ME killed drama student, landmark inquest told

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By JOHN SIDDLE

A devastating disease that some experts insist is all in the mind led to the death of a young drama student, a landmark inquest today ruled.

Merryn Crofts, 21, weighed less than six stone and had spent the last three years of her life totally bed-bound with severe ME - an incurable condition that affects 250,000 people in the UK.

The youngster was unable to take more than two teaspoons of food before suffering immense gut pain and vomiting, a coroner was told.

Merryn, from Rochdale, today became only the second person in the UK to have ME - myalgic encephalomyelitis - listed on a death certificate.

Despite being classed as a real neurological disease, many think the condition is not real - even within the medical profession.

Merryn's mum, Clare Norton, sobbed as she told Rochdale Coroner's Court how her "beautiful" and "energetic" daughter was left wheelchair-bound and reliant on tube feeding.

She said: "As a child, she was a bundle of energy. She didn't walk anywhere - she would hop, skip and jump.

"She was the kind of person that people gravitated towards. They wanted to be her friend.

"She was very social and loved drama. She was a total fashionista, a typical teenager. Her bedroom was a mess of clothes, hairspray and tan.

"But she was also stubborn and I think that helped her cope with her illness in a lot of ways. She never gave up."

In August 2011, Merryn, then 15, was diagnosed with hives and swelling shortly after coming back from a family holiday in Mallorca.

Tests in early 2012 revealed that at some point she had contracted glandular fever - a virus which can trigger ME.

Despite dozens of medical appointments - including mental health checks for panic attacks - Merryn's condition deteriorated as she suffered breathing problems, exhaustion and excruciating hypersensitivity to touch, light and sound.

She was eventually diagnosed with ME in the summer of 2012.

The would-be theatre star, who was forced to wear an eye mask, also suffered from severe migraines, brain fog, slurred speech and persistent infections.

Stomach problems, and problems swallowing, meant that her weight plummeted to just five-and-a-half stone.

Coroner Katherine McKenna was told that Merryn could take on just 100 calories a day because her gut was in so much pain, and that, by 2015, even two teaspoons of nutrients were intolerable.

Merryn was eventually fitted with an intravenous nutrition line but suffered intestinal failure and was given a terminal diagnosis in 2016..

She died on May 23, 2017, just days after her 21st birthday.

Mrs McKenna today concluded her cause of death as starvation caused by a withdrawal of supportive nutriition, caused by ME. She described Merryn as someone who "bore her suffering with dignity and good grace".

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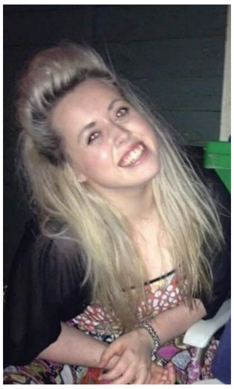

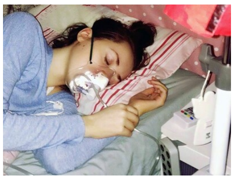

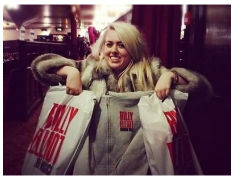

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She said: "Merryn had suffered with ME since 2012 which caused severe fatigue, gastointestinal failure, chronic pain, global hypersensitivity, loss of mobility and function.

"Despite extensive investigations no reason for her gastrointestinal failure which led to her reliance on supportive nutrition was found and most likely it was caused by her ME."

Mum Clare, who attended the inquest with daughter Amy Williams and Merryn's stepdad Dave Norton, told of her long-standing belief that ME contributed to her death.

She said: "With ME the key symptom is post-exertional malaise. That means if someone's energy is pushed beyond what they can tolerate, it will trigger all of their symptoms.

"The best advice we were given was for Merryn to do just 50% of what she felt capable of.

"But Merryn didn't even have 50% to give. She was always crashing, so everything that happened to her kept pushing her further behind."

Pathologist Daniel DuPlessis said that a post-mortem showed low-grade inflammation of nerve roots. It was suggested that this inflammation could have made her bowel hypersensitive to processing nutrients.

Dr DuPlessis pointed out that Merryn had inflammation of the ganglia - gatekeepers to sensations in the brain. A post-mortem into the only other UK death attributed to ME, Sophia Mirza, 32, in 2006, also found ganglionitis.

ME expert at Salford Royal hospital, Dr Annice Mukherjee, said she was convinced that the illness was responsible for triggering Merryn's intestinal failure.

She said: "I haven't come across a case of ME with life-threatening malnutrition before but I have come across many patients with severe ME that are bedbound that have global sensitivity issues and severe gut issues.

"But every single patient with ME is different, so I never see the same case twice."

The ME Association is at the forefront of improving access to care, treatment and research and removing the disease's stigma.

The charity today called for Merryn's death not to be in vain.

A spokesman said: "Firstly, the sympathies of the ME Association are with Merryn’s family today. We hope the result of this inquest provides some closure and allows them to cherish their memories of Merryn.

"It is essential that Merryn's untimely death is not overlooked and the urgent need for proper recognition of, and research into, ME is recognised.

"In our present state of knowledge, we don't know if ME can kill directly, but there are various consequences of having the illness that can increase the risk of early death.

"What we do know is this: ME is real. It’s devastating. It leaves people, at best, struggling to work. At worst, it leaves them enduring a tortuous existence, a living death, where they are unable to take their place in society.

"One in four are so severely affected that they are housebound, bedbound, and in some cases unable to shower, clothe, or feed themselves.

"People are taking their lives because they cannot bear the torture this illness brings. Others describe themselves as rotting behind closed curtains.

"Despite being recognised as a neurological disease, many doctors still don’t know how to diagnose and manage ME/CFS and lack or research means that we still don’t have any effective forms of treatment.

"This is a completely unacceptable situation for a disease costing the UK economy around £3.5billion in lost taxes, healthcare and benefit costs. There is no cure - and the longer it will take to find one unless funding dramatically increases.

"How many more people have to suffer before ME merits properly funded medical research?"

Merryn, who loved acting, had dreams of attending a performing arts school in Liverpool and adored musical theatre like Billy Elliott and Wicked.

Mental health expert, Dr Ross Overshott, told the inquest that Merryn did not suffer a psychological illness, such as depression or an eating disorder.

He said: "She was hopeful for the future, she could speak in a very involved way about her hobbies and interests, particularly musicals and films."

Before she died, Merryn revealed that she wanted her brain and spinal column to be donated to ME research. They were donated to the ME Association's Ramsay Research Fund, which conducts research into the causes of the disease.

Palliative care doctor, Stephanie Lippett, helped to look after Merryn in her final weeks.

She told the inquest: "I'd never met anyone with ME before and when Dr Mukhajee referred Merryn over to me it was clear it was exceptional circumstances.

"On my first visit she was bedbound, and she couldn't get up because of her dizzyness.

"She was never really pain-free. She had incredble nausea which would not settle and had sensory sensitivites which made my job more difficult than normal.

"Palliative care is normally about talking and holding hands and I couldn't do either of those, so I had to work differently."

Dr Lippett said she was convinced that Merryn had severe ME and was in real, physical pain.

But she said: "There are a lot people, medical professionals, who questioned the ME diagnosis and questioned whether it was psychological on Merryn's part."

Mrs McKenna said a summary of the rationale behind her conclusion would be released at a later date.

Outside court, the family welcomed the inquest conclusion.

They said in a statement: "Today's ruling is proof, as if proof was needed, that ME is a real, physical disease. It is a devastating and cruel illness that has robbed us of a beautiful daughter and sister.

"We have never wanted Merryn's death to be in vain and we hope this inquest conclusion is a milestone in the way that ME patients are treated from now on.

"This is the outcome that Merryn would have wanted and we take comfort in the hope that more will now be done to benefit the 250,000 people in the UK who suffer from ME.

"Merryn was desperate to raise awareness of ME and donated her brain and spinal column to research into the illness.

"But more research still needs to be done.

"We call on the government and NHS to drastically increase medical funding as a matter of urgency so no family has to endure the torment that we, and so many others, have."

Conclusion: Narrative

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