

More, more, more

You are meant to understand my illness but you all do is push, push, push. Nothing I do is ever good enough. I am proud and think you will be pleased with me as I have been going to school much more than before, but all you do is say I need to stay there longer, and if I feel ill I can't home early. I can't get to sleep at night and you make me feel like it is my fault. You tell my parents to ignore me at night time, even

when I am upset and feeling scared and lonely. Lucky for me they ignore you! I am so tired but you say I still have to get out of bed and walk even at the weekend after I have been at school all week. I don't like coming to see you, it makes me worry what you are going to ask me to do next. My mum tells you I sometimes feel much worse but you tell us I just have to do more, more, more. You speak to my school and I worry they

will be on your side and expect more of me too. I worry about what you are going to tell us to do next. I think you should care more about the children who come to see you and try to understand what they are going through.



From Isla aged 8

25 years of trusting TYMES

2014 is our 25th Anniversary year. Started by two youngsters reaching out to offer companionship, TYMES grew into a national charity, honoured in 2010 with the Queen's Award for Voluntary Service: the MBE for volunteer groups. It was for pursuing the educational rights of children with ME and advancing their care.

Many are too unwell for school. Education at home can help a) promote healing and b) facilitate achievement.

ME typically takes years to stabilise, and this does not happen while there is over-demand on the body and brain.

Children's words speak volumes. In 2004 we published *Young Hearts*, inspirational poetry by young people with ME. Terry Waite CBE kindly wrote the foreword and launched it at Warwick Castle.

Everyone at the Trust works pro bono. Although costs have escalated, we still send out publications, prizes, little gifts, and personally signed Christmas and birthday cards, to let children know they're remembered and that they matter. We don't employ fundraisers, we don't receive government grants; this preserves our vital independence.

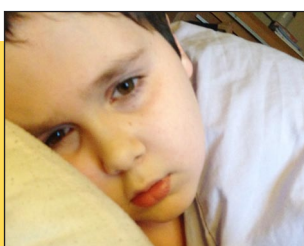
Our Advice Line Team all have personal experience of ME, or of caring for a

child with it. On Twitter, I wrote: 'Those who neither have to cope with ME themselves nor care for a loved one with ME, rarely if ever understand how fragile their health is.' It struck a chord, and swiftly, retweets spread my observation.

This disease is so potentially severe, disabling and long-lasting that it challenges public perceptions. It is regrettable that families are often poorly advised and the child pushed into repeated relapse. Parents frequently tell us they trust our advice. We seek always to be worthy of that trust.



Jane Colby FRSA
Executive Director
Former Head Teacher
Former severe ME sufferer, from a polio-related virus



Ben has been very ill

Debbie, Ben's mum says: *Until we found the TYMES Trust, all the advice we received - on what was best for my son - was telling me to go against my instincts and the reality of our daily*

lives. Talking to the Trust felt like finally finding someone that 'got it' and we have only gone from strength to strength since then.

Consultant Paediatrician and ME expert Dr Alan Franklin (1996)

Jane *What is the effect of trying to force children with ME into school?*

Dr Franklin *The family usually say, 'We've had enough of this and we're not going to see you any more. We're going somewhere else.'*

Jane *Do you feel that's a healthy reaction?*

Dr Franklin *On the whole, yes. I think parents are pretty good at recognising what's what.*

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

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The Queen's Award
for Voluntary Service
The MBE for volunteer groups

Teacher Information on ME (updated 2014)
<http://www.tymestrust.org/pdfs/teacherinfo2.pdf>

Overleaf: Ben Burgess