

T Y M E S

MAGAZINE

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TERRY WAITE

In Conversation with Jane Colby

THE FORGOTTEN CHILDREN

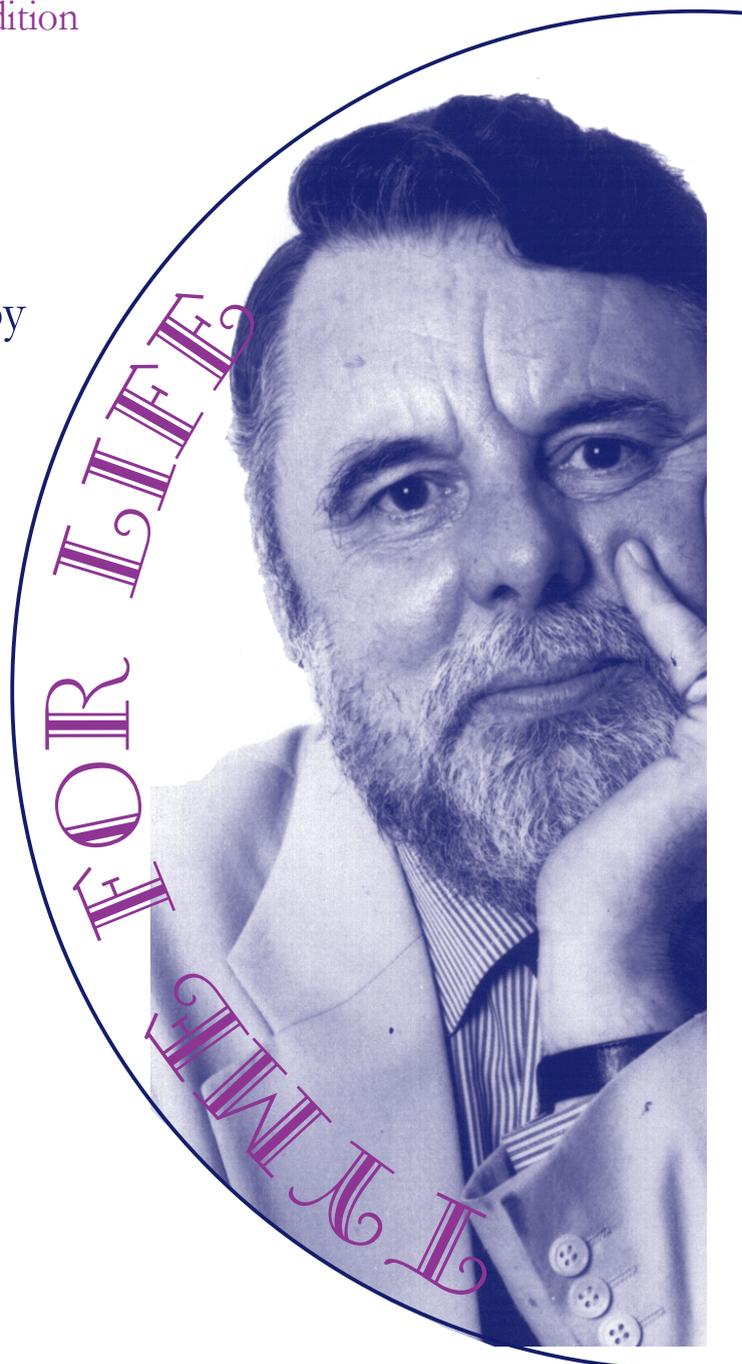
Daily Express Health Editor
Michael Day on the 'dossier
of shame'

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'STRENGTH AND
COURAGE'
KENNETH BRANAGH

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WHAT YOU THINK

Well done for *The Forgotten Children*. It is a timely reminder of what is really happening. In the hypothetical discussions it does seem to get forgotten that people, and especially children, are having to bear the consequences.

Mother of young woman with severe ME

Pat Kenny's show is the top rated show on **RTE**. To get on Pat Kenny is fantastic publicity. People all over the world listen to it on the Internet.

Vera and Tom Kindlon, Irish ME Group: a Tymes Trust Partner Group.

Have just read Judy Kerr's excellent article about the dossier in **The Big Issue** (May 12 -18). First time ever that I've finished reading an article about ME and danced around the room! A well-constructed, factually accurate piece! *Lynne Wax*

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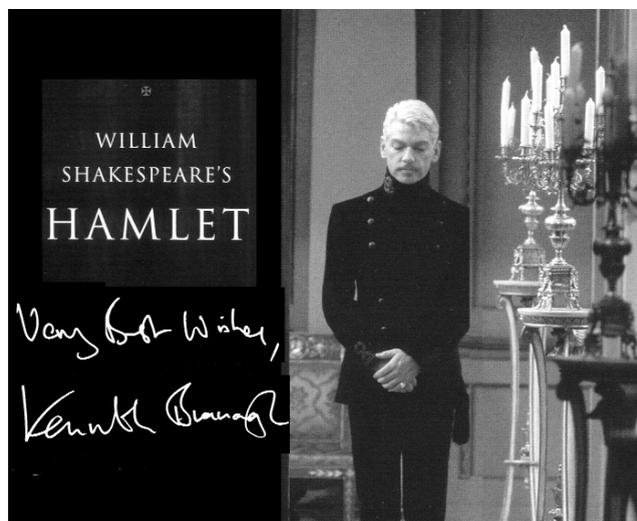
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'To all readers and supporters of Tymes Trust. Raw strength and courage in the battle with ME. May there be great Tymes ahead for you all.' Kenneth Branagh

DEAR READER

Let me make it clear – I like Morris Dancers. I adore bells and I think that stuff with swords and sticks is pretty neat.

That didn't stop me laughing at Terry Waite's joke. The Two Ronnies (repeats and all) once spoofed a Morris Dance; Terry has gone one better. But as always, he was making a serious point.

We all very much appreciate Terry's willingness to discuss ways of surviving isolation and hardship. Given his own terrible experiences as a hostage, his depth of

Recovery is a funny word in ME – it comes to mean different things to different people.

thought and wisdom has contributed greatly to the theme of this magazine – *Tymes for Life*.

You'll notice a 'y' in several headlines to link *Tymes Trust* closely with *time*. A dandelion clock is our emblem, for time is the one thing that makes a difference in this illness.

Studies claiming the effectiveness of various treatments or remedies have this in common – the improvements usually took place *over time*. These studies often fail to explain that the natural course in most cases of ME is to improve over time without any treatment whatsoever – so long as we keep up our spirits, endure through the bad times and support and nourish our bodies, instead of fighting or pushing them too hard.

We are used to a fast-moving world that

demands instant results. An illness like ME reminds us that we are creatures of the natural world. The healing process, whilst remarkable in its power, works to its own ancient timescale. We hurry it at our peril. We suffer the 'yo-yo effect' of rushing to recover and paying for it afterwards.

Recovery is a funny word in ME – it comes to mean different things to different people. Having recently become stronger, I like this golf definition: 'a stroke played from the rough or a bunker to the fairway or green.' That doesn't mean you've achieved the ultimate goal of getting the ball in the hole – but you're on track and out of the worst of the trouble.

You can't easily get on track or let your body heal if you're being unsuitably pressurised. Professional agencies like schools and clinics that expect fast results, a prompt return to school and resumption of normal service hinder recovery. This is why Tymes Trust has produced *The Forgotten Children* – exposing what is going on.

Kenneth Branagh's famous portrayal of Hamlet recalls Shakespeare's lines from that play: *Take thy fair hour, Laertes; time be thine, And thy best graces spend it at thy will.*

**Jane Colby
Executive Director**

Tymes Trust would like to thank Jane Bryant, mother of Ben, for acting as its Press Officer and achieving such widespread publicity for *The Forgotten Children*.

IN THE SPOTLIGHT

ME in Japan: In his Summary of the AACFS Sixth International Conference on CFS, FM and Related Illnesses, Dr Charles Lapp wrote: We were shocked to learn from Dr. Akemi Tomoda (Kumamoto University School of Medicine, Japan), that 2% of Junior High School students and 5% of High School students in Japan are disabled by CFS symptoms, especially fatigue and cognitive

dysfunction. In a study of 319 students with CFS, Tomoda demonstrated that 116 had abnormal responses to the 'Visual Evoked Potentials' test, most had shortened R-R intervals on the electrocardiogram - a sign of autonomic [nervous system] dysfunction - and all had low scores on the KANA 'Pick Up' Test, which measures attention and comprehension.



Tymes Trust's dossier *The Forgotten Children* was presented to Downing Street on ME Awareness Day. In this powerful independent exposé donated exclusively to *Tymes Magazine*, Health Editor of the *Daily Express* Michael Day describes the problems faced by families whose children have ME.

Thousands of British school children are suffering serious physical and emotional damage because doctors and teachers routinely fail to take ME – or chronic fatigue syndrome – seriously enough.

A new report by a children's charity says many of Britain's 25,000 child ME victims are being bullied, ridiculed and forced to do activities that aggravate their debilitating illness.

Jane Colby, Executive Director of the Tymes Trust, said: 'Our concern is that some teachers and health professionals are forcing them to do things that make them worse.'

'And what people find hard to accept is that exercise simply doesn't help. She has not been treated and she is now starting to get better.'

'They're still treating children with ME as if they have attitude problems, when as we know – and the World Health Organisation and the Royal College of Psychiatrists confirm – ME is a brain disease.'

Consultant paediatrician and child ME specialist Dr Nigel Speight of the University Hospital North Durham, agreed. He said: 'ME can be a devastating condition for many children.'

'Unfortunately this is one area where some doctors feel they can bully children into taking exercise treatments they don't want.'

'It's utterly unreasonable. It can do lasting physical and emotional damage. I've seen children who've been so traumatised by this

kind of treatment that they've completely lost trust in the medical profession.'

Mrs Colby added: 'The message behind this dossier is that the majority of doctors and teachers charged with the care and education of these vulnerable children are ignoring their duty and in many cases, bullying and intimidating entire families.'

'They're forcing them into graded exercise programmes when they're not ready for them. And the majority of health professionals don't understand that most of these children are not strong enough to be at school and that they need tuition at home.'

She said: 'It's not the Government's fault. They're introducing legislation to try and help things. And some doctors and teachers are excellent. The problem is that many health professionals are still being so narrow minded.'

ME can last years. It can cause extreme exhaustion, muscle pain, and problems with concentration.

Around 20 per cent of victims are either house or bed-bound and have great difficulty performing even basic tasks. But in the past the illness was dismissed as a mild condition and some doctors even doubted it existed.

The tide in medical opinion turned in 1996 when the Royal College of Psychiatrists and the Royal College of Physicians concluded it was a real disease with an unknown cause – probably a viral infection.

Frances Goodchild, 12, from St Albans has had severe ME for the past three and a half years.

THE FORGOTTEN CHILDREN

She has spent two of these years in bed in a darkened room, barely able to move.

Her mother, 49 year-old music teacher Kathy, described the family's treatment at the hands of health and education authorities as 'dreadful'.

When Frances's symptoms became so bad three years ago that school was out of the question, she saw a paediatrician who told Mrs. Goodchild that her daughter had chronic fatigue syndrome.

But she didn't know that the doctor had failed to put this diagnosis on the medical records and instead criticised the way the mother looked after her daughter, accusing her of pandering to complaints of tiredness and illness.

Once she had been off school for a year there were moves to place her on an at-risk register. 'It was a terrible time,' she said. 'They could have come and knocked at the door and taken her away. It was a very close thing. We were saved by our very good GP who told them that our daughter really was very ill.'

But she added: 'It's scandalous the way so many people refused to believe she was ill despite all the evidence to the contrary.'

'And what people find hard to accept is that exercise simply doesn't help. She has not been treated and she is now starting to get better.'

Last week a report by the campaign group Action for ME revealed that the condition is now costing the UK £3.5 bn a year. This amounts to almost £15,000 for each of the 240,000 Britons who suffer the debilitating condition. Despite this, virtually nothing is spent on researching the illness, the report said.



The Forgotten Children is at www.youngactiononline.com or send for a bound copy for £5.50 plus 50p post and packing. Especially suitable for your MP.

IS ME ILLNESS ALL IN THE MIND? asked the *Daily Mail* (26th May). 'Yes' argued two readers. 'No' said Jane Colby's feature letter.

[...] Tymes Trust has just presented *The Forgotten Children* to Downing Street. The 'dossier of shame' shows that 84 per cent of families felt bullied by professionals whose duty it is to care for them. ME can be devastating. Some children suffer paralysis and need to be tube-fed. A mother told how a doctor shouted at her bedridden child and threatened a social services inquiry. Another was cruelly told by her teacher that she was stupid and in the way. Thank goodness for the good doctors and teachers. May their example guide less enlightened colleagues.

Jane Colby, Tymes Trust, Stock, Essex



SUPPORT FROM THE MEDIA

National and local journalists put the message out. *The Times* highlighted our statistics: 'The report says that 84% of children or their parents [...] said that they had been intimidated by professionals, mostly doctors. Nine out of ten said that unreasonable demands made by schools were the biggest cause of relapse in children. [...] Expecting too much too soon can cause setbacks, the Trust says. It sought information from 126 families and found that 76% were dissatisfied with their educational provision. Only 40% of families found local education authorities helpful.'

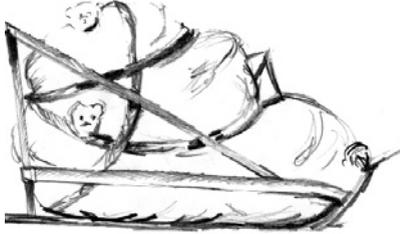
On *LBC Bodytalk* Jane was the guest of Michael van Stratten, with Dr Thomas Stuttford and actress Jenny Seagrove. This radio debate became a 2-hour marathon. *RTE's Today with Pat Kenny* and local stations eg *BBC Essex*, *Radio Guernsey* also carried interviews with Jane.

A Tyme to Give And a Tyme to Receive



Ideas for Calming Beanie Bears:
Food (of course); a kiss; dancing
for me; reading *Tymes Magazine*
(he likes Seb's pages); running
B A B F H B Y P W M E
(Bears Against Boredom For
House Bound Young People With
ME); my mum singing to him.

Eleanor Ward



I'm writing this for my daughter Tiffany as she is unable to write to you. She says if you were to send her a beanie bear, 'first of all I would give him a cuddle to say welcome to his new home. Then I'd introduce him to all my other little fluffy friends who live under and on top of my blanket on the sofa.

I'd make sure he had a cosy spot all for himself so he could snuggle down – after a snack – he must be tired. He's had a long journey. When he woke up, if he has been a good boy he could sit on my mum's shoulders and she could show him the house. That way he wouldn't want to go off and explore on his own and get lost. At bedtime, to stop him giggling when I'm dropping off to sleep I'd get one of the big grown-up cuddlies to tell him a story. Then he could have a snack in bed as we do too, and it would be easy for him to fall asleep with me. Then I would give him a cuddle and a kiss, say our prayers, tuck him in and snuggle up for the night'.

Salli and Tiffany Noble



Thank you very much for the 'sur-prize' you sent me for the Treasure Hunt. I had no idea I was one of the winners! The box (treasure chest) and necklace (piece of treasure) were lovely. I also want to say that the Shirley Conran and Media Man interviews were very reassuring and wonderful for my sanity.

Katie Durben
xxx



Thank you for the lovely prizes you sent me!! You never seem to run out of uniqueness.

Sazza Holmes



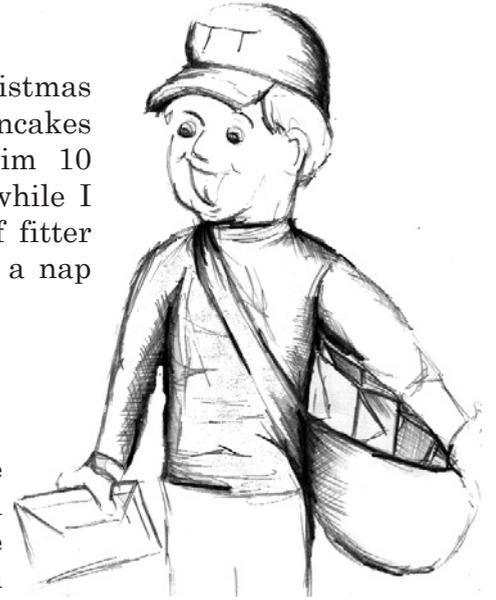
Just wanted to say thanks for the surprise parcel – my treasure chest prize! Very much appreciated.

Thank you
Love

Naomi Whittingham

My bear is going to have Christmas Dinner, cheesecake and pancakes with syrup, then she'll swim 10 lengths, then run 10 laps, while I sit and watch and dream of fitter days and then we can have a nap together.

Cheryll Neyt



I have just received my lovely beanie bear this morning and I would like to say a big thank you. I haven't been very well for the last 6 weeks (mum's typing for me). I have cuddled my bear nearly all day. I have named her Fudge and she has really cheered me up. She is going to bed with me now.

Cheryll Neyt

Heya! Thanks for the pirate treasure chest prize which arrived this morning. The balloon will work out great in a Halloween party I've planned in my bedroom tomorrow.

Eleanor Ward



Thank you very much for my Prize Treasure! It was such a great surprise, especially 'cos you wrote the note yourself ☺ The necklace and Special Box For Putting Things In are lovely and I shall treasure my treasure.

Anna Sheppard

When my beanie bear arrived, he wanted to run around the house and explore so I introduced him to everyone. We laugh together, and smile and dream. Like me, he is learning to pace himself most of the time.

Eleanor Ward



If you've never sent for anything or entered one of our puzzles, make this the time you write in. Male or female, young and not so young, we have things to suit everyone. One of our bears went to a great young lad. We love sending you things because you love receiving them. We get the best of the bargain, we think.



Tymes Trust Team

NAME: Dr Nigel Speight

POSITION: Medical Adviser to Tymes Trust

LIVES: Durham

FAVOURITE COLOUR: I have no strong feelings about colour except that I prefer the non-American spelling!

BACKGROUND: Trained @ Cambridge and UCH London. Early jobs in London, then 4 very happy years as Lecturer in Medicine in University of Dar es Salaam in Tanzania. Returned to train in Paediatrics in Newcastle, Consultant in Durham since 1982.

SPECIAL INTERESTS APART FROM ME: Underdiagnosis of Childhood Asthma; Child Abuse; Food Allergy/Intolerance; ADHD.

CURRENT STATUS: Married to Heather, 4 children, one grand-daughter (just recently). Paediatric Adviser to other ME charities.

RUNNING TOTAL OF ME PATIENTS: Upwards of 130 in N Durham, around 60 from rest of Northern Region and another 60 from further afield, including Isle of Man, Inverness, Somerset etc.

CURRENT TOTAL OF CHILD PROTECTION CASES: 14 of which 13 were successfully reversed. Still some potential cases in the pipeline.

SPECIAL BELIEFS: The preferability of Good over Evil!



Tymes Trust Medical Adviser and GP Tutor Dr Nigel Hunt with Jane Colby, at the Chelmsford PCT Training Evening. [Report on page 10]

Photograph: Dr Hunt, Janet Mills, Jane Colby, Barry Blake and Sarah Mills.



Tymes Trust Postman

*In late Spring we were delighted when another cheque arrived at Tymes Trust from **Amazon.co.uk**. Many thanks to everyone who remembered to buy their CDs, books, DVDs etc by going to **www.youngactiononline.com** and clicking through to Amazon from there. It doesn't cost you any more but it helps our funds.*

Insight: Nature's Power

Several years ago, Carly Jennings wrote the story of her life with ME. She included excerpts from her Diary and came to have a new philosophy of life:

'I think one of the most important things in the key to happiness is to accept your limits, to face your illness and accept it for now. I have only just discovered this and I realise now that it is pointless wasting your energy feeling guilty or frustrated. It doesn't change anything and only makes you feel worse.'

Dear Diary,

Today I have felt very positive and very relaxed. I feel that I can really see things – things the 'busy' people ignore. I can see the beauty of everything around me; the sea, the garden, the flowers. Everything is unique and everything is amazing. I guess most people get so self-absorbed by their own lives that these things can go unnoticed; it is not until you have the time that you can really appreciate them as I can. Earlier I went for a walk and even the smell of the outside, the wind in my hair and the rain on my face seemed wonderful and special and not to be taken for granted.

It is on days like today that I realise happiness is not just about 'fitting in' and being 'normal'.

There is so much more to it than that and happiness really does come from within. I have to focus on these other aspects of happiness. I have to forget yesterday, forget tomorrow and just take each day as it comes. I must try and hold onto the optimism that each new day brings and judge each day by its own merits.

Carly has now been proved right about the beneficial effects of contact with nature. In scientific circles it is known as the 'biophilia effect' and, writes Fred Hammerton in the *Essex Chronicle*, there is a growing body of proof that closeness to nature increases wellbeing.

Fred points out that 'bio' is a prefix from bios, the Greek word meaning life, and 'philia' means love of. So biophilia means 'love of life'.

A report from Essex University by Jules Pretty, Murray Griffin and Martin Sellers from the Biological Sciences Department and Chris Pretty from Suffolk College includes reference to: 'the effectiveness of wilderness in contributing to spiritually beneficial recreation and leisure experiences; the healing value of hospital gardens or of nature views [...] and the psychological benefits of companion animals and pets'. An American study found that hospital patients with tree views had shorter hospital stays and needed less medication than those looking out onto a brick wall.

'Please could you send me two Friends' Packs? I think they're a great idea. I don't know how to explain ME to my friends and I feel like I'm being awkward every time I have to say that I can't do something. I think it will be easier just to be able to quietly hand them a leaflet because it will make so much less of a big deal out of it.'

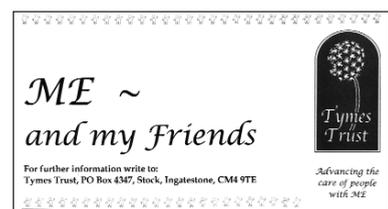
Becky Culver.

We now have three Friends' Packs at £1.90 each including post and packing, all in protective plastic wallets.

Pack 1: Leaflets for 6 friends, showing them how to help.

Pack 2: Quick Tour of ME for 6 friends, explaining the illness.

Pack 3: Leaflets for 3 friends with 3 copies of the Quick Tour.





Behind the Scenes

Trusty's choices from the latest activities of Tymes Trust

Chelmsford PCT

Chelmsford PCT Interactive Forum on ME PGEA x 2 hours approved

At Springfield Hospital in April, the Chelmsford Primary Care Trust held a multi-disciplinary training evening run by Tymes Trust Medical Adviser and GP Tutor Dr Nigel Hunt and Jane Colby. This session qualified GPs for two hours' Post Graduate Education Allowance. The following delegates were invited:

All Mid Essex GPs
Community Staff (particularly those involved in paediatrics)
Staff within Social Services
Educational Psychologists and Home Tutors

Out of area delegates were also welcomed, together with ME patients of differing ages. The evening was well attended, with a good balance between professions. A hot buffet set a friendly atmosphere; then came a joint presentation on practical ways of helping patients with ME, including children and young people, followed by an interactive session for multi-disciplinary groups to discuss relevant issues.

Marian Luketa, Training Manager at Chelmsford PCT, who was also at the event, said: 'I tried to think of a way in which I could have improved the evening and couldn't think of anything!'

Everyone was delighted that Dr Alan Franklin also came along in spite of his need to restrict activity these days.

Tymes Trust Open Day

In ME Awareness Week, Keith and Sally Player hosted the Tymes Trust Open Day at Westlands Nursery and Gardens, Chalk Street, South Hanningfield, Essex.

This was a happy occasion with tea and delicious cakes in the barn and a beautiful tranquil garden to visit. Tymes Trust Team members were there at various times during the day to meet visitors.

Sally thanks everyone who managed to attend and looks forward to seeing others of you, whatever your age, one forthcoming Wednesday or Sunday.

'Don't forget – on the back of the Spring *Tymes Magazine* you'll find all the dates when we are serving Tymes Trust Teas right throughout the summer,' she says. 'Come along when you're well enough and have a good rest, a cup of tea and a quiet look round the garden. You're welcome any time between 10.00am and 5.00pm.'



Philip, Anna, Peter & Ella enjoyed their day

An irresistible invitation, surely?!

For further information

Westlands Nursery 01245 400902
www.westlandsnursery.co.uk
www.ngs.org.uk

At the Chelmsford PCT Interactive Forum, Tymes Trust's new *GPs Good Practice Guide to the Education of Children with ME* was launched in draft form. After a final consultation exercise with the GPs who attended, the Guide will be available to purchase for your GP at £4.50 plus 50p post and packing.

Lecture at Swindon ME Support Group A Tymes Trust Partner Group

In early May, Jane Colby gave a talk to the Swindon ME Support Group entitled ME – The Hidden Epidemic. The resulting discussion was so animated that the caretaker had to send everyone home to their beds!

Most had apparently forgotten that after 10.00pm some of those with ME would turn into pumpkins (although others would wake as pumpkins in the morning).

Peter Allison, Chair of the Group, thanked Jane warmly for accepting the invitation and looked forward to another visit.

Many congratulations on the well planned and implemented recent training evening. As well as the constructive overview of the illness, the group exercises provided a useful basis for helping to understand the illness not only from the patient's but the doctor's perspective as well.

Dr Claire Carpenter (a Colchester GP) commented that it was one of the most beneficial training sessions she had attended.

Barry Blake, Vice Chair, Colchester ME Self-Help Group

Yes! *The Big Issue* in the North has done it again with the article on children being bullied and parents being afraid to speak out. Well done, Tymes Trust, for highlighting it and to *The Big Issue* for publishing it. *The Big Issue* in London also published it. When I read the London copy, I felt so proud that this was part of what was happening and privileged to be a part of it myself.

Trevor at CAME

ME Awareness Day – Monday 12 May

On ME Awareness Day, Castleford Aid for ME, which contributes to Tymes Trust's Advice Line costs, organised a static demonstration outside the Department of Health, followed by a presentation to Downing Street.

John Edmonds, General Secretary of the GMB, attended to lend support. He was very affected by the children's situation and sent kind greetings to all Tymes Trust members.

On behalf of young people with ME, Jane Colby presented *The Forgotten Children* to Downing Street. Rain could not dampen the spirits of all who joined in this good-humoured demonstration and lobby of MPs in the House of Commons. Many MPs expressed their support and concern.

We'd like to thank members and parents who sent best wishes for the event, saying how much they would have liked to attend.

Thorntons Educational Continuity Awards

In March, Tymes Trust Chair of Trustees Keith Harley was invited to present the first Thorntons Awards for schools or centres demonstrating excellent practice in enabling children with medical needs to continue with their education.

The Awards, given in Association with the National Association for the Education of Sick Children, took place at the Royal Horticultural Halls Conference Centre as part of the NAESC National Conference, where Jane Colby also ran a workshop. Each student received a book token and framed commemorative certificate and their school or centre received a cash grant of £750.00.

Thanking Mr Harley for presenting the Awards, Dr Carolyn Skilling, Executive Director of NAESC, complimented Tymes Trust on its support for children with ME.

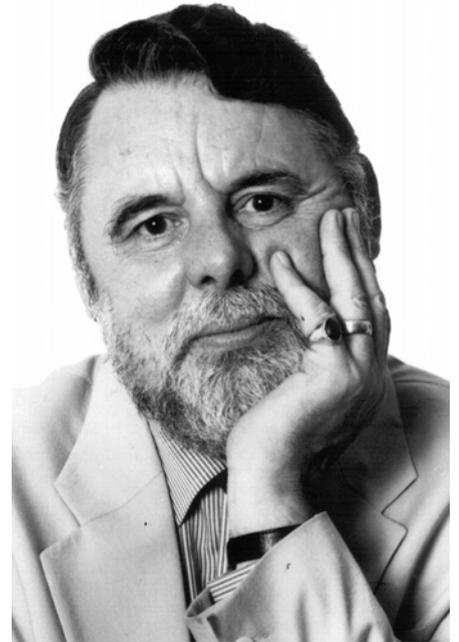
It was a wonderful surprise – and made us very proud – to find that Lyn Walker, who two years ago attended a Tymes Trust Teachers' Training Day, was one of the Award recipients, together with her entire Team, for supporting the education of two children with ME.

Lyn is Tuition Manager of Thurrock Pupil Support Service in Essex. She subsequently attended the Chelmsford PCT training evening to assist with group discussion and also came to the Trust's Open Day.



TERRY WAITE

In conversation with Jane Colby



Are there common themes in human endurance from which we can draw lessons for life? Terry Waite, the former Archbishop of Canterbury's Special Envoy and middle east hostage believes there are.

Jane: Terry, when we first met, it was the first time you'd been told that children suffer from ME. And you were very concerned to learn that.

Terry: Yes. I'd no idea it was an illness that could affect children. I thought it normally affected people in their mid or late teens and onwards. Do they know what causes it yet?

Jane: Well, it's a very polio-like syndrome. I wrote my first book about that in 1996. All the epidemiology, the brain problems and neurological signs and symptoms mirror polio in some way.

It's not a wacky theory - it was first told to me by the microbiologist I was working with and that's why I dug into it. She pointed out that we vaccinate people against some viruses in the polio family but not others. I interviewed the American polio expert Professor Richard Bruno and told him about it, and he's done a lot of work on this.

Terry: That's very interesting. The whole thing has been a mystery to most people, hasn't it? People who have no knowledge of it might say it's just a matter of laziness or the disposition of the person and they ought to shake themselves out of it and get back on their feet and pull themselves together.

Jane: Exactly. The ME community – and a number of doctors – feel that to use the term

Chronic Fatigue Syndrome, when exhaustion is only one aspect of the whole neurological pattern, has been very misleading and has actually aggravated this.

Terry: Yes. I would say that it conveys to the public an inaccurate and incomplete image.

Jane: In your latest interview you reminded everybody that you had been in captivity for 5 years, in solitary confinement for 4 years and even faced with a mock execution. That is the most incredible endurance test and you must have developed strategies to get through that kind of situation.

Might those strategies help young people with ME? They are often isolated, faced with hardship in a world that doesn't believe them. They have to dig in for an unknown length of time and have to develop some kind of survival mechanism to get them through it.

Terry: There certainly are similarities as well as differences. First of all, you've got to be able to maintain hope. In my situation, one had to find hope from within and from one's whole philosophy of life.

I imagine that children need to be surrounded by people who will not patronise them and not over-coddle them but at the same time enable them to maintain hope. In my case I had to deal with the situation by living for the moment – for one day at a time – not living too far ahead, trying to find meaning in the

moment. That's very difficult to translate into practicalities for children.

Jane: But you can't imagine how many times I've had exactly the same thing said to me by families of children. And I've been through this illness very seriously myself. I was bedridden for a long time and then in a wheelchair and I would have said exactly the same as you've just said.

Terry: Really?

Jane: Yes. You must find meaning in the moment, even if it's only 'I must just have a lovely warm bath'.

Terry: That's exactly right. Today's society encourages people always to be seeking that which is greater and better – to amass more and more possessions – always to be acquisitive in other words; but life is *now*, this moment – it's not about seeking to get better things for the future, it's about living at the moment.

That doesn't mean to say you have no regard for tomorrow and live recklessly, what it means to say is that you live fully in the moment – as you say, a warm bath – and develop other interests that maybe now, given you're in this condition, you have time for. Maybe you can say: look, I now have time for music – to listen to music – to really appreciate it.

I now have time, perhaps, for reading, or art, gently, gently, at your own pace, in your own way, and get into a subject that perhaps you wouldn't normally have done if you'd been caught up with the hurly burly of life.

Jane: That's how I'm in the position I'm in. I was a head teacher.

Terry: Well, there you are.

Jane: I would never have turned my hand to writing as much as I've written, or researching the illness. Your life turns a corner.

Terry: That's right. You might want to, for example, read something about the life of a great author and then begin to read his novels. Or the work of a great musician – read

something about Bach and then go through his works and listen to them – gradually do those things which will enrich you in spirit. Music enriches you in spirit, as does good literature because good literature stimulates the imagination and invites participation by the reader, so that you use your creative imagination in a way you don't use it in sitting before a television set.

Jane: When I was confined to my bed I decided I would read the whole of Dickens' novels – just exactly what you've said.

Terry: [*laughs delightedly*]

Jane: I had to read them very slowly, I couldn't lift the book for very long, I couldn't focus for very long and by the time I got to the end I could read the book a second time because my brain was so badly affected I'd forgotten the plot!

Terry: The basic point being that in most cases of suffering, which should not be minimised – suffering is real and it's painful and it's not easy – there is another side to it.

You can take a positive side out of a negative. You've got to keep in your mind that every negative has a positive attached to it somewhere. Even the blackest negative has a positive. That is a law of life, it's a law of physics. It applies as much in the psychological field and the spiritual field as it does in the material and in the physical field.

And so therefore, if you are able, when you are overwhelmingly in the control of the negative – be that in illness or whatever it be – remember you can find attached to it somewhere, the positive. What you have to do is gently explore that, so that you can begin to make that real.

Then you find that you lead yourself towards a greater state of balance between positive and negative which is the reality of everyday life. Life is always seeking balance between positive and negative – between light and dark.

Jane: This is certainly a journey I've gone through. You find a deeper meaning. One problem is that society is so obsessed with the 'moral value' of having energy. You hear phrases like 'Oh, she's wonderfully energetic'

Terry Waite continued...

as if it were some kind of virtue. But society has a very negative attitude to weakness and disability so people with ME have to find a new self-respect.

Terry: Yes. I think probably one of the reasons that society has a negative attitude to weakness and disability is that they are too painful. The individuals who view it are faced with the possibility of their own weakness and their own inadequacy. Therefore these things tend to be pushed away.

One of my daughters is in India at the moment. She specialises in working with brain-damaged children and I know exactly what she says on that subject.

Jane: Brain scans also show malfunctions in people with ME.

Terry: Really?

Jane: Yes. One doctor I've worked with says we should be treating the children as brain-injured and allowing the brain time and energy to recuperate without trying to push and push and do too much.

Those who are compassionate and understanding human beings treat the children best. Because they listen to the child, they believe what the child says and treat them accordingly.

I wonder if sometimes there is a danger in too much 'professionalising' rather than relying on our normal response to other human beings. You set up a system that's supposed to help the child but in practice the system takes over and you forget this is a real person.

Terry: Well, that is a result of living in a society where we are so governed by rules and regulations and systems designed, so they say, to promote efficiency, which is again based on an economic model. But in fact we're in grave danger, in so doing, of losing sight of people. The whole of life is to do with living. It's not just to do with efficiency and so on. We have to be reasonably efficient – of course we do – to exist. But more than that, it's to do with living and being and somehow we're losing the sense of what it is to live fully.

Jane: Which bring me to the subject of friends. Some friends forget about children with ME if they're not at school. And some seem to be afraid to talk to them – they're afraid to talk to someone who's going through some kind of trauma. My feeling is you try and talk to the person the way they were before – they're still a real person.

Terry: Yes, I take that attitude with the blind, for example. I have quite a lot to do with blind

I imagine that children need to be surrounded by people who will not patronise them and not over-coddle them but at the same time enable them to maintain hope

people – as I do with all sorts of people. The thing is we can be so scared.

Sometimes we're scared of offending. We treat people as 'cases'. Sometimes we're trying to be considerate and gentle and kind but really we're patronising people, unconsciously. I don't think we ought to do that.

When I meet a blind person I often tell the joke: 'Why do Morris dancers wear bells on their uniform?' They say 'I don't know. Why do they?' I say, 'So they can annoy the blind as well'.

[hearty laughter]

Terry: There's nothing wrong in making a joke.

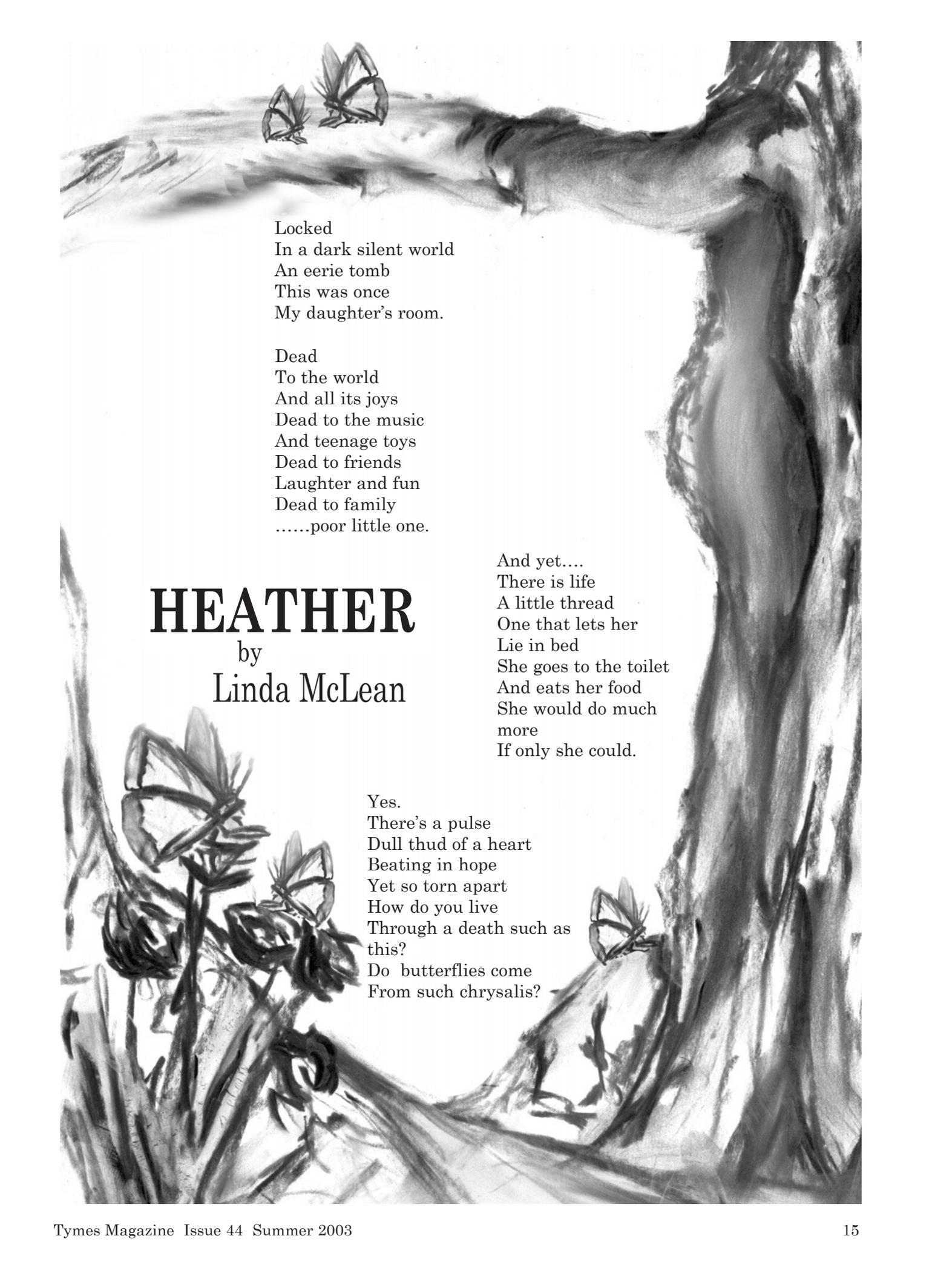
Jane: No. It's like the blind piano tuner who used to come up to me with his dog and say, 'Hi, how lovely to see you.'

Terry: Exactly.

Jane: People with ME do laugh about their symptoms and I think it's very healthy that they do.

Terry: Yes. I think it's important. You shouldn't be cruel to people but it helps if you can have a reasonable sense of humour, even with the greatest illness.

People are surprised because I can laugh about some of my experiences of captivity, but of course I can – because I've got through it. I've lived through it and not been over-damaged by it.



Locked
In a dark silent world
An eerie tomb
This was once
My daughter's room.

Dead
To the world
And all its joys
Dead to the music
And teenage toys
Dead to friends
Laughter and fun
Dead to family
.....poor little one.

HEATHER

by
Linda McLean

And yet...
There is life
A little thread
One that lets her
Lie in bed
She goes to the toilet
And eats her food
She would do much
more
If only she could.

Yes.
There's a pulse
Dull thud of a heart
Beating in hope
Yet so torn apart
How do you live
Through a death such as
this?
Do butterflies come
From such chrysalis?

EXPLORING : THE WAR ON FEAR

In early 2003, Tymes Trust began compiling its children's dossier *The Forgotten Children*. From statistics we had uncovered over a two year period it was soon apparent that this is, sadly, a dossier of shame, and thus it acquired its sobering subtitle.

the war on fear

this dossier has been compiled to raise awareness of the plight of children with ME

We constantly work with doctors, teachers and other professionals whose work is exemplary and whose attitude of compassion and dedication we applaud. Unfortunately, they still appear to be in the minority.

Tymes Trust has evidence that the very systems set up by the government to help sick children and young people are being interpreted in ways that either ignore children with ME or threaten, bully and intimidate them.

We take no pleasure in launching our War on Fear but it must be done. The Trust pledges itself to support children and young people with ME in their struggles for recognition, appropriate medical care and suitable education.

We are pleased to announce that the government is behind us and continues to support us.

**Letter to Lord Clement-Jones CBE
Patron of Tymes Trust
Liberal Democrat Spokesman on Health
in the House of Lords**

I share your concern that local authorities and schools should understand the particular needs of children and young people with ME.

I believe that the Tymes Trustcard is a very useful tool in helping to improve understanding of the needs of children and young people with ME and ensuring that they are able to continue to access education in a way that takes full account of their medical condition. I am therefore pleased to endorse the use of the Tymes Trustcard.

**Baroness Ashton of Upholland
Parliamentary Under-Secretary of State
for Early Years and School Standards**

The Tymes Trustcard is designed to be carried by pupils at school so that they can discreetly ask for help when they need it. It is endorsed by the Secondary Heads Association and signed by the school's headteacher. [Dossier, page 4]

risks of telling it like it is

The Trust's dilemma is that by publicly telling the truth about what is happening, we risk alienating the many doctors, teachers, social workers and others who are already doing a wonderful job.

However, without the truth, nothing will change. These dedicated professionals will continue to be obstructed and criticised by less enlightened colleagues.

We do not want children and young people with ME and their families to think that every doctor they turn to for help will fail them.

Therefore before highlighting the negative statistics we have uncovered, we much emphasise the fact that we have regular contact with doctors who consult, support and endorse the work of Tymes Trust and are extremely supportive of their patients. [Dossier, page 6]

I can't express my delight enough in your taking up the cause of the severely affected child. No other ME charity is doing this to anything like the same extent.

*Kathy Goodchild
mother of Frances, 12*



a balanced report

Shirley Conran wrote in to say she was 'very impressed' and Dr Alope Agrawal, Consultant Paediatrician, commented: 'I am very happy with it. It is a very balanced piece of work.'

Other comments were:

I hope the PM was as impressed as I was!

Dr Nigel Hunt

I checked out the Dossier on the website and it is super. Congratulations to you all. Seems like it's really moving things on, which is fantastic. With love *Sazza Holmes*

CAN GPs REFUSE TO REGISTER ONE ANOTHER'S PATIENTS?

Some families have been refused permission to change GPs.

Lord Clement-Jones asked Her Majesty's Government: What is the legal or contractual basis for National Health Service General Practitioners with the consent of their Primary Care Trust entering into a reciprocal arrangement whereby they will not take on any patient from within their area who wishes to change General Practitioners; and [HL2225] How many reciprocal arrangements exist within Primary Care Trusts in England under which General Practitioners, with the consent of their Primary Care Trust, agree not to take on any patient from within their area who wishes to change General Practitioners. [HL2257]

Baroness Andrews: There is no basis in the National Health Service (Choice of Practitioner) Regulations 1998, the National Health Service (General Medical Services) Regulations 1992 or the equivalent provisions which apply to General Practitioners (GP) working within personal medical services for a GP to enter a reciprocal agreement with another GP to refuse to accept one another's patients or for a Primary Care Trust to consent to such an arrangement. Accordingly, the Department of Health does not hold or collect data on any such arrangements.

Lord Clement-Jones therefore advises that this practice is 'unacceptable'.

2002/2003 : the statistics

we invited families to tell us their experiences and the figures shocked us

76% were not satisfied with their education provision

87% had had to struggle for recognition of their needs

81% had moved school to get recognition of their needs

84% had felt threatened or bullied by attitudes from professionals

72% did not give a vote of confidence to State Education for children with ME

Out of the 84% of our families who felt bullied or threatened by professionals, 88% specified doctors as being even more responsible than teachers.

who to send the dossier to?

We need a professional climate of justice and compassion. Please consider sending a bound copy of the Dossier to your own MP at the House of Commons. (If you are a child, please ask your parents' permission.)

Lord Clement-Jones recommends handing over the Dossier in person. You can go to the MP's surgery in your own constituency.

You could also send copies to your local paper, local councillors, Ofsted inspectors of schools, indeed any opinion former or public figure whose support you would like to obtain. Let us know of any response you receive.

We all need to pull together.

Those who are able can help stand up for others not strong enough to speak for themselves. We know this is right. Please lend your support if you can.

Bound copies of The Forgotten Children are available at £5.50 plus 50p post and packing.



Doctors of Philosophy

‘Doctor, was it Bad Luck to get ME?’

Tymes Trust Medical Adviser Dr Darrel Ho-Yen discusses bad luck, good luck and apple pie.

The title of this article is a question that many patients ask me. I remember being astonished when I was first asked this question, but now I am used to it. There is sometimes a need to decide if a happening was good luck or bad luck, and illness is a prime example. However, it took me many years to work out where luck figured in a patient’s ME.

I enjoy the occasion of eating out, but there was a time when I could not afford expensive restaurants. Whatever the restaurant, I still felt that I should have at least three courses. Starters were never a problem as there were many occasions where I could happily have three starters. The real problem was always the sweet course. I am picky.

Many patients look at me with incredulity when I refuse to believe that their illness is bad luck

It took me many years to realise that a safe and dependable sweet course was apple pie. No matter how poor the restaurant food was, the apple pie was always reasonably enjoyable. I can honestly say that I have never had a bad apple pie.

Recent research on luck has been fascinating. It appears that people who feel ‘lucky’ have some important attitudes to life. Lucky people make very many positive decisions, their decisions are in tune with their nature, and they feel that they are lucky. These three characteristics are often present in many ME patients before their illness. Very many ME patients tell me that

they always believed that they were lucky before their illness. Their illness was a turning point. After they developed ME they became unlucky.

Many patients look at me with incredulity when I refuse to believe that their illness is bad luck. To them, their personal history is clear. Before their illness, there was a long catalogue of accomplishments, well-being and love. After their illness, there was bleakness, failure, isolation and loneliness. The contrast was plain. It was obvious that ME can only be bad luck.

The last observation in the research on lucky people concerned what they did when they faced an adverse event. This is probably the most important factor in the research. It found that individuals who were lucky were able to turn adverse events into a positive outcome. In other words, they were able to turn bad luck into good luck. It is this capacity that separates lucky people from unlucky people. Where

does this leave ME patients?

For many years, I have answered patients’ questions on whether ME was bad luck in a simple way. I said that ME was like having



some cooking apples. With these apples, you could do whatever you wanted. You could watch the apples slowly rot as you wait for something to happen. You could eat the apples and enjoy them even though they were cooking apples. Or, you could take the apples and turn them into something else. If you could take the apples and turn them into a wonderful apple pie, this would be really productive.

Therefore, my solution is simple: ME is neither good luck nor bad luck; ME is simply a pile of apples. It is what you make of ME that determines whether ME is bad luck or good luck. It is best to avoid looking at the apples as they slowly rot. It would be better to make a wonderful apple pie, but please remember to send me a piece.

What are you doing with your pile of apples? Let us know. You could find yourself in Tymes Magazine.

PRESCRIPTION

Take one portion of joy per day

Positive and negative experiences affect your immune system.

Stressful, sad and scary experiences have been shown to suppress immune function for 24 hours after the experience.

On the other hand, fun, enjoyable experiences boost the immune system's function for 3 days afterwards.

*Dr Aristo Wojdani,
Director of the Immunosciences
Laboratory in Los Angeles.*

Tony Pinching's Mayonnaise of Mixed Metaphors

Approach:

You may be a hare but this is definitely a tortoise race. To get to the end soonest, go slowly and steadily. Do a tortoise training course.

Baseline:

If you find you are in constant retreat, make a tactical withdrawal to a safe place and start your advance from there.

Balance:

Balance work with play, to ease the long journey. Also, plot a straight course between the Scylla of doing so little that you get out of condition and the Charybdis of overdoing it so that you get a setback.

No See-Saws:

If you are alternating better patches with bad patches, try holding back on the better days – easing forward with the brakes on, not making hay while the sun shines and then spoiling it with a cloudburst.

Make Mayonnaise!

Take the baseline 'egg mixture' and add 'oil' of activity very slowly, one drop at a time, making sure that it is well mixed in before adding the next drop; later on you can add a teaspoon, tablespoon and, eventually, cupfuls. If you rush it, the mixture will curdle and you will have to start all over again.

Professor Tony Pinching

*(With apologies to
Aesop, Wellington,
Homer, Delia et al!)*



Energy-saving tip

When Darrel advised that a state of boredom was good for saving energy, Claire Wade wrote to say that boredom is not relaxing! Darrel laughed and agreed that to be bored can indeed be stressful, but said his underlying message was this: we should not feel we must always be doing (even making apple pies) rather than just quietly being.



by Sebastian the website spider (find him at www.actiononline.com)

Sebastian says:

Did you enter 'The Wrong Words' competition in Spring?

Here they are - The Wrong Words, I mean:

Grumpy talk, keep talking grumpy talk,
Talk about things you hate to do.
You've got to have a moan -
If you don't have a moan
How's the world to know you're feeling blue?

When Charlotte Stevenson (19) sent in *almost* the right words she won a prize because I *insisted*. She wrote: 'You are right in saying the real words aren't so miserable but I think your grumpy version is appropriate at times!'

Do you agree with her?

Make up an even grumpier poem than ours and I'll send you a prize myself.

When Charlotte was 15 she wrote a poem about 'the worst time of my life'. It ended:

*But I would not have come to be me
If I hadn't had ME*

We all understand what you mean, Charlotte.
And so does Terry Waite.



Have you nominated anyone yet for my

ORDER OF THE GOLDEN WEB

?

To qualify, they must have been *very* nice to you!

COLOUR ME IN



by Laura Shave

Web Letter

Our star website letter (I just decided to choose a star website letter – well, why not? It's my page and I can do what I like on it) wins a prize:

'Do tell Mark [BWKT – see Contents] that it is very easy for those of us who are rather hesitant regards web things to use and read.' Frances O

It is certainly designed to be easy to use so it's nice that Frances wrote and said it was (is). She deserves a prize. Doesn't she? Go to www.youngactiononline.com to see what she means. It really is easy – and it doesn't take a year to download.

DID YOU KNOW?

2.5 billion hours were wasted online last year as people waited for pages to download.

WRITE ME A POEM

I'm in a poetic mood this Summer. So here's another great poem by Sazza Holmes – who else? Adapted from Cliff Richard's Summer Holiday.

ME's going on a Summer Holiday
No more exhaustion for a week or two
Extinct are limitations for our own
Summer Holiday
We'll make our dreams come true,
come true
For me and you.

We're going where the sun shines
brightly
Yet our eyes can tolerate the fine view.
We can stay out late till sunset
Run and swim in the sea of blue.

ME's going on a Summer Holiday.....

SEB'S SUMMER COMP

Who's the sporting star hiding in this verse?

My first is in *Britain* but not in *Wales*
My second's in *bunnies* but not in *tails*
My third is in *biscuit* and also in *cake*
My fourth is in *tackle* and also in *take*.
My fifth is in *hide* but it isn't in *seek*
My sixth is in *pea* but it isn't in *leek*.
My last is in *Mum* but it isn't in *Dad*
I'm famous and rich - and my hair isn't bad!

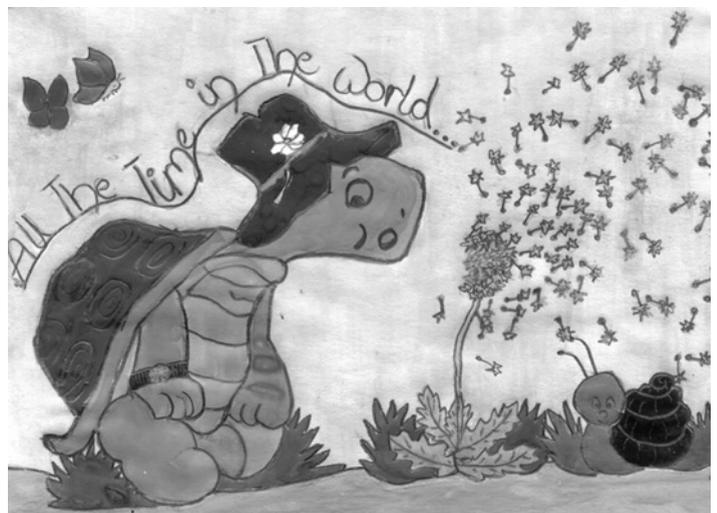
Here's a clue: The letters are hidden in the words in *italics*. The first letter is hidden in line 1, the second in line 2 and so on. Prizes waiting for the first ten correct answers. (If yours isn't in the first ten but we have enough prizes we'll stretch a point!)

Send them to: Seb's Summer Comp, Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE.

Please send any other letters or drawings to Seb's Manor, Tymes Trust and remember to include your name and age.



Seb says: This is Professor Pinching's tortoise blowing TT's dandelion clock!

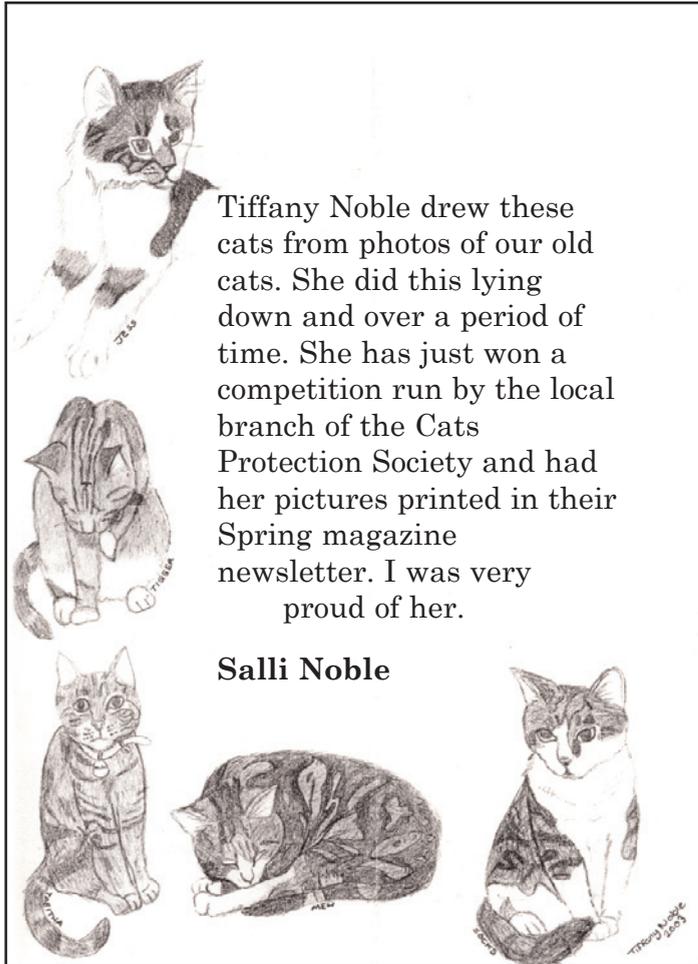


Portrait by Tamsyn Lewin when aged 14

Quotes-u-like

A journey of 1000 miles begins with a single step.

Chinese Proverb



Tiffany Noble drew these cats from photos of our old cats. She did this lying down and over a period of time. She has just won a competition run by the local branch of the Cats Protection Society and had her pictures printed in their Spring magazine newsletter. I was very proud of her.

Salli Noble

I love the rainbow paper that you sent. I think rainbows are beautiful and full of hope. The picture reminds me of Wordsworth's lines:
My heart leaps up when I behold a rainbow in the sky.

I really like the idea of a 'quotes corner'. I was interested to read Katie's choice and the others. Katie's reminded me of one of my favourites:
Life is marathon, not a sprint. E. Kennedy

Rosie Shorter

It is often said that if you have five doctors you will have between six and ten opinions!

Professor Tony Pinching

Saw your advert in *Tymes Magazine* about favourite quotes so thought I'd send you mine:

'Come to the edge,' he said.

'We can't, we're scared.'

'Come to the edge,' he said.

'We can't, we're scared.'

'Come to the edge,' he said.

They came.

He pushed them.

They flew.

Thank you for everything you do.
It keeps me going...

AP

X

What do you say in response to 'You look so well' ??

'I wish I felt inside how I look on the outside!' or 'I suppose I'm a bit like a shiny, waxed car - looks great but without any petrol inside it's not much use as a car!'

'It's not my face that's ill!'

Peter Allison,
Chair of Swindon ME Support Group

A Tymes Trust Partner Group

Lynne Wax,
Daliany's mother



PENFRIEND REQUEST

I'm 24 and would like a penfriend of a similar age (ie mid-20s). I'd be particularly interested in contact with anyone who has had ME several years. I enjoy reading (anything from Jane Austen to Harry Potter!) singing, watching films and writing letters (and receiving them, of course). I'm also a cat lover (my cat helps keep me going) and do a little bit of voluntary work for an ME charity.

Write to Rosie at Box No. 036

Tyme for Life

By Bryony Rees-White



You don't need to have a big garden to join the British Trust for Ornithology – Garden Bird Watch. Gareth is 14 and has had ME for over two years, still spending much of his time sleeping, but this is something he can be part of, any day at any time, just by looking out of the window. During March we wrote a report of what we do; I typed it while Gareth contributed from his bed:

I make up some food for the birds in the morning – usually some bread soaked in fat with biscuit or cake crumbs or cheese. At weekends, or when he doesn't have a lesson, Gareth puts the food on the bird table with some seed. We have peanuts hanging up and a seed feeder to try and attract as many different birds as possible. Then we sit down to our breakfast and watch to see which birds come to the table.

The Robin always comes first – in fact, he's often standing on the bird table before the food is put out, telling us to get a move on! We see Chaffinches, Blackbirds, Starlings and Bluetits to name but a few. Once a week Gareth writes down how many of each species we can see and during the week we add to the list if we see anything different. Sometimes we have a visiting Green Woodpecker looking for insects in the lawn or a little flock of Long Tailed Tits on the peanuts.

You could be part of this scheme too, and you don't even have to feed the birds if you can't manage it – just regularly make a note of any you can see from your window. In Spring, a House Sparrow survey began. Gareth and I are really pleased we joined – we think it's great to be part of something so useful, which also gives us so much pleasure.

To join, write to GBW, BTO, FREEPOST, IP24 2BR

My name is Kathryn Smith, I'm 21 and I've had ME for 2 and a half years. I've set up a website for young Christians with M.E.

From the site:

This website is here to encourage young Christians with ME and to let them know that they are not alone. Please contact me if you have anything you want to say or add to this site.

Kathryn Smith

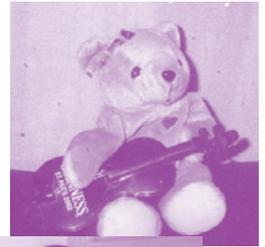
Find Kathryn's site at: www.godinm-e.co.uk.



THE ADVENTURES OF FUDGE NOW FAMOUS WORLDWIDE

A Tymes Trust Chair of Trustees Gift

Remember when our Chair of Trustees was busy with his yearly gift of bears? Many of you will remember that first he found some Benevolent Bears, the following year it was Bashful Bears and finally some Beanie Bears. These bears appeal to all ages and both sexes – quite right too. After all, this is 2003.



Sent: Saturday, April 26, 2003 8.04pm
Subject: Chair of Trustees desperate

Dear Cheryll

The Chair of Trustees has asked me to tell you that ever since your wonderful photos of the Beanie Bear we sent you turned up, it has been totally impossible for him to do any work. Seb keeps bouncing about, getting in the way, making important papers all sticky and insisting that the photos be put on his web page.



I have promised that I will ask permission from you. The Beanie Bear will obviously have to be consulted too, but you can explain that an invitation to be displayed on Seb's page is not made lightly and is really a Very Great Honour. Hopefully we can obtain the Bear's agreement. Do you want your name there too?

Jane

Portrait of Seb by Jamie Hewitt



Mark Colby in his capacity as webmaster has documented the exciting story of Fudge - with full technicolour photos in the proper order - on Seb's page at www.youngactiononline.com

Make this the day you visit!

Dear Jane

After finishing a game of hide and seek I found Fudge my beanie bear and explained what you have asked for. She got very excited and jumped up and down and said YES YES YES I would love to be on Seb's web page. So you have her permission and also mine. We can't wait to see it. Fudge says she feels very important.

Love Cheryll and Fudge