

Tymes Tidings

2021

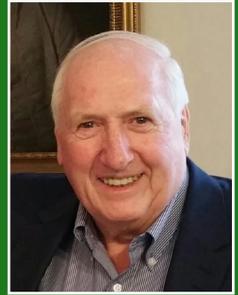


The Queen's Award
for Voluntary Service

The MBE for volunteer groups



I'm pleased to be writing to you all once again with good news. Following last minute delays, you may have heard that the 2021 NICE Guideline on ME/CFS has finally been published, replacing the much criticised 2007 Guideline. We are hopeful that it will improve the way families and their children with ME are treated. The Guideline states "Do not offer [...] any therapy based on physical activity or exercise as a cure" or "any programme that [...] uses fixed incremental increases in physical activity or exercise, for example, Graded Exercise Therapy." Indeed, we have always found that as the body recovers it is able to do more, not the other way around!



MR HARLEY'S PREZZIES

On a lighter note, we have a limited number of my knitted teddies in various colours just waiting for a new home! If you'd like one, let me know. You can use the Contact Us form at www.tymestrust.org.

YOUNG HEARTS CARDS AND GIFTS

Just like last year, if you missed our November announcements about Tymes Trust's Young Hearts Day, it's not too late. We've sent lots of Young Hearts cards and gifts and we can still send you one. Send a Contact Us form with the name and address.



Keith Harley
Chair of Trustees



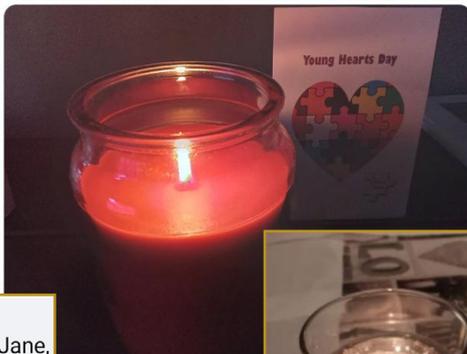
Tymes Trust's Young Hearts Day 29th November 2021

Each year we invite everyone to light a candle to remember children with ME everywhere.

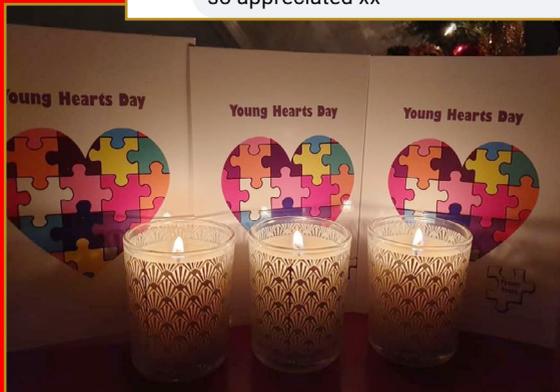


Sally Beach
@sallybeach13

Thinking about my own child who has had severe ME for 4 years and all children with ME on [#youngheartsday](#) ❤️
Thank you to [@JaneCColby](#) and [@tymestrust](#)



Sophie Samantha Sleep
Lovely that you do this every year Jane, so appreciated xx



Can you spot
your candle?



“My daughter was delighted to receive her card and present today. Thank you so much. She’s put a note in her calendar to light a candle on the 29th too. It gave her a real lift to receive that.”



Jean McDonald

Thank you so much for the lovely pressies and cards for my 3 boys for Young Hearts Day. And, for all the birthday and Christmas cards that we are kindly sent. It means so much to be supported and remembered year after year by such an amazing charity. 💜Xxxx



Our Young Hearts Day cards were designed by Tymes Trust Young Officer Rachael

Young Hearts Day



Parents of children with M.E./CFS Support Group

Jane Colby · Sat at 16:47 · 📍

REMINDER

You don't have to have children with ME to join in with Tymes Trust's Young Hearts Day. Help us to remember #kidswithME everywhere by lighting your candle on 29th November and posting it on your social media.



Janet Smith Parent of young adult
We lit a lighthouse candle! Thinking of all young hearts tonight ❤️

Janet Smith Parent of young adult
& we lit the fire & toasting marshmallows!!





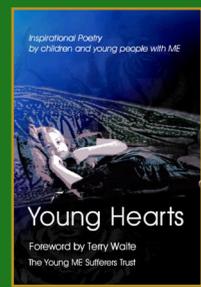
Mr Harley has some gloves and a few other bears too! Write and ask him if you'd like one.



Sue Forrest
@CakeItAwaySue
Candle lit for @tymetrust #youngheartsday for all those children with #MyalgicEncephalomyelitis 5 years for Luce now... ❤️



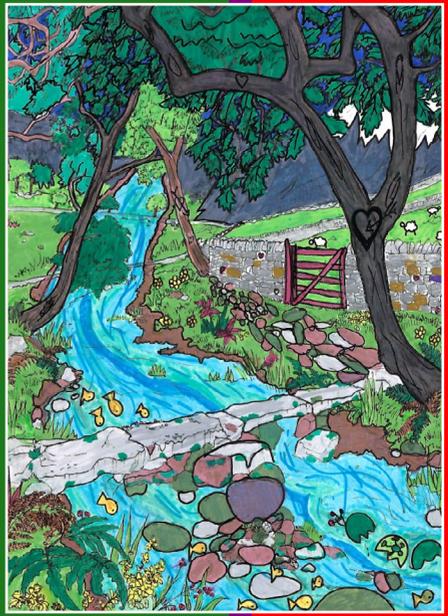
SuzieHenson-Amphlett @SHensonAm... · Nov 29 ...
Today's @tymetrust's YOUNG HEARTS DAY ... a special day each year when we remember all children&young people living with #ME. Heartfelt thanks to TYMES TRUST for your care&support over the years. This year I light my candle with renewed hope 🧡💙👥💙🧡
#MEcfs #NewNICEguidelines



Copies of Young Hearts are available from the Trust at £7.95 inc p&p

Your Artwork

We're so impressed with these beautiful colourings! We've sent certificates and prizes. Do send us yours. See our end pages for designs to colour.



India (18)

Kalayni (11)

Lucy (18)



Kalayni (11)



Lucy (18)



Lucy (18)



NICE Guideline

www.nice.org.uk/
guidance/
ng206

The new National Institute for Health and Care Excellence Guideline on ME/CFS (NG206) published 29th October 2021 replaces the 2007 Guideline.

SOME KEY QUOTES

Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a cure for ME/CFS [...]
- any programme that [...] uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy [GET]
- physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS.

Do not offer the Lightning Process, or therapies based on it, to people with ME/CFS

Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect. [eg]

- ..more than one child or family member having ME/CFS
- ..disagreeing with or withdrawing from any part of their care and support plan
- ..reduced or non-attendance at school

www.tymestrust.org/pdfs/falseallegations.pdf

Have management regimes been making children worse?
Why are parents suspected? A peer-reviewed paper.

KEY QUOTES ON EDUCATION

There may be times when they are unable to continue with work or education

Discuss a flexible approach to training and education – this could include adjustments to the school day, online learning or education at home and using assistive equipment



Dr Nigel Speight writes:

NICE has now clearly withdrawn support for both cognitive behaviour therapy (CBT) and graded exercise therapy (GET) on the grounds of lack of efficacy, and in the case of GET, likely harm. NICE received a large volume of evidence on this latter area. Instead, NICE now recommends an approach to energy management that is virtually identical to Pacing, a form of management long favoured by most ME charities and patient groups.



Lynne Blakey
@LynneBlakey

Replying to @JaneCColby @MEisNotFatigue and 2 others

The excellent FII paper on Tymes Trust site is really useful for parents to give to their Local Authority leads - be informed !

13:25 · 03 Nov 21 · [Twitter for iPhone](#)

Colour Young Officer Lucy's Design



Colour Lucy's Floral Fantasy and her Design (inside)

Turn our pictures into beautiful artworks. If you're not well enough to colour the pictures on your own, friends and family can help. You can just do one of them if you like. Felt or fibre tips should work well.

Cut off the page and post it to us at the address below.

For an Art Certificate and a prize, fill in your name, age and postcode (full address if not a member)

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PARENTS

Have you ever faced allegations of FII
(Fabricated or Induced Illness)?

Elaine Carlton at Turquoise TV would like to hear from you by 31st January 2022 for a Channel 4 programme.
elaine.carlton@turquoise.tv

Thank you so much to everyone who has donated to support the work of the Trust. Don't worry, we never put you on a list to ask you for more!

Tymes Trust, PO Box 4347, Stock, Essex, CM4 9TE
Joint Parent and Child membership available
Information 0845 003 9002
Register at www.tymestrust.org
Registered Charity 1080985

