strong advocate for better understanding of ME and support for children and young people with the condition. As a paediatrician with over 20 years expertise in diagnosing and treating children with severe ME he has been involved in some harrowing cases.

Dr Speight argues that the management and support of children and young people with ME should be the same as for any other chronic and disabling condition for which there is currently no curative treatment. He emphasises that ME patients need their doctors to provide: **sympathy**, **support** and **protection**, as well as advice and symptomatic treatment.

Doctors can support their patients in many ways. Examples include: providing sicknotes and letters to exam boards; and helping them to access home tuition or taxis to school. Patients also sometimes require protection: from pressure in the education system; from 'child abuse by professionals'; and from disbelief.

Crucially, ME patients require regular, ongoing medical support. Dr Speight recognises the hurdles GPs currently face but stresses the positive role they can play. He is also clear that children with ME need, and ought to have local access to, a qualified paediatrician who can make decisions such as signing a child off school.[viii]

Patient and parent views

Educating the professionals – patients and parents feel strongly that everyone would benefit from the education of health and other professionals about ME:

"*All personnel must open their minds and learn about ME*".

"*There should be no more concern about possible child abuse with ME than there is with any other illness. Disagreements with clinician… are not signs of neglect or abuse*".

The Lothian-based 'Sick Kids' group provides an example of a local initiative to increase professionals' understanding of patient and parent needs and experiences. The group grew out of complaints made by parents of children with ME in 2003-4. Medical and non-medical professionals were regularly invited to attend group meetings. The parents' aim was to open the professionals' eyes to the realities of ME. Parents participated in training for community paediatric/nursing staff and were instrumental in securing funding for Scotland's first (and only) outreach worker for children of school age with ME. The group also produced information booklets for distribution to all Edinburgh schools and through the hospital.

Educational support – patients need and want ongoing contact and support from their school to give them the best possible chance of continuing their

education as and when they are able. However, they should not be put under pressure to do more than their condition allows as this is likely to result in further health deterioration.

"*Obsession with education for under-16s at all costs must stop – health comes first. There is always a chance to catch up later. Over 16s must not drop off the radar – pupils on a roll should still be kept in the loop and offered careers/further education advice*".

"*School guidance staff should have a clear duty of care and MUST maintain contact with families e.g. once a month. If some education is ongoing teachers should keep a running tally of work missed so that it can be easily passed to pupils… There should be more use of email and online education*".

"*Education professionals could make accessing… home tuition… easier*".

Better communication – it is important to parents that they are included in meetings concerning the treatment and support of their child. Parents find it helpful to receive copies of written notes. There should be better, joined-up communication between professionals, patients and parents.

Above all, "*it is very important for the child and family to feel believed and supported and for professionals to acknowledge the impact of ME on children's lives*".

End notes

This article stems from a meeting of the ME Cross Party Group on the 21st May 2009. Members of the Children and Young People Cross Party Group (for which *Children in Scotland* and *YouthLink Scotland* provide the secretariat) were invited to this meeting to discuss matters of common interest. The focal point of the meeting was a presentation from Dr Nigel Speight on management of Paediatric ME/CFS, which has informed this article.   Members of both Cross Party Groups are currently considering ways in which they might usefully work together to push for better support for children and young people with ME in Scotland.

The article was written by Katrina Allen, with invaluable contributions from the parents and young people featured within. Katrina is a policy officer at Children in Scotland and herself, a long-term suffer of ME. She is a member of *edmesh*, the Edinburgh ME self-help group (www.edmesh.org.uk), and has recently joined the Cross Party Group on ME. For further information or to share your experiences and/or views, please contact Katrina, email: kallen@childreninscotland.org.uk

[i] ME was originally short for myalgic encephalomyelitis and has its origins in a 1956 article in the *Lancet* medical journal. In recent years, myalgic encephalopathy has been promoted as a more appropriate name in the light of emerging research. ME is the name preferred by most patients and support groups. Chronic Fatigue Syndrome (CFS) is the name most commonly used by health professionals. CFS has been criticised for failing to reflect the severity of the illness, and also for becoming a catch-all label for patients with persistent unexplained fatigue. The term, Post-viral Fatigue Syndrome (PVFS) was introduced during the 1980s to describe patients whose illness is linked to a viral infection, followed by an extended period of ill health [Shepherd and Chaudhuri (2007) 'ME/CFS/PVFS An exploration of the key clinical issues' The ME Association]. For simplicity, the condition is referred to as ME throughout this article, a definition which includes CFS and PVFS.

[ii] In the case of adults, diagnosis is usually made when symptoms have persisted for at least 6 months.

[iii] The Tymes Trust for children with ME.

[iv] Assembled by the Scottish Public Health Network. Currently open to consultation.

[v] NICE clinical guidelines relating to the management of ME were issued in 2007. Although they advocate patient choice from the full range of management methods available, the guidelines are ambiguous about the model to be followed. Many patients and carers feel they place too much emphasis upon graded exercise and cognitive behavioural therapies.

[vi] Dr Speight, Consultant Paediatrician, evidence to the Gibson Enquiry on the state of ME research in the UK, 10 July 2006.

[vii] Consultant Paediatrician at Durham University Hospital.

[viii] The Royal College of Paediatricians considers knowledge of ME to be an element of core professional competence.