

Experiences

The Young ME Sufferers Trust



Mummies Aren't Supposed To Cry

Articles by family members

The Young ME Sufferers Trust
Registered Charity 1080985
Founder Patron : Lord Clement-Jones CBE

www.tymestrust.org
Telephone and Fax : 0845 003 9002
PO Box 4347, Stock, Ingatestone CM4 9TE

Season of Goodwill

Glenys Thomas

It's almost Christmas and a time of mixed emotions. Nothing can take away that excitement but there is an anxiety underlying all the plans if there is a young person with ME in the house. 'How will we cope?'

For us, Katie had always been the lively, enthusiastic child who initiated activities and organised us and her friends. During term time she was the one who found the change for the bus, remembered the birthday card for a friend and volunteered to take in an old Ration Book for a lesson on the Second World War. So, for her, Christmas was the fest of opportunities.

ME struck her very hard, as it does all youngsters. Although it took away her energy, it didn't take away her drive. Even when she was confined to bed she would come up with ideas. 'I'll make hundreds of cards and then we can sell them to raise money for...' She would set her sights on tasks, such as cards, decorations, or mincepies. She would get completely exhausted and relapse, sometimes for weeks afterwards.

In my naivety, for the first few Christmases I often confused her enthusiasm with being on the mend. Each time my spirits soared; this was more like it. Her cheeks would become rosy, she would be organising us all again. Then, exhaustion would set in and I would see her skin slowly becoming grey with dark rings round her eyes. If she pushed herself at this point, her relapse would be much worse. So in order to survive Christmas, there was subterfuge and pretence.

We always went to stay with her grandparents, where there were aunts and cousins around. They tried to encourage her to do things she couldn't manage. 'Wouldn't she like to ... decorate the tree/make rum truffles/etc.' I felt like shouting, 'Of course she would, but she's resting so she can be up for Christmas dinner.' Katie, of course, wanted to join in. One year, we took her in her wheelchair to a neighbour's house a quarter of a mile away. We hid the chair at the side of the house and sang a carol standing in the porch. Then we wished them 'Happy Christmas' and said we had the rest of the village to visit. In fact, it was back in the wheelchair and home to bed.

We were not really aware of 'energy management' and so there was no concise way of explaining to relatives and friends the need for rest or the fluctuations in the illness. The exhaustion that followed, the attempts to keep up a pretence of normality, seemed to go on into the

New Year. Relatives would ask, 'Is she back at school now?' I would say, 'No, she's not well enough,' and the inevitable response would be, 'She seemed so well at Christmas.' I would find myself gritting my teeth: 'Well, she's not now,' and under my breath, 'She was just pretending to be OK then, and that's why she's so unwell now.'

Dr Ho-Yen draws the analogy of energy as money, with patients having a limited 'income' and needing not to 'overdraw'. I would hope there would be less pretence now. As a carer, we do not want to be seen as over-protective but as helping the young person to keep within their limits.

One of Katie's best presents at that time was a brightly coloured 'Lynx' T-shirt which said, in effect, 'I am a person concerned about wildlife.' She lay on the sofa wearing it. Opportunities for a young person with ME to make statements about their beliefs, ideals and interests are limited but so important in helping them maintain and develop their sense of identity.

In the fourth edition of his book Better Recovery From Viral Illnesses, Dr Ho-Yen advises: 'If one is honest, even with children as young as 6 years, a helpful relationship can develop. [...] It is critical that this approach is taken as recovery depends on the cooperation of the child. By [...] lack of total honesty, many recoveries have been delayed.'



Family Cluster

Val Sharpe

Reprinted with kind permission of Good Housekeeping June 2001.

'Illness can creep up on you. Mine seemed to start just after my son David was born. Taking him out in his pushchair, I'd have to keep stopping and sitting down on the pavement. By the time he was three, I felt totally exhausted but simply assumed that everyone felt like that at 40.

Outwardly, friends saw me as full of energy, but at the end of the day I would collapse. I had bad throats, flu-like symptoms, sound sensitivity, a heightened sense of

smell and pains in my chest, head, legs and joints. There would be shortlived periods of remission and I would think I was better, but then the symptoms would come back again.

I did seek medical advice of course, but because we moved several times during that period I saw a succession of different GPs. I was told I had depression, flu, and one doctor dismissed me as neurotic.

Family life was so disrupted, I couldn't even help make supper and visiting my father was impossible because I wasn't strong enough for the drive. For more than two years he must have thought I didn't care. Cutting down my college lecturing simply wasn't enough. Sometimes I could hardly walk.

Then, by chance, in 1991 I saw a locum GP who recognised the pattern and told me I'd been diagnosed with ME five years earlier. 'Why didn't anyone tell me?' I asked. He said, 'They probably just hoped that you'd get better.' I had heard of ME (or chronic fatigue syndrome) but never associated it with myself. There was a bigger shock to come when David, who by this time was nine, became ill and was also diagnosed with ME following a viral infection.

As I looked at his white face and the dark rings under his eyes, I remembered photos of myself as a child and I realised I'd looked just like David. Growing up, I'd seen doctors time and time again. I was in the junior Red Cross and desperately wanted to go to summer camp but wasn't allowed to because of my fatigue; I seemed to recover and went to college but relapsed again. I've now discovered five family members with chronic fatigue syndrome.

I think withholding my diagnosis probably did more harm than good. If I'd known, I could have paced myself to allow my body to recover. David was given graded exercise therapy but that actually made him worse. Our present GP supports home tuition rather than sending children back to school too early. She believes it's important to let the body heal itself and she's being proved right as David is slowly improving.

The more I've looked into David's illness, the more I've learned to help myself. Finding the Young Action Online website was wonderful and the Tymes Trust's magazine, a charitable organisation that supports ME sufferers, particularly children, is great for information and fun.

We now have a life. For everything we can't do, there's something else that we can. We can't party or shop so we'll relax on the canal. As a result we're both getting stronger and now take joy in things we used to take for granted.



Wedding Bells

Julian Staniul

The first time I met Rachael was at a school reunion. We had shared the same primary school, but at different times, so never knew each other. I was on holiday from Inverness, where I was living. When I saw Rachael, she was in a wheelchair sitting next to her mum. I looked at her and thought, 'Wow.'

At the time, I didn't really know what ME was, and couldn't understand why her mum was so dubious in response to my requests to let Rachael stay a little longer. I now know it was because this was the first time she had been well enough to go out for a while, and when it was explained to me that the majority of her friends had left her by the wayside, I realised that firstly I had to prove that I was responsible, and secondly I had to gain her mum's confidence and trust.

Rachael herself seemed to be hesitant. She explained to me that at 21 years old, and up until that point, no-one our age had ever offered to take Rachael out. I am a big strong biker, I had a car that had ample room for a wheelchair and for me it just wasn't an issue. It was the person in it that took my attention!

I spent the remainder of my holiday with Rachael and it was hard to leave when the time came to return to Scotland. We were engaged after three months, and I moved to Suffolk permanently about four weeks after that. We married exactly one year to the day since we had first met.

Our wedding was a wonderful day but it was only afterwards that I fully realised what ME could do; I had never had to be a full time carer before. Rachael never seems to realise that I don't mind what I do for her, and with proper rest and pacing throughout the day, along with the acceptance of help, she will be able to do more in time. I love being married and the only thing I'd change would be to make my wife well.



Mummies Aren't Supposed to Cry

Glenys Thomas

When my daughter Katie was ill at the age of 14, I, with the constitution (and stature) of a pit pony, just kept going. I admit it did completely exhaust me and I would often think, 'If I could just have one night's sleep, I could cope.' I didn't take any time for myself as I felt no-one could look after her as I did; this actually was true, as when anyone else was around she put on a magnificent show. Only with me did she let down her defences and cry and say how awful she felt.

I remember crying with her one awful afternoon as the grey winter sky hung glumly over Birmingham. I felt my levels of tolerance and energy had reached rock bottom. She stopped suddenly, looked at me and said, 'Mummies aren't supposed to cry.' I felt chastened; I needed more help to be the strong one.

Finding the right sort of help is important. Sometimes relatives don't really understand ME and seeking help from them can backfire. Katie went to stay with her grandma for a few days. Grandma felt that 'a bit of fresh air and exercise' would do her good. Katie didn't tell her how she felt and Grandma was really pleased with 'having got her to walk the short distance into town and back.' It took weeks for Katie to regain the strength she had before she went away.

Other family members accepted her limitations and looked after me too. Often on a Friday we put Katie, her duvet and her brother in the car and went to the Cotswolds where we were supported by aunts, cousins and Nainie (Welsh for grandmother). It made a major difference to me to be in the big old kitchen with family and friends around and the continuity of farming life going on around me. I sometimes did the milking while my sisters took Katie and her brother to see lambs or a new foal. Having a break from the isolation that ME causes helped all of us and Katie formed a close relationship with her aunts and cousins.

I've met parents for whom help has come from many unofficial quarters; friends, neighbours, other families also coping with an ill child. It can certainly help to talk to someone who's 'been there, done that,' like the Trust's Advice Line Team. I was fortunate to work part-time nearby and that helped me. I wish I could say I managed to take time off to go out with friends, have a massage or enjoy a long leisurely bath!

My fear was that Katie would never get better and after years when there didn't seem any substantial change, this became a secret conviction. If I had known that now she would have a full life, constrained only by being sensible and listening to her body, perhaps I would have looked after myself better. Little things can make a difference to carers. Finding a little time to relax, let off steam or absorb yourself in an enjoyable pastime can make the world of difference and can remind you that you are special too.



Powerplay

Glenys Thomas

Something strange can happen to us as parents when we encounter professionals on their own territory! We may be confident, competent and successful in our own lives and careers, yet when we visit a hospital consultant in the role of the parent of a child with ME, we can find ourselves creeping around on our eyelashes.

Several parents I have spoken to describe the feeling of powerlessness after half an hour in a waiting room. I remember a children's book that invited choices; would they prefer mum to eat a live caterpillar found in her salad in a restaurant, or dance on the table in public? Invariably I found children chose the caterpillar. So there may be some of that 'Oh Mum, please don't make a fuss' element. Sociologists say it relates to the power differential between patient and professional. People wearing uniforms or symbols such as badges, beepers, stethoscopes etc strengthen it, as these are indicators of power and control.

One may find oneself wearing inappropriate things - warm outdoor clothes when those who work there are in short sleeves. So there we are, feeling uncomfortably hot or having to carry coats around, sometimes with a child who is muffled up, feeling the draught every time someone comes through the swing door.

It is not generally seen as acceptable to ask whether the consultant is on a coffee break! My memory is of having a child who, on her worst days, could become hypoglycaemic and begin to shake. Knowing whether there is time to unpack the picnic basket would be very helpful

and in some clinics you take a ticket and your number flashes up on a screen.

One mother took her daughter to a 9.15 appointment with the neurologist. She was unable to get out of bed but her mother somehow got her up at 6.30 to dress her, give her breakfast, and get her into a taxi as parking is difficult at the hospital. This youngster was very ill, but sat in her wheelchair until nearly midday. She was seen for 15 minutes, was asked to wait for blood tests and then to see another specialist, who never came. A medical student asked if they minded talking to him. At 4.30 they left for home. Her mother could not believe that she had allowed this to happen to her daughter. 'Here I am, an assertive woman at the top of my profession, yet I behaved like a sheep.' The same reaction can happen when we encounter other professionals.

Our role seems to require compliance and doing as we are told so as not to upset people in authority. Our fear is that, if we are stropky, they may give up on us, label us difficult parents, or worse. Does this sound familiar?

Hospitals now have patient advocates under the PALS system. Tymes Trust Young Advocate Shannen Dabson was invited to address Havering Primary Care Trust about her experiences with doctors; see Vision 2006-2 at www.tymestrust.org or send for a copy for £2.95.

§

Group Values

Glenys Thomas

When my daughter Katie and her friend Toria were about fifteen, we started up a local group for young people with ME and their parents.

As parents, we provided the backup – administration, refreshments and transport. It was a very mixed group. Members included a 10 year-old girl, a young woman in her late teens and a 22 year-old ex-football professional, plus a smattering of people in between these ages. After a few meetings, we decided it would be better for us as parents to meet in a separate room for part of the meeting. But Katie found running the young people's group during this time utterly exhausting.

I remember her saying, after one meeting, 'How can you

make sure a group meets the needs of everyone when all they have in common is ME?' Like any such venture, the variables within the group were enormous.

After a while, the young people's group became colonised by adults with ME! It was hard to refuse the pleas to be allowed to attend when there was no other local group for people to meet one another. In the end, it was decided that it was better to have an open group.

Surprisingly, although this meant that the age range widened even further, this was not a problem. The more significant factor seemed to be the length of time that members had had ME. There were some who lived alone and who had been coping with ME on their own for years, but we needed to encourage new, recently diagnosed members that there was hope, via energy management – or pacing. I saw positive by-products of this. Due to the proximity of the university, the group had a small but regular number of students with ME. They were anxious to keep up their work despite their illness, but hearing the experiences of the other members served as a reminder of the importance of energy management.

Our group went through good, and not so good, patches, but many people benefited from being able to meet with others. We as parents found our group tremendously supportive. For us, it was the first time we had come across other parents whose children were going through similar crises, whether with doctors, educationists or relatives. Friendships between families grew and Toria's parents were wonderful, supportive friends to me and dozens of other families. Having met initially at the group, the young people were able to continue contact by phone or letter and, twelve years on, many of these friendships remained strong.

§

After the Event

Glenys Thomas

Many carers out there have to cope with a post-festivity relapse and my deepest sympathy goes out to you. I feel such a charlatan writing about coping with relapses as I never felt that I managed them very well at all.

On the surface I appeared to cope, but on my own, driv-

ing the car or washing up in the kitchen, tears would stream down my face and I would be searching for what I had done that had caused my teenage daughter to relapse.

For my ‘young person with ME’, the extra effort that went into managing a Christmas or other Festival invariably brought back some of the worst symptoms. The feeling that at the start of a New Year they are worse again can generate misery. The other hazard at this time of the year is people who say, ‘You should think you are lucky to stay in the warm and haven’t got exams.’ Katie, who was 14 when she developed ME, used to say wistfully, ‘I loved exams.’ She did indeed, because they had a beginning and an end, unlike coursework.

One person with ME I used to share ideas with said he had finally identified the signs that he was pushing himself too hard. He said he began to feel ‘hyper’, almost getting a buzz. He often did not recognise this sign until his partner said, ‘Just a minute, what’s going on?’ and he would realise that he had been speeding up. If he stopped at that point, he could avoid relapse.

My heart sinks when I hear a young person say, ‘Well, I’m going out to enjoy myself, no matter what the cost.’ It’s understandable, and my sympathies go out to the carers, knowing they may be picking up the pieces later. But everyone has to learn through their own actions. Energy management, or pacing, is a matter of trial and error and carers can’t always take full responsibility. Infections, dental treatment, accidents, holidays etc can all cause flare-ups but rather than trying to battle through, it helps to go to ground for a few days, as cats and dogs do, giving the body time to recover. Happy New Year!

§

Normality is in the Eye of the Beholder

Val Sharpe

‘Twas the night before Christmas...’ Have you read it? No, not the original – the Tymes variation, about sleep problems.

I remember when Tymes Magazine, Winter 2000, arrived

one morning. David, then thirteen, was asleep, so I read it from cover to cover and loved Jane’s version of the poem. So, later that day, I suggested that David have a look at it. He refused. He was tired and miserable (you know about those times?) So, I read it aloud to him.

As I read it, his mood changed, he began to smile, and then laughed out loud at the line, ‘It’s the people next-door who are wrongly adjusted.’ Apologies to our neighbours, but we know what Jane means. Looking back, we found it difficult to cope with the sleep problems of ME at first. But once we’d accepted it, it became easier. I remember the nightmares, the night sweats, having to remove covers, open windows and then reverse the process later.

To encourage sleep we tried to follow a pattern – warm, relaxing bath with warm fluffy towels afterwards. We sometimes played relaxing music. David had a bedside light, supportive cushions, books and maps (a hobby) and whatever else he needed to take his mind off the fact that he was ‘still awake’.

The two factors that seemed to help were acceptance and flexibility; accepting that he was going to be awake meant losing the anxiety about it (a crucial factor in aiding recovery) and flexibility meant doing things when he could, rather than at ‘normal’ times. I recall making soup in the middle of the night and then watching bleary-eyed as David wolfed it down. I recall David doing maths at 11.15pm – because, he said, his brain could work then! It also meant sleeping whenever we could, including catnaps, so that we could keep going.

Thinking back to those times, I wonder how we got through it, but we did and David is now sleeping normally. Often, just laughing about the situation helped us, and so this poem was one of those moments to remember (see opposite).

The Night Before Christmas

Jane Colby (ghost-written by Santa)

*Twas the night before Christmas and all through the house
Not a creature was stirring, so quiet as a mouse
I stole to the kitchen and put on some tea
And carried the mug to my trusty PC.*

*Since sleep wouldn't come, I sat making up rhymes
(I had to produce a new poem for TYMES).
'I'll write about sleep rhythms - that will be fun ☺'
I said to myself as the hall clock chimed one.*

*But all I could think of was being awake;
I thought of the children who lie there and ache
And the patient who rang up his GP at two
Saying 'I can't sleep doctor, so neither will you.'*

*And then, when you do sleep, come horrible dreams
Full of monsters and ghosties and bloodcurdling screams
And you plead with them 'Look, go and bother some other
Poor guy who deserves it ... perhaps my big brother?'*

*It's hard for a family to cope with these trials
On top of Dad's stomach and grandmother's piles
And Mum's got a migraine and Christmas is here
And who was it filled that umbrella with beer?*

*When someone feels terribly, horribly ill
It's no wonder we search for the one magic pill
That will help us to nod off and banish the pain
No wonder we try things again and again.*

*But napping in daytime can top up our sleep;
Like commuters in trains, we can often get deep
Relaxation from just dropping off for a doze
Which helps us recover and lessens the lows.*

*And if we're awake, there is email and chat,
Hot chocolate or milk in a ginormous vat
And soft soothing music and soft soothing lights
And friendly night radio for really bad nights.*

*Because there's no medicine that's really just right
We're often quite wakeful for part of the night
And what does it matter? Why quiver and quake?
Half of the rest of the world is awake!*

*Think about Santa and Rudolph's night scene.
It's obvious ours is the normal routine.
So here is my message, when all's done and dusted,
It's the people next door who are wrongly adjusted.*

*I hid as I heard Santa come to my door then -
I wouldn't get presents (I thought) if I saw them.
But I was exhausted, as Santa could see -
So he wrote this poem while I drank my tea.*

Mummies Aren't Supposed To Cry

Zoe's Win

Just how does Zoe win? A great story - fun to read - also good for reading aloud. Easy, clear print.

From a review by teacher Joanne, for Sheffield ME Group:

Zoe is a star pupil in Physical Education and when she starts to lose her abilities, no-one understands. The reader knows why and cringes when Zoe's is told to 'Pull yourself together girl! You can't win if you don't try.'

As a teacher I would have found this book beneficial if I had a child in my class with ME. Any professional dealing with children and their needs has to understand as much as possible about the health, welfare and education of children, and what can go wrong.

£7.95 inc p&p. Send us a cheque made out to Dome Vision and we will process your order.

Jane Colby



Zoe's Win

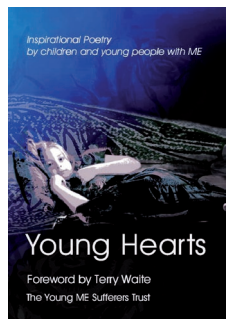
Young Hearts

A beautiful book of poetry and thoughts from children and young people with ME, fully illustrated throughout, was published for Christmas 2004 by The Young ME Sufferers Trust. Already into its fourth reprint.

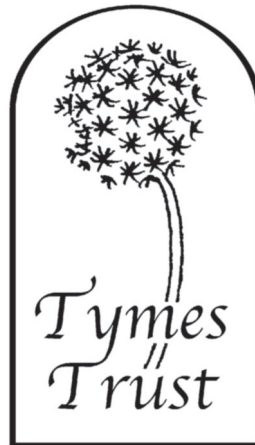
The Young Hearts project was the dream of 14-year-old ME sufferer Jade Louise Scarrott, one of our young members who was tragically taken from us in a random accident on our roads. Jade wanted to raise awareness of ME and of the thoughts and feelings of young people with ME. No-one with a heart will fail to respond to these children's words.

We are honoured that Terry Waite, former Special Envoy to the Archbishop of Canterbury, agreed to launch the book on 29th November in Warwick Castle.

See the book at www.tymestrust.org. To order, send a cheque for £7.95 or use the donations button on the website.



Young Hearts
Foreword by Terry Waite
The Young ME Sufferers Trust



The Young ME Sufferers Trust

PO Box 4347

Stock

Ingatstone

Essex

CM4 9TE

www.tymestrust.org