Experiences
The Young ME Sufferers Trust

Whispered Words

The experiences and needs of young people severely affected by ME/CFS

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Whispered Words

Whispered Words has been produced by The Young ME Sufferers Trust to highlight the experiences and needs of the many children and young people severely affected by ME/CFS.

These personal experiences have been compiled using parents' notes and semi-structured interviews, and where possible, the young sufferers themselves have given their views. They are representative of the spectrum and frequency of issues raised on the Tymes Trust Advice Line by families caring for severely affected children.

Names have been changed but all the families involved were keen to take this opportunity to make their voices heard.

Amy

Amy's experience reflects a common problem for those severely affected by ME/CFS - the need for appropriate care when inpatient treatment or investigations are necessary. Sensitivity to stimuli - including light, noise, and touch - and sleep reversal are major features of ME/CFS but these symptoms are rarely managed appropriately on main hospital wards.

Amy first became ill in October 1998, aged 11, and was initially diagnosed with arthritis. Six months later, her condition had deteriorated to the point when she was unable to walk and was fed by naso-gastric tube. Having been diagnosed with ME, she underwent graded exercise therapy for two months while an inpatient at a psychiatric unit. This precipitated severe cognitive difficulties and Amy feels "My head was fine until they messed with my legs."

A major feature of Amy's illness had been stomach problems; she began to vomit constantly during tube feeding and rapidly lost weight. Despite the insertion of a duodenal tube, Amy continued to vomit on feeding. When her weight became dangerously low, she was admitted to a main children's ward with what her parents considered to be an inappropriate routine and an unacceptable standard of care.

Through the Trust's Professionals' Referral Service, doctors found an elemental feed she was able to tolerate and vomiting ceased.

The paediatrician involved Social Services, assuring Amy's parents that they were being assessed for support and they would be fully involved. However, a case conference was held without their knowledge and doctors threatened to make Amy a ward of court.

After the family raised their concerns with hospital managers, Amy was assigned a new doctor who implemented more appropriate care, including a separate room, improved nursing care and the inclusion of Amy and her parents as part of the "care team". However, Social Services involvement proceeded with little parental consultation and Amy's mother believes this was due to lack of understanding of the severity of the illness "It's frustrating you can't get any answers from the doctors. Because of the severity of the symptoms they'll say 'We've never seen anything like this before.' but they won't read the literature we give them. The professionals don't respond to Amy's particular needs - we can but we need practical and emotional support to be able to care for her at home."

Georgina

Georgina's experience highlights another common problem facing severely affected sufferers; symptoms such as pseudo-seizures and temporary paralysis occur in severe cases but professionals tend not to equate these presentations with ME/CFS. This results in a gulf between the family's everyday experience and the professionals' understanding of ME which often hinders appropriate management and the provision of much needed practical and emotional support for the sufferer and his/her family.

Georgina's illness was triggered by a viral infection in 1997 when she was 8. Early symptoms included severe abdominal pain, headaches and fatigue and by 1998 she needed a wheelchair and tube feeding. She was finally diagnosed with ME/CFS in May 2000.

Her health improved greatly at times, enabling her to return to school and hobbies for short periods. However, she relapsed twice due to viral infections. After the second relapse she became bed bound with frequent daily episodes of spasms and seizures that cause temporary paralysis and render her unconscious. She constantly had severe pain throughout her body together with visual disturbance and difficulty swallowing. Her mother describes her pain as "intolerable for carers to witness, let alone for her to suffer." Georgina describes the sensations as "like my brain is on fire. There's a red hot wire pain in my back and legs and it's like having severe electric shocks."

Professionals who haven't witnessed these episodes believe she is "putting it on" or exaggerating her symptoms and this attitude causes great distress to Georgina and her family. Those who have seen the full severity of Georgina's illness are very supportive, understanding that both Georgina and her family need care and support.

As Georgina's Social Worker and the District Nurse began to organise practical support, her mother commented "We have finally been awarded benefits and these are a tremendous help - it takes the pressure off us as a family. But things are awful just now and we desperately need help to stop things worsening for Georgina."

Hayden

This account of Hayden's illness, told by his mother, highlights many families' need for support in coping with personal care and the need for severe sufferers to be heard.

"Hayden is 15 and has now been suffering with ME for almost three years and has not been able to walk for two years. He used to go for physiotherapy but I stopped this as it was doing more harm than good - it took all his energy to get there and the physiotherapists just didn't understand the illness and were determined that he should stand and walk - the after-effects were dreadful.

"When the physiotherapy was stopped, his condition did improve a bit; although there was no physical improvement I saw a definite improvement cognitively. I could hold a conversation with him and he remembered things from a few years ago. He still had continual muscle pains, headaches, no proper appetite, no energy and felt cold although he was clammy. However, he was optimistic about the future, and we were able to purchase a second-hand electric wheelchair. Hayden also had a home tutor and she was excellent - she just talked to him about the work (Personal and Social Studies) as he cannot read or write.

"Unfortunately, Hayden developed 'flu last Christmas which caused a major relapse. Five months on, he can't move his arms (I move his arms into position so he can use his hands a little), he can barely speak, he doesn't recognise his dad or his brother and he has to ask me what his name is in the mornings.

"We desperately need practical help and understanding from the medical profession. It seems that, because this isn't an 'injections or dressings' illness we can't get help with his personal care. I think it would help him keep his dignity too. And because Hayden struggles to form sentences and can only speak in a whisper, no-one takes the time to listen to him."

Isabel

The Trust feels it is important to acknowledge that many families caring for a child with ME/CFS face disbelief from professionals who assert that their child's illness has a psychological basis. In many cases, this disbelief leads to inappropriate advice or treatment, and, in some instances, child protection proceedings. Calls to the Trust's Advice Line suggest that such measures are often triggered by the family declining what they consider to be inappropriate treatment such as graded exercise therapy. Isabel's experience illustrates the distress caused.

Isabel is 11 and has been severely ill with ME for two years; she is unable to stand or walk or to recognise letters and numbers and has great difficulty finding words.

Her first paediatrician made a prompt, firm diagnosis of ME, was understanding and supportive, and involved Social Services purely in order to ensure the family received practical

aid. Unfortunately the process was complicated by referral to another paediatrician, who retracted the original diagnosis leaving Social Services unable to proceed with the provision of ramps, stairlift etc. This happened despite the family receiving top rate mobility allowance and being referred for a wheelchair by a GP.

Six months later, Section 47 Assessment (child protection proceedings) began. The family was not kept informed during the process; their letters requesting information were not answered, meetings were postponed and they felt some Social Workers were aggressive or threatening.

Isabel's mother commented "Our assessment experience has been even more distressing and traumatic than the actual illness - and that's saying a lot when you've got a child who can't do anything. It's a constant worry and it's taken so much time to find out what's happening and gather evidence for objections and to counter possible misunderstanding in the reports.

"Finally they sent a letter to say we *were* meeting Isabel's needs and that they'd decided not to assess us further because it's not in our best interests. They've passed on information to the Occupational Therapist so we can be assessed for practical aids again but there's still the threat that, if anyone objects, proceedings could being again. So we still don't quite know what's happening and we still don't quite feel safe. And all we really want to focus on is caring for Isabel and giving her body every chance to heal."

Fiona

Fiona's story is an example of how the provision of information, practical aids and emotional support enables a family to care for the severely affected sufferer at home.

Fiona became ill after a viral infection aged 12. Despite repeated vists to the GP, the symptoms were dismissed. With her condition worsening rapidly, the family saw a different GP, who diagnosed ME.

Fiona than suffered a "fit" but was sent home from Accident and Emergency. Soon afterwards, she spent five weeks in hospital, tube-fed and barely conscious. Fiona suffered loss of short-term memory, fine motor control, coordination and the ability to read and write. She was also highly sensitive to sound and smells.

The family were keen to care for her at home and this aim was supported by their doctors; they received a hospital bed (placed downstairs), support from District Nurses and Fiona's mother was taught to administer the tube-feed.

Fiona's mother explained "It was a frightening experience to go through - heartache for all the family. The worst thing was that I lost faith in people - many didn't understand how severely ill Fiona was and didn't take into account her cognitive difficulties or the fact she was so sensitive to sound. One professional decided she should have a glockenspiel - this when I hadn't been able to use the vacuum cleaner for months!

"Having her at home was definitely best - we've been able to give her time and love. Three years on she's making progress, both physically and educationally, because she's been able to do things at her own pace. Our GP helped so much by giving the strength and hope we needed - because he gave us the facts we were able to cope with what was happening."

The Knight Family

Clusters of ME/CFS are common in families, schools and communities. The Knight family - Bob, Chris, Ella and Edward - have all been diagnosed with ME/CFS. Their account highlights the importance of early diagnosis, the value of an understanding, coordinated response from professionals and the tremendous impact the condition has when it affects several family members.

Bob became ill 20 years ago and was finally diagnosed with CFS in 1998. His wife Chris was also later diagnosed. Their daughter Ella was born in 1988 and suffered recurrent respiratory infections and breathing difficulties from infancy.

In 1997, a myriad of symptoms began to emerge, starting with loss of balance, lack of temperature regulation, cognitive difficulties and recurrent headaches. She was diagnosed with ME/CFS in 1999 following a total collapse.

Her brother Edward was born in 1993 and suffered similar respiratory problems in infancy. In summer 1997 he suffered an acute viral infection which was diagnosed retrospectively as "a viral encephalitis". The severe cognitive dysfunction lasted many months and still affects his speech, motor control and concentration. He was eventually diagnosed with PVFS (Post Viral Fatigue Syndrome) in 1999.

Bob and Chris commented "If we'd known earlier, things wouldn't have got as bad as they did. Energy management could have been learnt so much sooner. The children's initial symptoms were very different to ours and because fatigue wasn't immediately present, their illness wasn't recognised."

Edward's teacher played an important role in identifying his symptoms: "Educationally, Edward is making appropriate progress, relates well to peers, plays cooperatively, and puts a lot of effort and hard work into his school life. However, when he speaks or answers a question during a discussion there is a slight delay, comments seem to be deliberate and almost come with sustained effort rather than spontaneously. Normal classroom routines seem to be an effort for him - he cannot cope with following several instructions given at once and tasks have to be carried out at his own pace. The jerky body movements evident last term have been noticeable again. At times he seems unable to function - work seems to be a huge effort for him, not just the thinking processes but the actual physical movements when writing, and he looks pale and ill."

Symptomatic relief was tried for various symptoms, including pain, but none were effective and many had side effects.

The children's sleep reversal has been the most difficult factor, as Chris explained "Because I've got to be up in the night for both children, I don't get to bed until 5AM and I'm left thoroughly exhausted. Dividing my time between them is so difficult - deciding 'who's more ill tonight?' Both have such distressing symptoms - hypoglycaemia, pain and restless legs to name but a few.

"In the beginning we were advised to try to bring the sleep cycle back to 'normal' but this was disastrous, causing severe relapse.

"This illness has had a devastating effect, particularly as we are all sufferers. We can't go anywhere as a family and we've become isolated from relatives and friends - they can't understand the daily fluctuations and the delayed effects of activity. The support of our GP, paediatrician and some teachers has been second to none though. They've been understanding about the condition and our needs and have been willing to listen, learn and believe our experience. It's imperative that sufferers and families are believed if they're to cope with this illness."

This section is taken from the Trust document *Children and Young People - The Key Points*, which quotes from the *Report of the Chief Medical Officer's Working Group on CFS/ME*. All the statements below are contained in the text of the Report; they are not our interpretation of the Report, but direct quotes from it.

Treatment/Management

- No management approach to CFS/ME has been found universally beneficial, and none can be considered a "cure". Patient responses suggest that […] all can cause harm if applied incorrectly.
- As with many chronic conditions, the emphasis should be on improvement and adjustment rather than "cure". The goal of rehabilitation or re-enablement will often be adjustment to the illness.
- Experience suggests that provision of a wheelchair or other mobility aid does not stop patients working towards mobility without the equipment in the long term; indeed, such aids probably assist remobilisation, with suitable supervision.
- The notion of "once in a wheelchair, never out" is prejudicial: each case must be assessed according to clinical and functional need.
- Although there is no cure for CFS/ME, the condition has been found to improve in most patients both with and without* treatment; it is good practice to encourage patients to become experts in self-management and to choose between treatment options.[*Patients may therefore decline active treatment.]
- Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician.
- Careful listening and respect for parents/carers' opinions are important factors.

Educational Management

- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. Some young people will be too severely affected by their illness to participate in any form of education, even at home.
- An educational plan is not an optional extra but an integral part of therapy.
- A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.
- Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.
- Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

Child Protection

- In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court.
- Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.

Prognosis

- Overall, there is wide variation in the duration of the illness, with some people recovering in less than two years, while others remain ill after several decades.
- A minority of those with CFS/ME remain permanently severely disabled and dependent on others.
- Most people with CFS/ME can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.