

T Y M E S

MAGAZINE

EXPLORING
ME and the Family
With Jill Curtis

STARS WITH ME
In Conversation with
Jane Colby

DOCTORS WITH ME
Dr Anne Macintyre
Dr Charles Shepherd



Published by Tymes Trust
In partnership with
www.youngactiononline.com

EASTENDERS STAR SENDS
SEASONAL MESSAGE

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Tymes Trust Data Protection Policy is available

Printing by Prontaprint, 11 Runwell Road
Runwell Wickford Essex SS11 7PS

WHAT YOU THINK

My son is largely better, it was a 2 year haul. I think what you do is really valuable and worthwhile. The young inevitably became isolated at a time in their lives when they should be out and about, growing up. Thank you for all your efforts. You are doing such great stuff.

Jenny Budden

MAKING FRIENDS WITH STARS



Freddie Kanoute, the famous Tottenham Hotspur player, meets our chair of Trustees, Keith Harley.

Have you made friends with a star? Write and tell us. If you can, send a photograph as well.

TYMES TRUST

Registered Charity Number 1080985

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Dear Reader

As this edition of Tymes Magazine goes to print, Tymes Trust begins a new era under its full name – The Young ME Sufferers Trust.

At the same time, our new website www.tymestrust.org goes online. Star of the site is Tymes Magazine itself. As each new magazine goes out to our subscribers, we will add the previous one to the site.

Starting with Issue 44, featuring an interview with Terry Waite, your teachers, doctors, friends and family worldwide can read previous issues as they appear on the printed page, and access articles from earlier magazines as we add them.

But there's far more. As soon as you feel well enough, go visit!

We are also delighted to feature below, a letter from the Rt Hon. Charles Kennedy MP, Leader of the Liberal Democrats – whom you'll also know from starring appearances on the TV news quiz *Have I Got News For You?* How fitting for our Winter magazine with its theme of *Seeing Stars!* From cover to cover you will find well-known personalities from within and outside the world of ME. And as always, we send you our love and wish you well.

Jane Colby
Executive Director

A MESSAGE FROM THE RT HON. CHARLES KENNEDY MP

I am delighted to be able to send my wishes to all at the Tymes Trust for the work that you do in helping children with ME and their families.

Without the charitable endeavours of your organisation many young people who suffer from this condition would not get the help and support that they need. May I take this opportunity to thank all those at the Trust for the caring work that you do and wish you well in your future endeavours.



Rt Hon Charles Kennedy MP

FUNDS RECEIVED FROM AMAZON

Our thanks to everyone who supports the Trust by buying their CDs, DVD, books etc by clicking through to Amazon from www.youngactiononline.com

We are an associate site and recently received a further cheque from them. It costs no extra to use this facility and there are no extra forms to complete, so please consider this method next time you buy online.

IN THE SPOTLIGHT: THE TYMES TRUST VIEW

The Government has allocated £8.5 million for services to people with ME nationwide. This will go mainly to Primary Care Trusts, who must obtain backing for their bids from their local ME Support Groups. It has come to our notice that many such proposals involve setting up clinics that will deliver services such as diagnostic facilities, alternative therapies and cognitive behaviour therapy, to those able to attend. We are concerned at the potential emphasis on CBT and/or graded exercise therapy, known in some cases to

exacerbate this illness or be ineffective.

The Young ME Sufferers Trust wishes to put on record that we would like to see finance available for specialist home facilities. This would encompass domiciliary visits from specialist nurses who would deliver care in the home in order to support and relieve the carer, on a periodic basis to be agreed according to need and resources. Diagnostic facilities should also be available in the home where necessary and respite care should be available to those in need.

stop press

DOCTOR magazine, read by all GPs, has featured Tymes Trust's latest publication, *The GPs Good Practice Guide to Education for Children with ME*.

The Guide was produced to help GPs protect children's health from over-demand and maximise their achievement through modification of their learning arrangements.

Price £4.50 plus 50p post and packing from Tymes Trust.

do naps really work?

Daily Mail, 21 October

As part of a wide-ranging report on sleep, the following information backs up the clinical experience of Tymes Trust Medical Adviser Dr Darrel Ho-Yen of Raigmore Hospital, Inverness.

'There is evidence to suggest that "normal" sleep does not consist of one block of seven or eight hours during the night. It is more likely that our biology is designed to allow us to sleep for about six hours during the night and an hour-and-a-half during the day – as in cultures where siestas are the norm.

'The modern demand for day-long alertness not only prevents daytime napping but also has an impact on night-time sleep. If someone prefers to have a daytime nap and sleep less during the night (assuming this fits in with their lifestyle), that's fine. It is the amount of sleep over 24 hours that is important, rather than the amount that takes place during the night.'

No longer should proponents of fashionable but rigid 'sleep hygiene' regimes with their implication that daytime napping is somehow 'unclean' tyrannise the lives of people with ME, who may need daytime sleep to supplement their often disturbed nightly rest.

supporting pupils with CFS/ME

SENCO update, October 2003

The Birmingham University School of Education approached our Executive Director to write for their journal for SENCOs. Every school has a Special Educational Needs Co-ordinator. Covering a typical pattern for the illness and also a typical school attendance pattern, the feature explains how to break out of the cycle of attendance punctuated by relapses. It guides SENCOs on liaison with other staff. Tips include: 'Monitor whether the pace of work is sustainable. If symptoms are abating, the body is healing. Increased demands from school can set back this progress.'

SENCO Update also ran a separate feature on the Tymes Trustcard, a pass card for use in schools endorsed by Education Minister Baroness Ashton and the Secondary Heads Association. The editor states: 'In this month's feature article, Jane Colby refers to the Tymes Trustcard. Here is some further information about this simple but potentially invaluable resource.'

If you are able to attend school, send for an application form for your Tymes Trustcard. Further Information is at www.youngactiononline.com

children with ME

Young Minds Magazine 66, 2003

In September, a feature letter by Jane Colby alerted readers to the new *GPs Good Practice Guide to Education for Children with ME*. Jane wrote: 'My GP colleague Dr Nigel Hunt first approached me when a young patient of his own developed severe ME. He soon became convinced that other GPs needed to know what he had learned about education. [...] Out of our collaboration came the new Guide, launched this autumn. We sincerely hope that it will move us a step further to increasing support for children with ME.'

viral particles cause muscle malfunction

Journal of Neurology, Neurosurgery, and Psychiatry, 1 October 2003

Dr RJM Lane and researchers at Imperial College, London have shown that some patients with chronic fatigue syndrome show evidence of virus in their muscles, linked to abnormal muscle function. The researchers found RNA from enteroviruses (the same family as polio) in muscle biopsy samples in 10 of the 48 chronic fatigue patients but 'all 29 human tissue controls [...] were negative for enterovirus sequences.' The RNA most closely resembled that from the Coxsackie B virus.

An exercise test was carried out on the same day as the biopsy. The patients' blood levels

of lactic acid were measured before and afterwards; 28 patients had an abnormal lactate response to exercise, 'reflecting impaired muscle energy metabolism.' In addition, 9 of the 10 subjects who tested positive for virus in their muscles had this abnormal response.

Tymes Trust has always argued that there are sub-groups of the so-called 'chronic fatigue syndrome' and those with ME-proper are the ones affected by these viruses. They have a polio-like illness and need to be cautious about exercise.



Dr Alan Franklin and Jane Colby in 1996

On 19 November, Tymes Trust was asked to convey to the ME community the sad news of the death of Dr Alan Franklin, surely one of the kindest, most compassionate paediatricians it has been our privilege to work with.

I first met Dr Franklin during the days of the National ME Task Force, on which we worked together. He later became one of Tymes Trust's medical advisers and gave many lectures at our teacher training days.

During the late 1990s I accompanied him to the Isle of Lewis for a week-long programme of talks and visits to the local ME community. On the flight to Scotland he talked of his personal beliefs in Christianity, in justice and fairness for the children he cared for, and reminisced about why he first became a paediatrician.

For three years we worked together on the Chief

in memoriam dr Alan Franklin

Medical Officer's Working Group on CFS/ME, pressing for suitable medical and educational provision for children and young people.

There was also a very humorous, jovial side to Alan. During the many events that we attended or organised together, there were often incidents that revealed his sense of humour or his stoicism. One of these was at the Churchill Intercontinental Hotel in Portman Square, where Alan's lecture was unexpectedly interrupted by a pneumatic drill. It took three interventions by the Chair of Trustees to silence the drill, but nothing silenced Alan, who was determined to carry on, and was quite unperturbed.

Despite the later years of his life being affected by illness, he displayed the same courage and dedication, continuing to support the Trust's work for as long as possible, and recently surprising us by attending and taking part in our local GPs training evening.

Alan is irreplaceable because he was unique. But the work goes on, as he would have wished.

Jane Colby

Seeing my mum
when I wake up

My family

The warmth of
my friends

Dreams
and goals

Writing,
singing, acting,
dancing when
I can

Seeing other
people happy
and having fun

Seeing stars in the sky – I
can only open my blackout
blind is when it's dark

Birthdays

Warm sunny weather

Walking to the end
of my road and back in
the dark. (I'm Dracula!)

What makes
you smile ?

Thoughts
contributed from: Helen
Brierley, Sazza Holmes, David
Hales, Jade Scarrott, Sarah
Wilcox, Jade Smith, Emma Gray.

Knowing it's not long till I can
give my Christmas presents

Christmas time

Receiving mail

My physio who
tells jokes that are
not very good!

My guinea pig
greeting me

Feeling well

Opening letters from my
penfriends and writing
back when I can

Music

Laughing
with
friends

Funny jokes

Keanu Reeves!

Comedy programmes

A good movie

Watching my kitten
and dog rolling
around on the floor

Roller blading - for a few minutes!

Learning
something new

The day when the sun enters my
room again

Tymes Trust Team



NAME: David Teece

POSITION: Head of Service Education for Children Out of School, Warwickshire County Council; Director Nisai-Iris Partnership

POSITION AT TYMES TRUST: E-learning Adviser for our Professionals Referral Service

LIVES: Leicestershire

AGE: Very significant birthday next year-that's all I am prepared to say!

FAVOURITE COLOUR: Blue

BACKGROUND: Grew up in Cheshire, youngest of four brothers. Trained as a teacher at Warwick University and worked in Coventry and Warwickshire Schools until 1994. Since then employed by Warwickshire Support Services. Founded Nisai-Iris Partnership, a consortium of UK LEAs interested in developing e-learning approaches in 2003.

HOBBIES AND INTERESTS: Not much time at the moment, but if I had it would probably involve Art (painting with pastels) or Music (listening to). My real love is walking in dramatic mountainous areas, which I try to do whenever I have time (living in the midlands makes this rather difficult!)

PERSONAL MESSAGE: The time is right for new methods of education to hit the fore. Our work in developing flexible e-learning approaches is beginning to gain wider recognition. We have just registered the 100th Warwickshire pupil onto the IRIS on-line system and we are seriously examining how we can make this service available to young people everywhere. Now we need some support from the government to make this a national scheme.

Interested Parents should contact the Tymes Trust Advice Line: 01245 401 080

NEWS FROM TYMES TRUST PARTNER GROUPS

Sheffield ME Group held their Annual Conference on Saturday 18 October at the Platinum Suite, Sheffield United Football Ground.

Chair Ute Elliott, who accompanied Jane Colby to Bonn for the Tymes Trust lecture there, gave the opening address. Tymes Trust Medical Adviser Dr Charles Shepherd presented the lecture on ME/CFS: What's New in Research, Diagnosis and Management?

Speedway Ace Gary Frankum, whose career was cut short by ME, talked of his experiences and sent a message to all Tymes Trust members (pg 12-13).

In the audience was Jacob Essex, one of three

young people with ME to receive a Tymes Trust computer sponsored by Ronald McDonald Childrens Charities and presented by Lord Clement-Jones CBE at the House of Lords last year.



Insight: Top Tips

Top Diet Tip

Don't forget the humble prune!

In a lecture on 'The Intelligent Fruit', chemical engineer and professor of physical science Dr Jean Marie Bourre explains that prunes not only provide glucides for energy, they assist the functioning of the gall bladder and intestines and also contain minerals including magnesium and boron, which helps maintain healthy bones.

Vitamins in prunes include both A and E; these help memory and protect against cerebral aging.

Benedictine monks discovered prunes by mistake; they left some plums in the sun. For months afterwards, these dried plums were edible. The word 'prunus' is simply the Latin for 'plum tree'.

Delicious in ready-to-eat packs, they can be eaten hot or cold. Great on their own as an energy-giving snack, or with muesli, ice cream,

fruit salad, yogurt or milk pudding. Refrigerate after opening.

Prunes are particularly helpful to avoid constipation due to a lack of physical activity.

Have frequent drinks to add to this effect.

Top Energy Tip

Quality rather than quantity.

'You have to know when to stop, to be able to keep going.'

Melanie Carter, 19

Do you have some Top Tips to share?

Send them to:
Insight, PO Box 4347,
Stock, Ingatestone,
CM4 9TE.



Tendring ME Support Group has featured *The Forgotten Children*, which was presented to Downing Street on 12 May 2003, in their regular newsletter.

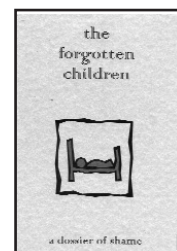
'Tymes Trust, whose Partner Group we are, has published a dossier of shame called *The Forgotten Children*. This gives examples of how children and their families are being treated by professionals, because of their illness. It is going to be a most useful document for those of you who have children with ME and who are having difficulties with doctors, teachers, social workers, local authorities and home tuition providers. Also it is a useful document to send to your MP. It is available in a well-presented form for £5.50 plus 50p postage. Don't forget Tymes Trust have a team of professional advisers ready to answer your questions. I think Tymes

The Forgotten Children

Trust nicely complements our Group, because they are working really hard to help young people come to terms with and live with this illness now.'

Note: *Alongside the shameful statistics we uncovered on the treatment of children with ME, The Forgotten Children also highlights the excellent work of good doctors and teachers and makes positive recommendations from our Focus Group. It also contains a message of support from the Prime Minister.*

Tymes Trust Patron Lord Clement-Jones CBE recommends that a bound copy be given personally to members' MPs at their local surgery, or otherwise sent by post via the House of Commons.



The Sky's the Limit

Everyone – children, families, professionals and charities alike can achieve change for the better and we believe in aiming high for the common good. In this new series we'll give you examples.



Doncaster Royal Infirmary : ME Update

Organised by Doncaster ME Support Group and presented by Jane Colby

Speaking to an audience of hospital doctors in the Postgraduate Medical Centre, Jane explained why graded exercise therapy and cognitive behaviour therapy can only have limited application in ME despite the publicity surrounding them.

She said: 'ME is often referred to as Chronic Fatigue Syndrome, a name originally coined for research purposes rather than clinical use. The

Department of Health uses the term CFS/ME. In practice, Chronic Fatigue Syndrome is a heterogeneous condition within which subgroups may respond differently to therapies.'

In this update, Jane discussed differences between the polio-like 'ME' and 'CFS'. She covered therapeutic implications and gave examples of new research demonstrating physical abnormalities in people with ME. She also reviewed the work and final report of the Chief Medical Officer's Working Group (Department of Health 2002) and some essential issues of case management including:

- Severity of the illness including stages of progression
- Support mechanisms to prevent deterioration
- Suitability of popular therapies such as Graded Exercise and Cognitive Behaviour Therapy for different cases
- Childhood ME and related issues including education

Doctors were given a summary of Jane's professional credentials as presenter, which you can find at www.youngactiononline.com

'Thank you for a most interesting presentation on ME. I think this should be an annual event.' Dr Dinesh Chadha, Head of Postgraduate Studies, Doncaster Royal Infirmary.

NEW YORK, NEW YORK...

As part of her degree in Graphic Design, *Tymes Magazine* Designer Kerry-Ann Edge flew to New York and interviewed the Managing Director of YBServices and the Interactive Designer from KajaCircle.

'Though both interviews were only supposed to be an hour I landed up spending three hours at each company. The Interactive Designer was working on a film of a rock star. He explained how they were putting it together, showed me how to use special effects not just on the titles or words but also on the rock star. (I don't think the rock star would have liked the caricature version I created!)

As a teenager, Kerry-Ann was one of the first young people with ME to be diagnosed in South Africa. Her work with the Trust led her to embark upon her degree. Kerry-Ann's story was published in *Tymes Magazine* Issue 43 (Spring 2003). *No charity funds were used on this trip*



Behind the Scenes



BEEFEATER BEARS!

Ready and waiting...

Behind the scenes, our Chair of Trustees has been scouring the British Isles for bears. Not so many bears live in the UK these days, but every year he manages to find some.

First he found some Benevolent Bears.
Then he found some Bashful Bears.
Then he found some Beanie Bears (like Fudge and Caramel).
And THIS year
He's found some Beefeater Bears.



'Mind you,' he explains, 'the children will have to come up with something important for the bears to guard. After all, their real title is "Yeoman Warders". They have had to be especially released from their duties at the Tower of London. They're going to need something else to guard.'



So, if your room keeps mysteriously getting into a mess and you don't know which of your toys is doing it behind your back, or if you have another Very Important Task that a Beefeater Bear could perform, write and let us know.

Be sure to explain exactly what your Bear would be doing, and why. Letters from parents, teachers, doctors or Other Important People are accepted too.

The Chair of Trustees says he will have the final word on the Bears' new homes.

ABOUT TYMES TRUST

Would you like to tell other people what Tymes Trust does? If so, send for our pack 'ABOUT TYMES TRUST'. It's very helpful if you are raising funds for us, so people know what we are here for.

HOW TO RAISE FUNDS AND HAVE FUN - TYMES TRUST TEAS

Tymes Trust is famous for its Teas. Maybe you remember our Afternoon Tea at the House of Lords to present three computers to our members? Westlands Nursery in Essex provides delicious Tymes Trust Teas during Summer, as well as an Open Garden to rest in and walk through.

You could hold a Tymes Trust Tea too!

Foody themes are best. You could have a Mince Pie Party, where everyone gets a mince pie and a drink and puts a donation for Tymes Trust in a festively decorated pot or box. At other times of year you can have a Danish Pastry Party or an Iced Cake Party or a Bakewell Tart party.....if you remember, we've always had a weakness for Bakewell Tarts...

Contents of the pack include the Prime Minister's endorsement, 3-fold leaflets, examples of the Trust's work and a master party invitation. Send for yours now.

ABOUT TYMES TRUST packs are free of charge

STARS WITH ME

In conversation with Jane Colby

Shirley Conran is the best-selling novelist whose first book *Superwoman* took the UK by storm. As Woman's Editor at the *Daily Mail*, she developed and launched *Femail* before being struck with ME as the result of a severe viral infection.

Last year, Shirley offered us her very first interview about her illness, since when many national newspapers have featured her story. Here she gives a message of hope for young readers.

Shirley: I think it's important for me to say that I was a success before I was ill, I had to change jobs and I've been successful again.

Jane: So that's very encouraging for young people with ME who might be anxious for their future.

Shirley: Yes. You see, I couldn't rely on my doctors – I had to trust myself, and that's what led to *Superwoman* and my second career. I wrote notes on doing housework with minimal effort. So, although I didn't mention ME in *Superwoman*, that was how it came to be written and that started me on a new career as an author.



With love to you all
Shirley Conran

Jane: What message would you like to send young people with ME at this time of year?

Shirley: Christmas is danger time for us. Anticipation and excitement are exhausting. It is up to you – and nobody else – not to overspend your energy over Christmas.

I know how hard it is – I'm seventy-one years old, but I *still* get impatient and reckless. (Maybe it won't happen...just this once, please God...but it always does!) So my Christmas wish is that you all look after yourselves with special care over the holiday period – and so have a happy Christmas.

AN INVITATION FROM SHIRLEY CONRAN

I'm writing this in bed. I look at the sky. I look at the frost. I treasure my electric blanket. I stroke my cat. I enjoy my breakfast egg. I read *Tymes Magazine*.

We all have so many things to be grateful for, and I enjoy the little things best. What little things do you enjoy most? Please let me know.

Write to Shirley at Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE.

Gary Frankum was a speedway ace until his career was cut short by ME. Gary has been in touch with Jane for some years. Recently he started giving talks about his experiences, most recently for the Sheffield ME Group, a Tymes Trust Partner Group.



Jane: Gary, how are things going for you at present?

Gary: I was shattered after my speech at Sheffield's ME conference, which was fantastic with so many people attending. My talk went down superbly, which is nice. I have been asked by so many people to do talks but will limit them as I don't have the energy to travel.

Jane: As you know, Tymes Trust stands for 'The Young ME Sufferers Trust' and we're now using our full title, because it helps to explain what we're about. How do you feel about children having ME?

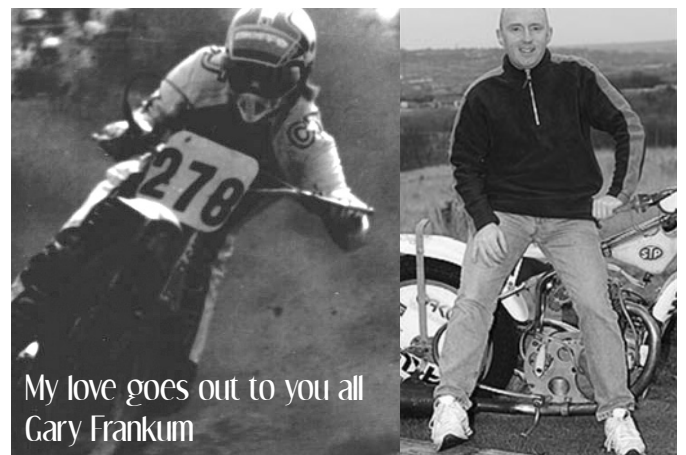
Gary: It upsets me when I think of kids with ME. Life is not fair at times.

Jane: What's your message for young people with ME?

Gary: My young little stars, I know how it feels with ME and you are not alone even

though at times it feels that way. I send you all the best wishes in the world – to feel a little bit better each day.

I promise all of you I am using what little fame I had as a speedway star to bring greater awareness of this awful illness and get the help and understanding we so rightly deserve.



Message from Eastenders Star



The amazing Barbara Windsor, star of *Eastenders* and already famous from the Carry On films, has had an illness similar to ME in its effects, so she understands how things are for you all.

We have just received this beautiful photograph with a loving message. Barbara's husband has asked us to send copies of *Tymes Magazine*.

Barbara writes: **'My love and thoughts are with you all at Christmas Time.'**

Barbara was in a number of Carry On films eg *Carry On Camping*. Her other film credits include *Chitty Chitty Bang Bang* and *A Study In Terror*.

On TV, she played Saucy Nancy in *Worzel Gummidge*, and made guest appearances in *Dad's Army* and *One Foot In The Grave*. In 1994 Barbara started playing Peggy in *Eastenders*.

POSITIVE RESPONSE

For GCSE English, Elizabeth Colley explained ME to her school. Here is what she said, edited for space.

You all know about ME

I'm the one who is always off school, gets every virus that's going, misses most parties – even my own – doesn't go on school trips or to the cinema. It wasn't always like this. Until just before my tenth birthday, I had friends round all the while, danced, did gym and one year didn't have a day off school.

What other people think about ME

There is a theory that ME is closely linked to the viruses that cause polio. Many doctors have their own ways of treating it. One of our GPs told me cognitive behaviour therapy could be a way forward. I am not going to take this route. I've tried graded exercise, where you gradually increase what you are doing – but too much of this didn't help. Others try to tell you to snap out of it. A lot of the time you feel as though you are the guinea pig for someone else's latest bright idea. You might think that being off school isn't that bad, but when you've had over 90 days off in a year it becomes really boring.

What I now know about ME

My consultant says there is no cure so I must manage my illness. I have had to take on ownership of my ME. During summer I managed to go on an activity holiday and had some good times with friends and cousins. My goal this term is to go to the Somme and on the German Exchange.

How ME feels

My ME started in year 5 with 'flu'. I kept falling asleep and my body clock went haywire. Even after lots of sleep I was tired. I still get exhausted, lots of nasty headaches, stomach pains, dizziness,

aching limbs, and brain fog – a dense fog, like cotton wool, which sometimes fills up my head. It completely takes over and it seems as though I'm listening to a foreign language. It stops me from remembering anything. I have learnt that what happened last term was a relapse. I couldn't read, write or even stand up some of the time. Doing the most basic things was a real struggle. Sometimes my body closes off, I go pale, my eyes go odd and my brain stops working. My body doesn't have energy to function properly so it shuts down everything that's not vital. When it feels a bit better things start up again.

On a good day I'm like everyone else – the only drawback being that if I really go for it I'll be ill – usually one or two days later. I have lots of moderate days when doing ordinary things is hard. Then there are bad days when I can't wake up, have great difficulty getting out of bed and often fall asleep while trying to get up. Sometimes my legs collapse and I don't have energy to talk, or function as a normal person. This all sounds grim, but I'm fortunate; many young people with ME are much more poorly than me and some are even tube fed. Did you know 51% of all children off school long term have ME?

I've found some really good information from ME charities. I've discovered that people with ME and those who really understand it have a totally different outlook on the illness to most other healthcare specialists. From now on I'm listening to them! Charles Darwin, like me, had ME, as did Florence Nightingale – so I'm in good company.

Elizabeth gained a perfect 40 marks. Her mother says she was 'thrilled by this and by the very positive response she received from her classmates'.

CHRISTMASTIDE

Christmas is near,
Eyes filled with Tears
Can't tell people my fears
Wishing it be over,
Perhaps I can cope
Better next Year.

The thoughts of opening the Gifts
Which take Energy just to lift.
Time drags watching films.
Mealtime affects you more,
Family keep asking if you want more.

Christmas Tree lights shine Bright.
Decorations sparkle in the light.
I remember Houses decorated with lights.
Going to friends Boxing Night.
I try to remember things in the past
Patches of memory that don't last.

Jade Smith

Jane explains: 'If you're wondering what King Canute has to do with it, he stubbornly tried to hold the tides back but couldn't. Christmas can also seem stubborn, insisting on us being happy all the time. Don't feel guilty if a tide of sadness sometimes mixes with the Christmastide of joy. Send us a Christmas email!'
**First published in ME – The New Plague.*

Over the hilltops
came Christmas
shining in baubles
of song
pricking the bubbles of
sadness
all night long.

Synthesised
by an ad-man
furry and cuddly
and cute
over the hilltops
came Christmas
like King Canute.*

Jane Colby

Christmas tree all sparkly and bright
Windows warm with candle-light
Decorating every space
With holly, mistletoe, ribbons and lace
Presents lying round the tree
What's in them we'll have to wait and see
In every house that festive feeling
Of giving, sharing and receiving
Crackers, glasses, forks and knives
Waiting while the food arrives
Turkey, stuffing, mmm so good
Mince pies, cream and Christmas pud
Delicious smells everywhere
Christmas dinner made with care
Stockings hanging on the door
Full of prezzies and much more
With presents, laughter, food and wine
Oh Christmas is the BESTEST time

Rachael Marshall

Exploring: ME and the Family

Jill Curtis is a psychotherapist and author of *Does Your Child Have a Hidden Disability?* Writing her chapter on ME brought her into contact with many families. Here she looks at managing family festivities with sensitivity.

There is nothing like a celebration to bring to the surface recognition of how ME affects the whole family. It widens the divide between those who recognise that anyone suffering with ME has an exceptionally hard time, and those who believe that anyone can 'rise to the occasion' and that 'a bit more excitement will cheer you up'.

We all like to hold onto the idea that occasions like weddings, birthdays, holidays and especially Christmas have a touch of magic about them. So, all too often, we go into a family celebration hoping against hope that all will be well. This prompts both carers and sufferers on these special days to be less vigilant than normal.

I spoke with Jenny, mother of 10-year-old Rebecca. She told me that her greatest anxiety centred around her parents, who are visiting over the holidays. They just do not believe, or let themselves accept, that their beloved granddaughter has ME.

Jenny says her parents are convinced that it is all a fuss about nothing, and that a more robust approach is all that is necessary. Rebecca tries to live up to her grandparents' expectations and take part in all the jollity, and it is Jenny and Rebecca who have to pick up the pieces in the following weeks.

This is what happens at holiday times when, from a desire to leave behind all day-to-day

burdens and – for once – to let go, a carefully worked out programme is put on ice.

One child with ME whom I know is very aware of the weight it places on her parents and siblings. Ruth told me that what distresses her most is when her family think up a treat for her, since she feels as if it is a demand which must be met. This increases her anxiety in advance that she won't be able to enjoy the festivities. Anxiety and stress can make an already sensitive situation worse.

Her deepest fears were mobilized when her younger sister said 'Please try not to mess up Christmas this year'.

Ruth keeps her tears to herself, but others need to remember that what may seem to be a treat, may be just the opposite. Honesty must be the name of the game here. All the family must have confidence to talk to one another and say: 'I don't feel up to this', or, 'Be sure to tell me when you have had enough' without feeling they are hurting the ones they love.

Parents may have to be vigilant about which invitations are accepted, and be prepared to support anyone struggling with ME to do what they feel is best. Saying 'no' may be done with a heavy heart and be the last thing a parent feels like saying, but keep in mind that any festival is yet one day out of 365.

what friends think

The fact that ME is an 'invisible' disability can cause distress and confusion. Ruth told me that her school friends used to come and visit her, but after a while they became impatient that there seemed to be no end to her malaise, and the social visits tapered off.

She discovered that they had turned their attention to another friend who was confined to bed with a broken leg! There was fun in drawing on the plastered leg, the busyness of the hospital ward, and discussing the excitement of how the accident happened. They enjoyed planning expeditions when their friend would be fully mobile again.

Comment: 'I didn't know how to explain to my school friends what was wrong with me. "Tired? We are all tired!" they laughed.'

carers and their role

It is not only mum and dad who support a child with ME. In the families I have had contact with it is often the extended family who are involved and affected. The last thing a family needs is disagreement amongst themselves about the way forward. And yet this can happen in even the most loving families.

Sometimes when one thing doesn't seem to be working, another way may be tried. There may be some initial improvement, but when there is a relapse the disappointment can be all the more devastating. Caring friends and relatives may discover all kinds of recommended treatment and be full of enthusiasm about a 'new' diet or exercise plan. Nothing makes some carers' hearts sink more than: 'Why don't you try...' or 'Have you thought of...?'. As one mother told me: 'It makes me feel I have been neglectful and not been trying hard enough to help my son.'

Ellen told me that she was asked to be a bridesmaid. She thought longingly about the excitement of that, but was crushed when the bride-to-be said it was on one condition, that on the wedding day she behaved and performed the duties of a bridesmaid without a fuss. How could she guarantee that on the day she would feel rested and well? This is where a carer needs to step in quickly and protect a child from this kind of ultimatum.

cautionary words from children

'I dread the idea of Christmas. I can sense the excitement growing and even the very enthusiasm in the air make me feel worse.' These words come from a 12-year-old who could recall feeling very low at the same time each year.

With the wisdom of a child, she sensed it arose from sadness about having ME, and remembering long years before she was diagnosed. 'That was the worst time. People got very fed-up with me. When I had a good day all I would hear was, "See, you can do it". What I heard was an implied "when you try". So when I felt really poorly I believed I had let everybody down.'

Other children report being upset by comments such as: 'Look what you are doing to your family', 'I think you are just spoilt' and on one Christmas morning being told, 'You are just sulking because you didn't get a Walkman.' No wonder that children with ME are full of anticipation about what a celebration in the family might entail!

how to deal with ME and the family at this special holiday time

Plan in advance, but be prepared to make changes if necessary. James told me that he was more than willing to let his son go to a party if he felt up to it, provided that next day would mean rest and there would be no recriminations from others. 'He is only young once so let him enjoy himself when he can.'

James has met parents who are worried about letting their child party at all, because of the downside of overexertion. 'If your child is a bit low in spirits over the festivities, recognise this for what it is – the pain of having to take notice of their symptoms.'

There's no magic in having ME, and no magic Christmas cure, but with loving understanding on all sides there is no reason why a family cannot genuinely enjoy being together as much as it is possible.

All names have been changed to protect confidentiality.

Find Jill at www.familyonwards.com

Does Your Child Have a Hidden Disability was reviewed in Tymes Magazine Issue 42

HELP YOURSELF
DOES YOUR
CHILD HAVE A
HIDDEN
DISABILITY?

JILL CURTIS



DOCTORS WITH ME

Dr Anne Macintyre

Dr Anne Macintyre, former member of the National ME Task Force and the Chief Medical Officer's Working Group on CFS/ME has had ME for many years. Here she discusses her Christmas...

I try not to think about it until mid December. This saves energy and anxiety! I look at last year's cards and realise with shock how many people I meant to contact after last Christmas to say 'sorry I forgot/thanks for your news/this is now my address' etc...

I fish out unused cards from last year and find most of them have no envelopes that fit. I buy great sheets of stamps that *then* get crumpled or self stuck in my handbag. I start with cards to people I never see, especially distant friends and relatives (to whom a card means a lot) but then remember to buy the special overseas airmail letters, which got sent as always too late last year.

I carefully write a list of those I have sent, to refer to next year, but often forget to put which year this is. I am told that it's a good thing to keep all these lists on computer, also

all the addresses on a system which prints them on sticky peel-off labels; I have not discovered how to do this. Wouldn't that be a useful way to occupy the long hours after New Year?

As I cannot walk round shops, I do my present shopping either before, by mail order (there are some lovely things to buy from various charity catalogues) or at the last minute in local charity shops. Some years when I have been too ill, I haven't sent cards or presents, but phoned special people instead.

If I have any advice, it's this: Christmas is about sharing yourself and your love with people who matter to you.

It's not about cooking a perfect meal, or giving perfect presents, or being the perfect guest/son/daughter/parent. The greatest gift you can give anyone is yourself, your love and your understanding, these can be given unconditionally even if you are unable to physically join in all the activities!

Read Anne's complete 'Story of My Christmas' at www.tymestrust.org

What does your consultant believe?

Doctors *without* ME have to understand it 'from outside'. There are essentially two different schools of thought. You could think of them as Type One/Type Two, but doctors are people and will have their own approach.

Type One

Patients with ME have a physical illness and need to take life easily and live within the energy limits imposed by their condition. They need to avoid stressful situations or working too hard. This will slowly enable the body to heal. Children may need supporting letters for wheelchairs, transport, blue badges, home tuition/distance learning and benefits.

Type Two

Even if ME was triggered by a virus or other physical cause, patients don't need to go on living restricted lives for such a long time.

Children should go back to school as soon as possible. Patients may need Cognitive Behaviour Therapy to counter unhelpful 'illness beliefs', and graded exercise/activity to help get back to normal.

The doctor considers the main problems as: fear of doing more; being unfit due to inactivity.

Some doctors who believe that ME is physical in origin may still prescribe these types of treatment in the hope that they will help anyway. It is up to you to tell the doctor how treatment affects you. There is no proven 'cure' for ME; it is one of those illnesses that depend on your body to heal itself. Therefore, keep using your own judgement.

Read the complete 'What does your doctor believe?' at www.youngactiononline.com

Dr Charles Shepherd

The author of *Living with ME* and member of the CMO's Working Group on CFS/ME writes here as 'a doc with ME'. His countdown to what he looks forward to at Christmas shows he is much recovered – as you can see!

The days before...Stopping work!

My sons coming back from university with all their news and an even bigger overdraft

My daughter's primary school Christmas concert - especially when things go wrong with the youngest ones

Going round the village delivering Christmas cards
Visiting Santa in his Christmas Grotto at Wesonbirt Arboretum, following the floodlight Christmas Trail in the woods, and then picking up the tree (well worth doing if you live in this part of the world)

Christmas Eve

Shopping in Stroud for some last minute presents
Going with the whole family to the Blessing of the Crib service

Wrapping up presents - something which I still always leave to the very last moment

Midnight Mass - with anyone who's still vertical
Phoning relatives in Australia on our return

Putting out sherry and mince pies for Santa - and carrots for the reindeer - on the fireplace. And hoping that the logs will have finally gone out by the time they arrive!

Christmas Day

Starting off by taking the dogs for a walk in the woods - hopefully on a bright but frosty morning

Coming home and preparing the main part of the meal - that's my job!

Opening presents by the fire in the afternoon
Christmas Dinner followed by total relaxation

Boxing Day

Going to the Boxing Day dive - I don't but my son does. They hyperinflate their wet suits like Michelin men [don't try this at home...] and have a race down the river near Cirencester!

Followed by lunch at the pub

And I hope that all members of Tymes Trust have a really good Christmas and a Good New Year.

[You too, Charles. But we're exhausted just reading this! Ed]

THE DUTIES OF A DOCTOR

Guidance for doctors from the General Medical Council

Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life.

In particular, as a doctor, you must:

a.. Make the care of your patient your first concern.

b.. Treat every patient politely and considerately.

c.. Respect patients' dignity and privacy.

d.. Listen to patients and respect their views.

e.. Give patients information in a way they can understand.

f.. Respect the rights of patients to be fully informed in decisions about their care.

g.. Keep your professional knowledge and skills up to date.

h.. Recognise the limits of your professional competence.

i.. Be honest and trustworthy.

j.. Respect and protect confidential information.

k.. Make sure that your personal beliefs do not prejudice your patients' care.

l.. Act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise.

m.. Avoid abusing your position as a doctor.

n.. Work with colleagues in ways that best serve patients' interests.

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.

SEB'S MANOR



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

Send letters, drawings, photos and competition entries to:
 Seb's Manor, Tymes Trust,
 PO Box 4347, Stock,
 Ingatestone, CM4 9TE



Daniel Hales sent a great drawing of my 'spot the differences' Clown Comp from the Autumn magazine, showing the answers.

Did you get them right?

Sebastian says:

Laura Howlett who's 11 and has had ME for 6 years sent this poem:

Why me to have ME?
 Why not him or her
 It's not fair to me
 Why should I have ME?
 Some can jump about
 And run and shout
 But not me because I've got ME.

That's sad. So I'm sending a serious message this time. Look after yourself well – lots of hugs from friends and family. I'd send you a hug, but some people are arachnophobes – are you? (If anyone knows what that means, I'll find you a prize!)

Rule No 1: Find something to enjoy (however small) today, tomorrow, and all the tomorrows after that. I read in the Summer Tymes Mag that happy experiences help you heal. Take it day by day.

Laura's mum helps her look forward to better times. But to live in the moment is good too. Famous quote: '**Only live in tomorrow when it becomes today.**' (Well, it will be famous, because I said it. Oh, I'm a very intelligent, philosophical, cool – but modest – spider.)

We'd rather no-one got ME. Not Laura, but not him or her either!

Sebs Star Letter

Hi Sazza,
 Thank you for letting me have your competition prize. It was very kind of you. It cheered up my day after feeling so low lately.

I am 13 years old and like listening to music: Dido, Sugarbabes, Miztiq and Robbie Williams.

I have had ME for 4 and a half years, been in bed a year and on a NG tube since March. I take every day as it comes.

Hope this card finds you AWAP.

Luv and soft hugs, Jade.



SEB'S AUTUMN COMP

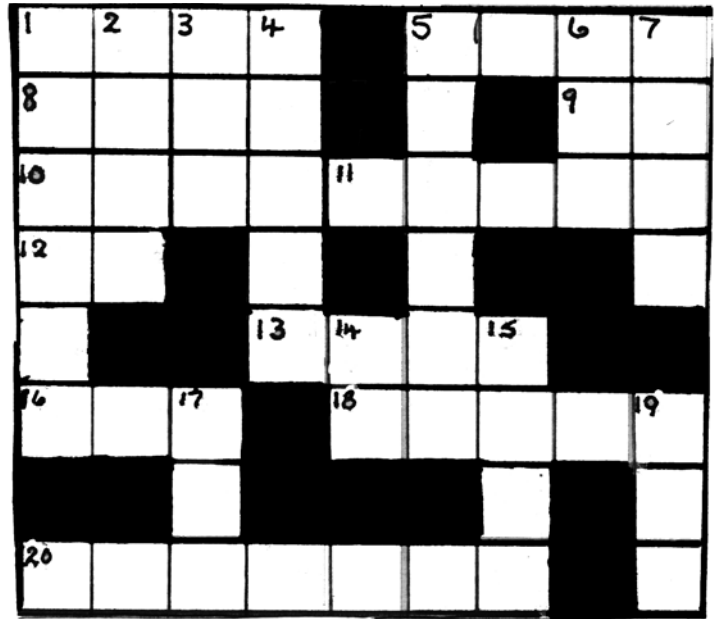
Margaret has drawn me a crossword for you. Send the answers to her at Tymes Trust (or a photocopy of the completed crossword). Lots of prizes waiting. No deadline.

Major Clue:

Many of the words refer to the Festive Season

Across

- 1, It guided the Wise Men (4)
- 5, You may ___ on the above answer (4)
- 8, Do not __ yourselves (4)
- 9, The beginning of a greeting from Father Christmas (2)
- 10, Grown-ups drink these on occasions (4)
- 11, An ___ always watches over you (5)
- 12, To ___ or not to ___ (2)
- 13, You may need these for your gifts (4)
- 16, A fairy like creature (3)
- 18, It sparkles on cold mornings (5)
- 20, At Christmas we hear children ___ carols (7)

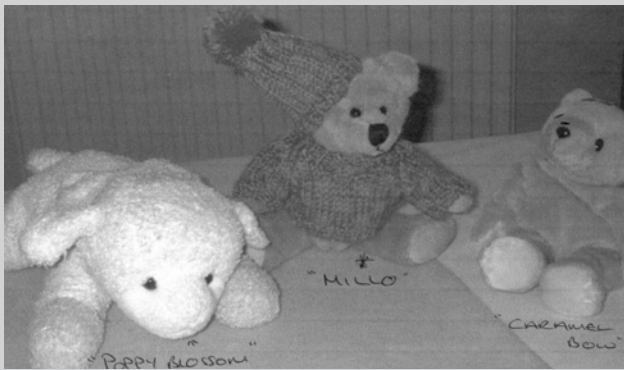


Down

- 1, The first home for baby Jesus (6)
- 2, Used for floor and wall covering (4)
- 3, Who __ we? (3)
- 4, Make sure to ___ the video (5)
- 5, Very much in season (6)
- 6, Female (3)
- 7, The aura of the Nativity (4)
- 14, __ snow were only ice cream! (2)
- 15, A child's party piece (4)
- 17, You are bound to have ___ at Christmas (3)
- 19, The end of mistle__ (3)

BEARS, BEARS EVERYWHERE....

Emma Gray sent us a photo of Milo, her Tymes Trust Winter Bear, with Caramel (Fudge's cousin). 'Milo has settled in very well with his mates. They lie on my bed with me all day. Thank you so much for sending him, it means so much. Love Emma XXX.'



SEB'S SECRET

Remember that Christmas confetti you've been sending us in your cards? All those shining trees, stars, angels – red, green, purple, blue, gold, silver?

I've been sticking them on my web. I'm a Soppo old Seb at Christmas!



Seb and web for Seb's Secret drawn by Jane Fawcett

I PAY A VISIT TO FUDGE!

Cheryll Neyt sent an email to Head Office from her Tymes Trust Beanie Bear, Fudge. (Fudge is now almost as famous as me.)

'Fudge says a big "hello" to Matthew Eccleston [look at this Matthew, we spelt your name right this time - Ed] who seems to be her biggest fan, and also to her long lost cousin Caramel who she hasn't seen for a while. Fudge was a little concerned about Seb and hopes they can be friends.'

Well, I've gone to stay with Fudge. So we can. Watch this space.



QUOTES-WE-LIKE

Our readers usually choose the quotes for 'Quotes-u-like'. This time we've joined in! Here are our favourites.

'Even the smallest person can change the course of the future.'
Gandalf in Tolkein's Lord of the Rings.

Thank you so much for your inspirational magazine. I especially appreciated Dr Ho-Yen's article and reference to a bag of apples. I have had ME for 8 years and have recently begun to be able to view my life more positively, very restricted as I am. I enjoy reading and find audio books relaxing. My favourite quote comes from Dietrich Bonhoeffer who said: 'It is only with gratitude that life becomes rich'.

With gratitude, Judy Toy

MY SPECIAL ROOM

My special room is a place called APTCOO (A Place To Call Our Own). It is a relaxation room for anyone with something life-changing, age 0-19. I go with my friend Emma who also has ME and we have lots of fun!

In the room there is: a heated water bed, fibre optic light, glow-in-the-dark stars and moons, bubble tubes, light pen, calming music, a disco ball, twinkly lights and a relaxing scene.

Kirsty Watts (15)

Support Worker Linda Tasker says: 'APTCOO is a carer-led organisation, set up over 10 years ago by a small group of carers of children with additional needs. Now we have mobile, sensory and outreach support. To offer somewhere to "hang out" in a quiet environment for "teenage time" is great.'

APTCOO is in Mansfield, Nottingham.

Tel: 01623 629902



'I will honour Christmas in my heart, and try to keep it all the year. I will live in the Past, the Present, and the Future. The Spirits of all Three shall strive within me.'

Scrooge, in A Christmas Carol by Charles Dickens.

GET OUR YOUR MAPS OF ESSEX!

How many Essex place names can you spot? Some of the spellings have been slightly altered...and there's a major road in it somewhere...

I don't know if you like jazz.... I write to bring you details of a fabulous new band - Essexperience - nice.....

The line up is as follows:

Saffron Walden on Vocals

Jay Wick on Piano

The Wood Brothers (Brent & Harold) on Alto & Tenor Sax

Col Chester on Drums

Buck Hurst-Hill on Double Bass

Woodford Green on Trumpet.

Plus special guest trumpeter - the legendary Stanford Lee Hope - who will be showcasing his lead trumpet virtuosity with the loosely improvisational *Lee on C*. Stanford Lee, fresh from a recent tour of Nu Orleans, will be wearing his trademark yellow suit and Matching Tye. Also don't miss Col Chester's drum solo on the stupendously great *Dun Mo 'Drummin*. Nice.....

Of course all the old favourites will be performed on the forthcoming tour, including:

Billericay Blues

Tiptree Jam

Maldon Mudflat Moods

Hazy Days in Walton on the Naze

Wanstead Flats

Goin' Nowhere - Jam on A12-Bar Blues.

Tickets available from Sybil Hedingham. The band appears courtesy of Ben Fleet Promotions Ltd.

Send the answers to author M.E. [Matthew Eccleston - who else?] Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE

CALLING ALL FRIENDS!



Phoebe Jameson writes:

This photo was taken of me just before I relapsed two and a half years ago. I have had ME since I was 11 and I've just had my 18th birthday. I haven't been able to walk since I was 12 and I'm in a lot of pain.

I don't have the energy to see my friends but I collect signed photographs and hope to get a record-breaking amount of them! It's great to see so many faces. I'm still collecting so if anyone would like to send me one, I'll look forward to seeing them.

Phoebe's mother says:

I wrote this for Phoebe as she cannot write or read. We are so grateful for all the support you give to families like us. Phoebe is severely affected by ME and the past two and a half years have been the worst. Many thanks. Amanda Beard.

I met Martin Clunes, star of *Men Behaving Badly* when he came to film *The Acid Bath Murders*. I saw the actors coming and going in their period costumes. Yorkshire television sometimes use our street for filming and I watch out of my window. I had my picture taken with Martin and he gave me his autograph. I felt really small at the side of him because he was so tall. He was very funny and *really nice*.



When I was four or five years old, my dad had a laptop. He let me go on it to do my homework, browse the net, and many other things. That gave me a really good start in the computer world.

I strayed off to start doing electronics and such. At about eight to ten years old I was making very basic robots. I ended up accidentally making a mini circular saw. It was comprised of a small three volt motor, a watch face, and some LED lights. It worked as a dynamo as well. Enough of that.

At eleven and when I got ME (I know I haven't said much but I want to keep it quick and I've forgotten most) I learned web design. I started to build a site, which is www.tech-devil.co.uk

Now it's up with forums, a constantly growing links page, reviews and some news. And for anyone who reads this article, please, please, please register on the forums of my site. It needs more people to get active.

Ben's mum says: In September 2001, Ben got shingles and then encephalitis. He was subsequently diagnosed with ME. He has not managed any formal schooling for some considerable time. He has nausea 24/7, brain fog, bone crushing fatigue and other symptoms so familiar to carers of children with ME.

One of the hardest things that this disease imposes is isolation, the loss of a social life and friends. Ben has very bravely tried to overcome this by designing his own website that lets him stay in touch with his friends and make new ones. He gets on to his computer and then he rests as he must. He no longer feels quite so alone and this has helped him.

Before registering with any internet chat rooms or anything similar, children should always check with their parents.

SEEING STARS

Dear Tymes Trust

I wanted to say how much I enjoyed doing the Treasure Hunt. I chose to do mine using pictures of famous people because I could do it in bed without getting any help from anyone else. It was really fun.

I also wanted to say how good Dr Darrel Ho-Yen's article about apples was. It made me think back to what I had done with my 'bag' of apples' over the last ten years. I have made so many good friends with ME. They are there for me more than any friends I had before I was ill.

Despite the time and energy it takes to make 'apple pie', it's worth it. During the course of your illness you may have time to make more than one! But when you have finished there is nothing more delicious than savouring what you have made and sharing it with friends and family.

When you look back on your time with ME, don't see wasted years, but all the apple pies you have made.

Claire Wade

Dr Darrel wrote: '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 the apples that matters. It is best to avoid looking at them as they slowly rot! It would be better to make a wonderful apple pie, but please remember to send me a piece.'

For the full article please see Tymes Magazine, Issue 44



Orlando



Penelope



Robbie



Tara



Victoria



Will W



Xander



AZTOZY



JULIKA



Britney



demolt



Justin



e ella



Ian



Frank



Guy



Marilyn Monroe



nicole

TYMES TRUST I SPY

Above, we have featured some of the stars' pictures that Claire Wade found for the 'Tymes Trust I Spy' fundraising game. Trustee Sally Player invented this Annual Treasure Hunt to keep you busy over the Summer and some of you have been lucky winners of the secret treasure! Thank you for your entries and donations. Can you think of a game for next summer? Write to Sally at Tymes Trust with your ideas.