

Merryn Crofts - Died May 23rd 2017 age 21

Severe M.E has a myriad of horrific symptoms but it is also an illness of losses. M.E is a thief, it robbed Merryn of the life she dreamed of, of studying Performing Arts at LIPPA, seeing her friends, a family of her own.

M.E robbed her of these in increments as she struggled to be able to talk, lost the ability to walk, to even sit up at the slightest incline, becoming housebound, then bedbound, unable to care for herself in even the smallest ways, unable to swallow, unable to eat or drink at all due to gastrointestinal failure resulting in the need to be fed intravenously via a line in her chest leading to her heart. For the last 4 years of her life Merryn lay in a dark, quiet room.

Light, noise, touch and movement (of herself and others) hurt her and caused Post Exertional Neuroimmune Exhaustion – a worsening of symptoms following any type of exertion. Movement hypersensitivity meant just someone being in the same room caused all her symptoms to worsen, leaving her unable to tolerate much of any social interaction without having myoclonic seizures, becoming confused, disoriented and her pain worsening.

And this worsening of symptoms didn't ease, each time it happened compounded and got worse causing further deterioration. With Severe and Profoundly Severe M.E every action has to be thought through carefully and the impact they could have. Even when in unbearably worsening pain and needing extra pain relief on top of the syringe drivers she had 24/7 Merryn would have to weigh up the benefits of feeling some ease to her pain against the damage that would be caused by having a nurse in her room administering the top up injection.

So Merryn lay in the dark, tube fed, often catheterised and in such pain, pain beyond measure or imagining and unable to even have the comfort of a proper cuddle. We devised a way of me lying carefully on the bed next to her with my arms around her but not touching her except for her hands or face which were places that she could sometimes tolerate touch.

Merryn was cared for by myself and our local hospice at home for the last 2 years of her life. Her hospice Dr had worked in palliative care for 10 years and she said she had never witnessed such suffering as she saw Merryn endure. So many losses and so much pain. M.E took so much from Merryn but it never took her giant heart, her gentle, loving, caring soul. Merryn died aged just 21 after suffering from Severe and Profoundly Severe M.E for 6 years. She donated brain and spinal tissue to further research into ME and following a post mortem and inquest her cause of death was recorded as Severe ME.



https://stonebird.co.uk/merryn/index.htm?fbclid=IwAR192xjsYuOBfyh90wZp1wkGTc2MhMyw4LGpaq89ekP_Lh4ScuwtY-6A-4k

https://meassociation.org.uk/2018/05/inquest-ruling-young-drama-student-merryn-crofts-killed-by-m-e-18-may-2018/?fbclid=IwAR05pMxZLIZvxxSP6YDPiPrkAqfJ1b7sC_lwxzee9V7sW-17wjKTdsvuB8