

M.E. Hurts!

“One day I caught a virus... and I never got better.....!”

M.E. often starts that way – with something like a ‘flu virus that knocks you sideways. You expect to get over it in a week or so, but weeks, months and even years go by, and you feel no better... We believe that well over 250,000 people in the UK are living with this nightmare of an affliction.

M.E. stands for myalgic encephalomyelitis. It has other names, including CFS – chronic fatigue syndrome - but the end result is always the same: M.E. hurts! It hurts in so many ways - Physically. Mentally. Socially. Financially. Emotionally...

But don't just take our word for it – we asked our supporters to tell us what M.E. felt like, and this is what they told us.

M.E. is REAL. It's physical!

Pain and extreme tiredness are all too common. Pain that pain killers barely touch. Your senses go into overdrive – light and sound can hurt. You sleep but wake unrefreshed. Or worse still, you don't sleep.

“I have to choose between brushing my teeth and washing my hair – I don't have enough energy to do both”

DAWN



“At its severest M.E. can be fatal. The very severest lie bedbound in dark rooms, tube fed, catheterised, paralysed, in horrific pain and unable to tolerate even a slight comforting touch. Merryn, was just 21 when she died”

CLARE

M.E. shatters families and destroys friendships

Around a quarter of M.E. sufferers are so badly affected that they cannot leave their homes, or even their beds. For some, the most social part of their day is when someone caring for them comes in to check up on them.

For many, the effort of just talking on the phone is too much.

You can't see M.E!

M.E. is invisible. You cannot tell, just by looking at someone, just how ill they feel; how much pain they are in; or how much energy it is taking just to talk to you.

the ME association



“Everyone has forgotten about me”

SUE G

M.E. messes with your brain

People with M.E. often talk about ‘brain fog’ – something that clouds their thinking so that they struggle to think, (or to think straight). Each and every year, some people with M.E. take their own lives because they can no longer bear the torture it brings.

“My employers don’t believe me. Even my mother says that I look fine and should just snap out of it!”

NICKY



M.E. is a thief. Your life is on hold

People of all ages are forced to adapt to their new lives. That includes around

2500 young people (M.E. is the greatest cause of long-term sickness absence from school). M.E. breaks up families, wastes adult lives and robs young people of their education.

“Four years of feet growing but shoes never worn out... I’m 14 and my neighbour of 93 can do more than me... I’ve missed so much school that I’ve had to give up on my studies”

LOUBY

M.E. hurts family finances!

M.E. is a fluctuating illness. Some people manage to hold on to full time jobs, but have to sacrifice family and social life to do so. Others struggle to work part-time. But some have to give up because working makes their health worse.

“I used to teach English, now I struggle to string words together in a sentence”

ALISON



M.E. hurts emotionally

Life with M.E. can be an emotional rollercoaster. Pain and worry lead to a muddle of intense feelings which can spiral out of control.

“It is hell every single day and the thought of living the rest of my life like this is utterly depressing... I hope to be more positive about it one day but at the moment it feels like I’ve been given a life sentence for something I haven’t done.”

NATALIE

M.E. Fluctuates

You might feel well one day, and crash the next. For no reason. One day you might feel up to doing things and the next day or week, or month, you can’t. You can’t predict how you will be.

“In a continuous cycle of hourly changing symptoms. It’s exhausting to manage, and frustrating to watch my life go by.”

SALLY



“At its worst, it’s like you’re dying.. Very scary!”

SHARON

M.E. destroys hope

There is no treatment that your doctor can prescribe that will make you better. Some people are able to ‘manage’ their illness and get better over time, but many cannot. And nobody knows why.

What is M.E?

M.E. is defined by the World Health Organisation as “a chronic complex neurological illness”. The main symptoms are severe exhaustion, muscle fatigue, muscle and joint pain, cognitive dysfunction, and un-restorative sleep.

If that weren’t enough, other M.E. symptoms include:

Brain fog; nerve pain; numbness; sore throat; sweating episodes; headaches; flu-like symptoms; chest pains; balance problems; insomnia; heat/cold intolerance; reduced stress tolerance; painful glands; extreme sensitivity to heat and light; allergies to food, drugs and chemicals; nausea and vomiting; dizziness; heart palpitations; blurred vision; faintness on standing; confusion; word retrieval difficulties; pins & needles and tingling; difficulty staying awake; bladder dysfunction; disorientation; alcohol intolerance...

For around a quarter of sufferers, their symptoms are so severe that they may become wheelchair bound, housebound, or even bedbound.

- There is no diagnostic test for M.E.
- There is no effective treatment for M.E.
- There is no cure for M.E.

This needs to change.

M.E. hurts everyone it touches

The ME Association works to support people with M.E. and their families – to help relieve the hurt. Please help us to make a difference to peoples’ lives.



The ME Association works to relieve the hurt

The ME Association plays a vital role giving people with M.E. the long-term support they need now. We are also funding biomedical research to give everyone hope of a better future.

- We support M.E. sufferers and their families through our ME Connect helpline.
- We campaign to have M.E. recognised as a severe neurological disease that deserves to be taken seriously.
- We campaign to ensure early and accurate diagnosis, improved healthcare access and specialist provision
- We invest in and promote biomedical research into the physical nature and causes of the illness so that, we hope, one day, it will be diagnosed quickly and successfully treated and cured.

“Severe ME is the pits! - all the good things of life: light, company, entertainment, activity and stimulation become potentially harmful or can feel torturous”

KATHRYN

PLEASE SUPPORT THE ME ASSOCIATION IN ANY WAY THAT YOU CAN - TO HELP US IN OUR VITAL WORK IN CAMPAIGNING, EDUCATION, SUPPORT AND RESEARCH.

How you can help

We need your help.

The ME Association does not receive government grants or other outside assistance, and relies solely on the generosity of its members, donors and fundraisers.

Our website gives full information on how you can help support the valuable work that we do.

But in brief:-

Donate:

- Direct by cheque, bank transfer, debit/credit card, or by standing order.
- Online donation or direct debit through Justgiving.

Fundraise:

- Challenge yourself or have fun organising an event to raise funds and awareness.
- Raise funds by selling through Ebay or Give a Car, or buying using Paypal Giving, or Amazon Smile, or by Recycling for Good Causes.

Leave a Legacy:

So that you make a positive difference to peoples' lives long after your death.



Join us:

Become a member of the ME Association.

How you choose to help the ME Association is entirely up to you, and we are incredibly grateful for any support you can provide.

For more information please visit: www.meassociation.org.uk or contact our Fundraising Manager by emailing: admin@meassociation.org.uk or calling **01280 818 963**

“Today I feel: age of about 105, fluey, chilly, sweaty, limbs are lead weights, bones are sore and stiff, vision blurred; dementia feels like it has a hold; exhaustion controls everything so tasks are small; Frustrated but still hopeful , after 29 years, that I'll be well again soon!”

SUE

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