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# Tackling the brain head on

Mark O'Sullivan, who suffers from ME, looks at acquired brain injury in his latest novel

**O**NCE MY Dad was the perfect father. We were the perfect family. Now he's got the mind of a 10 year old. From one crazy day to the next we lose a little more of the man we knew and loved."

When Bisto and International Youth Library White Raven award-winning author Mark O'Sullivan chose acquired brain injury (ABI) and the devastating impact it has on sufferers and their families as the subject of his eighth novel, *My Dad is Ten Years Old*, he drew on first-hand experience to inform his writing.

O'Sullivan's father suffered a catastrophic loss of brain function as a result of an operation and O'Sullivan has lived with a chronic illness for 22 years.

It started with a mysterious viral infection. "I was literally struck down and had to go and lie in a darkened room for three weeks with no light and no sound," he says. "I had this sensory overload. It's really hard to explain. Everything seemed amplified."

Confident that he had recovered, O'Sullivan returned to soccer training but soon realised something was wrong. "I found I couldn't run. Physically my legs wouldn't let me. I had to walk back into the dressing room, change and go home. I never played football again."

After a similar incident at work, he sought medical advice. "I spent the next two years going in and out of hospital being tested for absolutely everything – it's the same for most people,"

he says. "Basically I got a diagnosis after about three years, which in itself was a very strange experience. I knew there was something seriously wrong but no one could tell me what it was. Then finally a GP said, 'Have you ever heard of chronic fatigue syndrome or myalgic encephalomyelitis (ME)?'"

He had his diagnosis but had lost his lifestyle. "I was a very physical kind of guy and played a lot of soccer and a bit of rugby. I had a big garden, two-thirds of an acre, and I grew vegetables and kept it well. I had this very busy life."

ME is a profoundly debilitating condition that affects an estimated 17 million people worldwide. O'Sullivan says that quality of life studies done around chronic illnesses, such as Aids, cancer, multiple sclerosis and ME, have found the decrease in quality of life generally for those with ME is just as bad as it is for many of those with the other conditions.

He believes medical research is closer to finding the cause. "Nowadays the focus of the research is mainly away from the psychiatric area and concentrated on finding biochemical markers for the condition."

Inevitably his work rate has suffered and one side effect is an inability to concentrate. He has finished just two books in the past 10-11 years, he says, though he has started, but been unable to finish, several others. Happily this one made it and draws attention to the plight of ABI sufferers in an entertaining, enlightening and empathic fashion. *My Dad is Ten Years Old* was heavily influenced by an incident when his father woke up from a serious operation delusional and speaking like a child.

O'Sullivan speaks fondly of his father as a "very bright, very intelligent man". The two were exceptionally close. "We were good friends for a long, long time. It was probably one of the worst experiences of my life speaking [after his operation] to the man who I knew had taught me everything.

"Unfortunately he died shortly afterwards so I never had another real conversation with him. As I was going through the book I realised I was writing about this."

ABI encompasses any sudden damage to the brain received during a person's lifetime. There are no official statistics for the number of people in Ireland with ABI but it is estimated that 10,000 people sustain a traumatic brain injury annually, with a further 7,000 being diagnosed with a stroke.

Each case is unique and symptoms vary widely according to the extent and locality of the damage to brain tissue. In the worst cases, sufferers and their

families face dramatically altered lives.

The book describes how Jimmy, a 42-year-old football fan and professional illustrator, suffers a freak accident and wakes up behaving like a 10-year-old boy with no memory of his past.

His wife, Judy, and children, Tom, Séan and Eala, who narrate the story, struggle to care for him while mourning the loss of the husband and father who has left their lives.

O'Sullivan describes "the lack of resources, the fragmentary nature of facilities". The lives of ABI patients can be enhanced significantly by long-term assisted living. Unfortunately only a handful of such places exist. One of the primary providers is Acquired Brain Injury Ireland, an organisation that promotes the belief that with the correct environment and appropriate supports, people with ABI can live mean-

ingful lives in the community.

Formerly the Peter Bradley Foundation, ABI Ireland was founded by the relatives of a young man who suffered major head injuries yet was unable to access essential community support services following discharge from hospital as they simply didn't exist.

O'Sullivan sees the provision by ABI Ireland of assisted living services, home and community rehabilitation services, day resource services, rehabilitation support, case management, education programmes and individual development as a "great working example of people not finding the services they need but refusing to despair".

There are parallels with ME sufferers who "focus their energy on living their lives. There's a kind of reticence about it too. People do have a sense of ambivalence about speaking about the condition. In the past there has been scepticism."

O'Sullivan has kept quiet in the past but is motivated to speak out now by a desire to help fellow sufferers. After two decades, he understands the limitations. "What I would like to get across about ME is that what will help you most is to pace yourself. You wake up and what you say to yourself is 'I feel a hell of a lot better this morning, I think I can do X' and what you should do is 75 per cent of that. You won't be able to do it all and you'll knock yourself back."

O'Sullivan has fundamentally altered his lifestyle, and writing has helped. "I can do it at my own pace. Maybe I can work three hours a day. Even though my life has been devastated in many ways by 22 years of ME, I still feel like I'm one of the luckiest men on earth."

He paraphrases Tolstoy to emphasise his point: "The ingredients for a happy life are love and work. You need something to be doing but you also need someone to care."

O'Sullivan cares deeply about those living with chronic illness and his wonderful book will help readers to understand the devastating realities.

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*My Dad is Ten Years Old* is published by Puffin Ireland

**ELEANOR  
FITZSIMONS**

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## USEFUL ORGANISATIONS

### Acquired Brain Injury

■ **ABI Ireland:** Provides assisted living and home-based rehab.

■ **Headway:** Gives support and services to people affected by brain injury. Brain injury information and support line: 1890 200 278, [headway.ie](http://headway.ie)

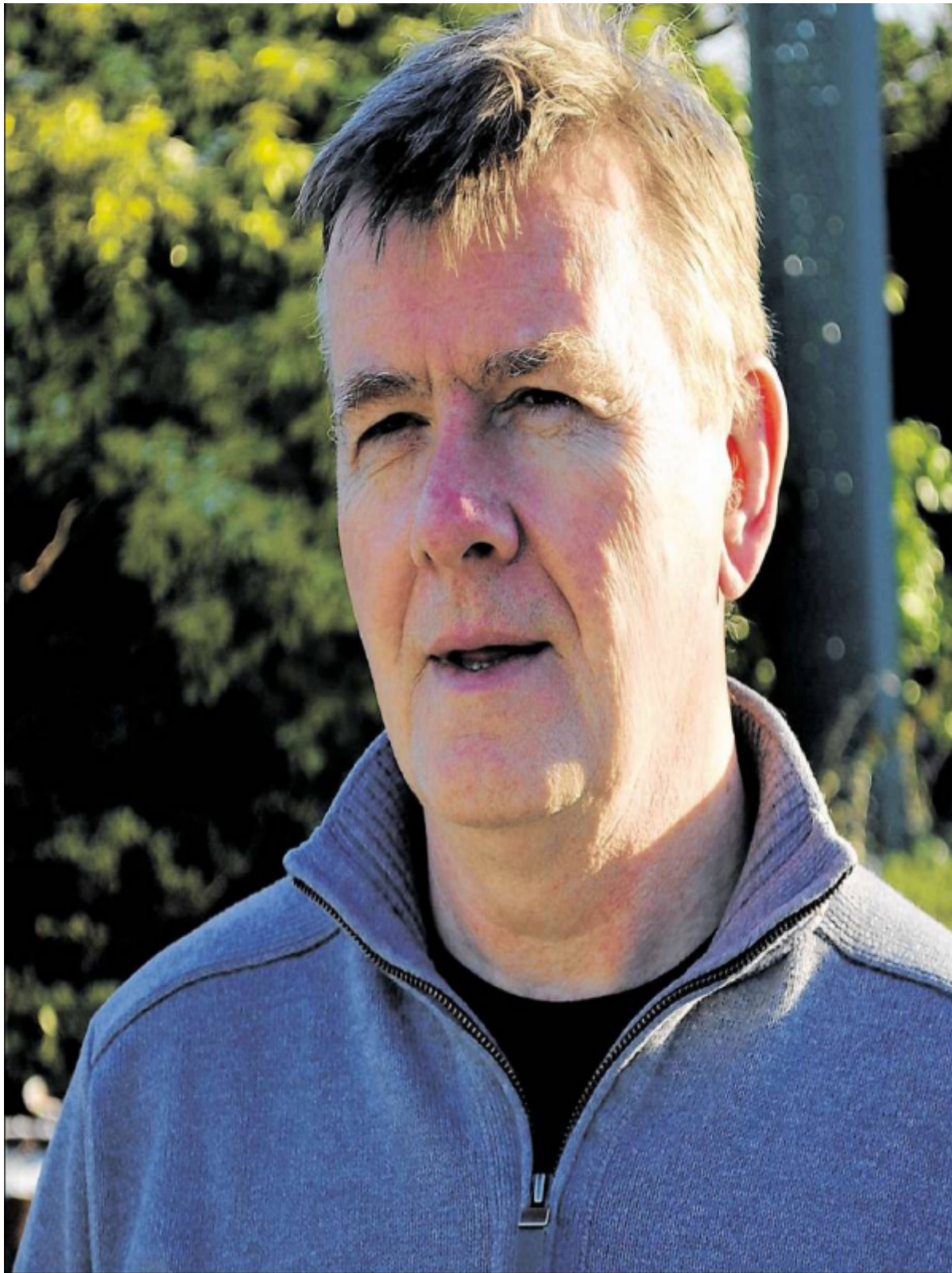
■ **BRÍ: Advocacy Group** [briireland.ie](http://briireland.ie)

### ME:

■ **Irish ME Trust:** Provides information and a counselling service to those affected with ME as well as targeting individual problems on behalf of sufferers, [imet.ie](http://imet.ie)

■ **Irish ME/CFS Association:** [irishmecfs.org](http://irishmecfs.org)





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