

The 25% M.E. Group

Support Group For The Severely Affected

*In Remembrance: Emily Rose Collingridge
17th April 1981 - 18th March 2012*



*On gossamer wings, fly up!
Your soul set free
Chase the morning glory
Until the end of day
How brief thy visit!*

4th Annual Day for Understanding & Remembrance
August 8th 2016

CHARITY No. SC034265

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Severe M.E. Day Aug 8th

Emily Rose Collingridge

Born 17th April 1981

Died 18th March 2012



by Jane Collingridge, 2016

During 2009 Emily had made significant progress. She was beginning to cope with exposure to daylight, to sit in a chair for 30 minutes twice a week, to take a few steps with a walking frame, to have a bath using an electric reclining bath chair and to manage a small amount of physiotherapy.

Years of suffering and of campaigning to raise awareness of ME, had made Emily realise how desperately those with illness in its most severe form needed practical, understanding advice; so with the improvement in her health she set out to research and write a comprehensive guide to living with severe ME. The book was published in 2010 and was highly acclaimed by professionals and patients alike. According to Emily's wishes, it is sold at cost (www.severeme.info).

The publication date coincided with one of several admissions to hospital. Emily dipped to 0%, but by the end of 2010 had improved very slightly.

However 2011 saw a year-long battle over dental treatment. Initially visited at home by the community dentist, it was planned for her to receive treatment in hospital under general anaesthetic. But, protocol and the refusal of the hospital management and dental department to understand the gravity of her situation failed to generate a date for the treatment and resulted in two emergency trips to A & E for pain relief; while there her symptoms became very dramatic, triggering seizures and some kind of mental breakdown as the suffering was way beyond what she could stand. At Christmas she was really ill and on New Year's Day 2015 was once more rushed into A & E in excruciating pain, this time caused by a kidney stone which eventually passed. She was kept in for rehydration and to get her pain under control.

The next eleven weeks were an absolute nightmare, the only consolation being that after much persuasion Emily was given a side room and I stayed with her throughout.

What was most distressing was that the wonderful and trusted consultant who had looked after her in hospital and at home for six years and therefore knew her well, had read her book and saved her life on more than one occasion, was no longer allowed to look after her. The hospital would give no reason for this except to say that he was not an ME specialist. Nor was the consultant assigned to her. He professed to have some knowledge of ME, but finally was forced to admit that he

was ignorant of the illness in its severe form – up until then he had thought he was going to cure her. His attitude towards her was arrogant, bullying and rude. He refused to listen to her and to speak to her ME specialist in the community. He allowed her to go without food and vomit three or four times a day for weeks on end with a 'wait and see' attitude. When questioned on how long it was safe to go on like this he replied that he didn't know. He subjected her to treatment completely contra-indicated in ME which made her crash; for example he refused to let me talk on her behalf, allowed visits from several clinicians at a time, pushed her body with constant cannulation and difficult blood tests which wouldn't have been necessary with a central line (which she would have been prepared to risk) and pressed for procedures when she was not well enough to tolerate them. He talked of rehabilitation despite being shown a letter from an ME champion clinician saying what was appropriate for severe ME. He frightened her by wanting her to see a psychiatrist and when Emily said that she had no confidence in him, he merely answered "well I'm all that you've got". There were many more examples of what seemed to me like abuse.

By March she had deteriorated further and there was evident concern among the doctors who were so out of their depth. While screaming in agony she was subjected to a barrage of intrusive tests – she could not move her legs, her breathing was strange. In the early hours of March 18th, the nurse on duty wished me "Happy Mother's Day". Six hours later Emily had a respiratory arrest. Seven hours after that she was dead.

Naturally, we made official complaints both to the hospital and GMC, but no real responsibility was taken for what had happened. At the inquest on May 24th 2013 the Coroner was extremely thorough in her questioning of the consultant who looked both nervous and uncomfortable. She summed up by saying that ME is a condition that is not understood and that more research was clearly needed.

I can only hope that having seen the reality of severe ME, the hospital will treat future patients with more understanding and appropriate treatment.

My husband, Jim, and I were overwhelmed by the hundreds of messages of support that we received on Emily's death.

When Emily died I felt relief that her suffering was at an end. She had been ill for most of her life. But I miss her every single day and think about her all the time.



2016 - *in Remembrance*

There are so many awful memories of what she went through physically and emotionally and even the memories of happier moments are tainted with the knowledge that to achieve most of these she had to draw on all her courage and determination. Emily and I were a team and now there is a huge gap. But I have her in my heart. She was my only child, but I am lucky to have been a mother. And life does go on. In 2014 her dear friend, Lydia, gave birth to a beautiful daughter whom she has called Emily Jane.

Emily fought for ME awareness and bio-medical research; and while so many are still suffering so terribly from this dreadful illness, the fight must go on.

by Emily Collingridge, 2007

Emily wrote this for 'Lost Voices from a Hidden Illness' a beautifully compiled book by Natalie Boulton for Invest in M.E., published in 2008.

Emily had been very, very ill and wrote this after making some improvement. She was 26 years old at the time

Fear; my own mingles with the doctor's. He's known me since the day I was born, was there when I fell ill in 1987 aged six, has visited me regularly in the last ten years that I have been housebound, but now... now, I know I am unrecognisable to him. Unable to eat I am suffering starvation; unable to drink I am dehydrated, taking in under a fifth of the fluids I need; I am doubly incontinent; I don't always recognise my own mother or know where I am or what is real; I am in constant agony; my sickness is not dissimilar to that experienced with bad chemotherapy... I am barely alive. Rushed to hospital on the brink of death, my kidneys fail and I hear the whispers of doctors in the High Dependency Unit worrying about my heart. They nurse me, but I can't see them or thank them - I am blind and mute.

Returned home in a more stable condition and with stomach feeding tube and catheter, I can hardly bear the presence of my mother in my room, let alone any sound. I will her to go away. But when she does, I long for her to come back – please, please help me, anyone, please. The doctors are supportive; their drugs, the morphine etc., keep me going, but I still doubt whether I want to go on.

In early childhood I loved bossing, chatting, working, cycling and swimming; I loved roses, my friends and babies. What's changed? Nothing, except now I am the baby; totally dependent with my natural feisty temperament washed away. Yet I cannot cry as a baby does, I am too weak, and I cannot be soothed by a cuddle for pain surges through me when a touch hovers near. My mother changes my nappies, washes me, holds a beaker to my lips – all the things she did in my infancy. How long? How long will this go on?

Finally a light in the darkness - I manage to wash my own face. The cheers from the sidelines are louder than when I did it as a toddler. But what am I supposed to feel now – pride or embarrassment? Will I ever be able to do more than a six year old...?
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Stop!

Ignore M.E. At Your Peril

'Stop!'

No!

'Stop, I said!'

Well, I said no!

'Stop now', says the voice.

I won't, say I.

'Ignore me at your peril!'

I will, I think defiantly;

I will, I think hesitantly;

I will, uncertainly.

Suddenly I feel impatient, irritable, nothing is right,
There is an urgency to stop, quickly.

An instant later I know I must stop, immediately
I feel distanced from the world around me.

For a few moments the inside of my body is being scraped
out -

Scrape, scrape, scrape -

And is hollow before the acid flows in;

The acid spreads around my burnt body,

Burns everything in its path.

The whole of my body is throbbing with it.

It seems the room is pulsing with me.

I shake,

I feel sick and hot, no cold, no hot

And am pouring sweat.

My body is screaming; it's deafening.

I try to follow what is going on inside of me, but I can't;

The screaming is too much;

The simplest of things no longer make sense.

I want to shout, but my voice is surprisingly difficult to get
hold of.

I force it from me and it comes out too soft.

Now everything is too much.

The tiniest movement around me grabs and shakes me vio-
lently.

I need absolute stillness, absolute silence and absolute dark
Nothing must touch me.

If I could stop the earth from turning, I would.

Ignore M.E. at your peril.

Emily Collingridge

By Emily Collingridge, January 2010

Following the success of 'Lost Voices' Natalie Boulton continued to gather personal experiences. Emily sent this to her in early 2010.

2009 was quite a year for me. In the summer we FINALLY got two wheelchairs I could manage to sit in. One was a super duper tilt-in-space model. Tilt-in-space options, as you probably know, are designed for very poorly people; they are big with lots of support and not only recline but tilt so that your posture is completely supported. I haven't been able to sit in even a reclining wheelchair to go out for years and so tilt-in-space was my only option. They're very hard to push if not motorised and I got a power version. Sadly we couldn't get a tilt-in-space model in our house and so for my indoor chair the wheelchair service had to adapt a recliner which took ages. They built a customised back so that there is support all the way up to the base of my spine, got a special headrest and added leg elevators.

So I was managing to get out of bed quite a bit before Autumn came and disaster struck!

Over the summer major bladder problems put considerable strain on my health and left it very vulnerable. I had just started to cope better with the aid of catheters when an OT visited and stayed too long. What resulted was a very major relapse. I had the full works with paralysis, dizziness so bad I couldn't use a pillow, awful pain, uncontrollable jerking, vomiting water, loss of speech, loss of swallow *etc.* It was scary and upsetting as I had thought I'd left that degree of illness behind me.

But thankfully the worst lasted only a few weeks. Over the last 4 weeks progress has come relatively quickly and I'm enjoying working on my book. I'm still on much higher levels of morphine than normal, still entirely bedridden, still needing even more help with personal care (I'd love to be able to brush my teeth again! Still it's better than when I couldn't cope with having them washed at all!), but I'm immensely grateful for the improvement I have made and am hopeful for the coming months. I am struggling to keep up with things though and so I would appreciate it if you shared this email with xxxx as an explanation of why I'm never in touch.



Pain

I am being beaten, my side kicked, my face stamped on.
It's crushed and caving in on itself, the cheek feels thick and swollen
I must look hideously deformed
Now my insides are being hollowed out and replaced with an acid
The weight of the liquid makes my limbs heavy and pins me to the bed
The acid burns everything it touches so I am being worn away from the inside out

I try to lie still, but this does not stop it from sloshing back and forth
Back and forth, back and forth
Spreading from the left hand side across my shoulders to the limbs on the right
Something cold and sharp is piercing my skull
It makes my stomach heave
There's no way of getting remotely comfortable now
Pain is screaming from so many different parts of my body
I don't know which to listen to
The noise is deafening
It's driving me insane and taking my breath away

Surely this is the point in the nightmare when I must sit upright in one sudden movement
Gasp for breath
And then feel everything recede
But no, it does not happen
I am not asleep
So on the screaming inside me goes
Relentless
Somehow sleep does come
But the pain manages to follow me in and take over my dreams
More screaming
Now it releases itself from my throat in small moans

My mother tries to comfort me
But even when I stir and wake I do not hear her
I have lost the boundary that defines reality
I have been consumed by pain
Pain is the only reality
I want a way out
Any way out
Oblivion
Peace
All those drug related words, that's what I seek
I do not truly want my life to be over
But I am alone in fighting this
And the pain feels stronger than I am

I am lost, worn out and weepy
What now?
I rest, I wait, I blot out the screaming.