

The 25% M.E. Group

Support Group For The Severely Affected

A Day for Remembrance

August 8th 2016

Sophia Mirza

8th August 1973 - 20th November 2005



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

CHARITY No. SC034265

PATRON: Dr Byron Hyde MD

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Severe M.E. Day Aug 8th

Sophia Mirza

Born 8th August 1973

Died 25th November 2005



By Sophia's mother, Criona Wilson, 2015

Criona Wilson originally wrote this piece for Natalie Boulton, author of 'Lost Voices from a Hidden Illness' (2008), a remarkable book where Sophia's story had featured.

Following publication of the book by Invest in M.E. In 2008, Natalie was collecting updates from patients and families. Criona sent hers in May of 2015, explaining a long delay in writing. "Each day I promised myself that I would write and each day I found it just too painful to remember."

We are profoundly grateful to Criona Wilson for permission to print this.

In 2005 our Sophia died. The post mortem did not show up the cause of her death. It was only when Dr Chaudhuri and Dr O'Donovan requested that I allow them to investigate her spine that the true physical cause, Ganglionitis, was found.

I tried but was not allowed to take legal action against the professionals for the grievous wrongs that were perpetrated on her.

My partner Mike and I had looked after Sophia in shifts during the long years of her illness. After her death we learned how to make a website and in 2008 www.sophiaandme.org.uk was launched. In 2014 the daily average to Sophia's site was 698.

I had failed to protect Sophia from the wrongdoings of the doctors and social worker, but I thought that if others, through these letters from the various professionals themselves, could see the pathway that we had walked, maybe they could be spared from such a fate.

However, from the various letters of reply I received over the years from the doctors, social workers, Members of Parliament, General Medical Council and the World Health Organisation it would appear that they are all dominated and ruled by the psychiatrists' views. There is no one to stop them.

One day I hope that somehow, someone who has power

and integrity will eventually cause the facts and truth about this devastating illness to be laid bare for the world to see.



Sophia with her friend Kevin in 1995

We couldn't think of a more fitting way to honour all those lost than these powerful words from Linda Crowhurst

The roll call of the dead

There is a trail of dead ones,
 the loved,
 the honoured,
 the valued,
 the precious,
 All now lost to this illness, in death,
 Negated away by the denial and untruth
 Of the severe physical illness they did battle with
 Every day.
 My heart cries endlessly as I remember their names
 The warriors who are with us no more
 Gone to rest now.
 But why? I cry.
 I have to ask why?
 I have to demand honesty.
 Even though I do not get it

2016 - *in Remembrance*

Yet still I must demand and demand again.
 Their death demands we ask for integrity and truth.
 But there is so little of it out there
 All lost in compromise or outright denial and ignorance.
 The dead grow,
 Shockingly.
 Loved ones depart out of the blue, without prior expectation.
 The shock leaves tremors in the community of the sick still left behind,
 Not knowing who will be next.
 Fearing the worst
 Yet hoping for the best.
 There is so little truth.
 There is such little accurate representation.
 There is such little helpful information.
 And even less reliable help.
 No one knows any more if the diagnosis is even reliable.
 If what I have is what you have
 Or what they, who died, had either.
 It is all such a deliberately orchestrated human tragedy.
 And whilst we weep,
 The names of the dead and their unjust suffering
 Demands we do more
 Somehow
 To explain
 To answer
 To justify
 To insist
 That it stop
 Now
 Once and for all.
 Their precious lives unfairly lost too soon.
 Outrageously hidden in a fatigue lie
 That did not represent them
 Could not help them
 Could only harm them.
 As the long line builds
 The roll call of the dead
 Grows
 As does the unrest in my soul,
 The indescribable suffering of all those living and dead

Could never be condoned
 Acceptable or compensated for.
 For it is unimaginable
 Unreasonable
 Unacceptable
 And were it to be recognised and fully admitted
 By those who should do so,
 The tears of remorse would flood the whole universe
 And the shame be so overwhelming
 That people would turn their heads in shock at what has been done to us (or not)
 In the name of science and medicine and politics.
 And people would hang their heads and never dare look up again
 If they had any insight or honesty in their hearts
 Of their contribution
 To this unending torment,
 Only silenced
 By death itself.
 Whilst the names and the faces
 Linger tenderly
 In the hearts of those who do know
 And remember with love.

by *Linda Crowhurst*

*The Roll Call of the Dead and
 'Remember ME' image reproduced courtesy of
www.stonebird.co.uk*



“If there is no change in the politics underlying ME, as a physical illness, with neurological symptoms, then there is no hope for thousands of people for generations to come. It is that stark.

Please open your eyes and see the truth, reach out in understanding and speak up about it NOW.”

Linda Crowhurst

From Lost Voices from Hidden Illness

Compiled by Natalie Boulton
 for Invest in M.E. 2008

Webpage: <http://www.investinme.org/LostVoicesBook/liME%20Lost%20Voices%20home.htm>

