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The theory of helping Eddie Redmayne to portray motor neurone disease

Krishna Chinthapalli talks to the consultant neurologist and film producer behind Eddie Redmayne's Oscar tipped portrayal of Stephen Hawking and his life with motor neurone disease

Stephen Hawking is on stage answering questions about the universe and notices an audience member drop her pen in front of him. He slowly steps out of his wheelchair and walks down the steps to pick it up and hand it back to the girl.

In this scene from the new film *The Theory of Everything*, Hawking is played by Eddie Redmayne. He is shown helpless as he looks at the pen and imagines himself being able to walk over to it. It had been 25 years since Hawking, former professor of mathematics at the University of Cambridge, was diagnosed with motor neurone disease, and by then he could only just move his fingers and facial muscles. The irony is that he was at an event to publicise his best-selling science book, *A Brief History of Time*, but he could not pick up a pen.

Lisa Bruce, the film's producer, explains, "That [scene is] more for able bodied people thinking what it would be like if you were trapped inside your body. Wouldn't you dream of yourself moving and wouldn't you just want to do the simplest act—not go run a marathon—but simply walk across and hand somebody a cup of tea."

The Theory of Everything is based on Jane Hawking's memoir of her marriage to Stephen Hawking and begins when he is a 20 year old student in Cambridge. Bruce says "One of the biggest challenges was how to show that physical decline and leap years but also have it seem

realistic in terms of its arc . . . because in a two hour film we're covering about 28 years."

"Something that we learnt is how rapid the disease is," she says. Within the first few minutes of the film, Hawking is shown already struggling to pick up a pen between his fingers during a conversation with his professor. This simple action was the result of months of research and preparation by Eddie Redmayne.

Bruce had already planned to use a voice coach in the film to help Redmayne produce the dysarthric speech that Hawking had before his tracheostomy. However, Redmayne also asked for a movement coach, and Bruce recalls him saying, "I'll need a movement coach to be there the whole time to really be tracking if I'm doing movements or the lack of movements in the correct way."

Redmayne's job was made harder by the film's shooting schedule. "We were unable to shoot in sequence . . . for a number of reasons both logistical and financial—so he had to jump back and forth between periods," Bruce says. "When you're doing that in one day of shooting it would be quite easy for an actor to potentially lose track and think, "Oh now my left wrist is stiff" when actually it should be floppy. That's why the movement coach was there every single day to forensically watch him."

She adds that this made it easier for the director and for Redmayne to focus on the emotions and plot in a scene rather than the disease. The



movement coach, Alex Reynolds, watched Redmayne in every take, and would point out that, for example, he had moved his left elbow whereas Hawking would not have had any power in it at that time in the storyline. Bruce chose Reynolds for her experience in "everything from the zombie walk in *War of the Worlds* to whole musical set pieces."

Learning from patients

However, neither Reynolds nor Redmayne knew much about motor neurone disease before working on the film. The film crew therefore contacted Katie Sidle, consultant neurologist at the National Hospital for Neurology and Neurosurgery in Queen Square, London, who has a weekly motor neurone disease clinic. She obtained clearance for the pair to attend her clinics over a few months.

Sidle says, "He wasn't present for anyone we were breaking a new diagnosis to, only for patients who had already been diagnosed. Patients were all very keen to be involved for a number of reasons: the interest of being involved in the film making process, the opportunity to leave a small legacy in awareness of motor neurone disease, and also the chance of meeting a well known actor."

"Eddie [Redmayne] would sit in the waiting room and I would see each patient to make sure they were happy and had no issues to discuss privately first. Then he and Alex would come in. They actually found it very helpful just to sit in the waiting room to observe the patients in wheelchairs, to listen to how they spoke and also how they interacted with their carers."

Inside the clinic room, Sidle explained how the disease caused upper motor neurone signs of spasticity or dysarthria and lower motor neurone signs of wasting or fasciculations. Redmayne and Reynolds observed these signs in patients and made notes as well as recordings to help them



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other forms with slightly different characteristics, such as primary lateral sclerosis or progressive muscular atrophy. The conditions may be associated with emotional lability or dementia and so do not just affect motor neurones.

There has been much speculation about the type of motor neurone disease that Hawking has, but experts recognise that even amyotrophic lateral sclerosis, the commonest type, could account for Hawking's clinical features and has a variable prognosis. Hawking acknowledges this: "I have been lucky that my condition has progressed more slowly than is often the case. But it shows that one need not lose hope."¹

Sidle also explains that there is much to offer those who have motor neurone disease diagnosed. "These patients always perform better in a multidisciplinary team setting," she says. "We can look out and manage problems that can impact further on their quality of life, such as early signs of respiratory involvement, poor nutrition, cramp, or excessive drooling."

Regarding *The Theory of Everything*, Sidle says, "Eddie's performance in the film was

utterly remarkable. At some points, I really had difficulty recognising whether it was him or Stephen Hawking. What struck me as particularly impressive was the fasciculations. He somehow managed to mimic them on the face. He also understood the combination of upper motor neurone and lower motor neurone signs, so



early on when he was walking and falls over, he demonstrated a spastic gait but with foot drop . . . The patients and carers loved the film. They thought it was very relevant to them." They were not alone, as Redmayne has won a Golden Globe award for his performance and is nominated for a BAFTA and an Oscar.

At the end of her memoir, Jane Hawking expresses her hope that she would "reach the medical profession with the aim of improving the otherwise sketchy awareness within the NHS of the ravages of motor neurone disease and its effects on the personality, as well as on the physical bodies of its victims."² The film may help her achieve this.

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recreate the movements during shooting. One action Redmayne observed was how a patient picked up a pencil without the use of his thumb.

Sidle says, "[Redmayne] actually struck up a really good relationship with a few of the patients, who invited him to their homes, which was very useful for him to see. Felicity Jones [who portrays Jane Hawking] also had the opportunity to talk to carers about how to manage, for example, the physical burden and the communication burden. Redmayne invited some of the patients and carers to the film premiere, and it was particularly touching that he mentioned them by name in his speech afterwards."

Accurate portrayal

Another challenge was that the film makers did not know exactly how the disease had progressed in Hawking's case. "Stephen really didn't involve himself with doctors very much at the beginning of the disease. He only really went when he absolutely had to or someone dragged him there because of some medical issue," says Bruce. "So there isn't one doctor or even a few doctors who had much experience with Stephen."

Sidle was therefore asked to help Redmayne and Reynolds with a timeline of Hawking's disability. She says, "Hawking's precise clinical findings were unknown to us. So we had to work through old photos to try to work out the stages of his disease and see which features of upper and lower motor neurone disease he had. This could be looking for wasting, neck muscles, foot drop, or seeing how his hands were placed on the chair to suggest whether they were spastic or wasted."

Reynolds and Redmayne categorised the disease stages on a chart and used it to work out the degree of weakness, stiffness, and dysarthria needed in every scene of the film.

One of the key scenes in the film is when Hawking is told the diagnosis in a hospital corridor. "We

actually softened it a touch in the film from what they described, just because that's one of the only doctors that we show" says Bruce.

"The doctor's actually shot at a slightly different speed because when you're getting information like that, we imagine it would be quite surreal for someone. You wouldn't even really be hearing everything they're saying because it's such dramatic news . . . so it was almost dream-like or nightmarish. And we chose to have the doctor make his statement and then walk away partly to emotionally play the idea that Stephen was completely isolated."

Hawking himself says he wasn't told a diagnosis: "They didn't tell me what I had, except that it was not multiple sclerosis . . . I gathered, however, that they expected it to continue to get worse and that there was nothing they could do, except give me vitamins. I could see that they didn't expect them to have much effect."¹ Jane Hawking also recalls meeting Stephen after one appointment in Harley Street at which the doctor had told him not to bother coming back because there was nothing he could do.² He had been given two years to live.

Sidle says she thinks the portrayal of how the news was broken to him doesn't just reflect the patient-doctor relationship at that time but sadly still happens. "We hear all too often from patients that the diagnosis has been broken to them very poorly, and they are told that they have a few more years to live and that's it."

Motor neurone disease is a rare condition and general practitioners may see only one case in their career. Sidle thinks it is better to think of motor neurone diseases, an umbrella term encompassing not just amyotrophic lateral sclerosis but

A new era of free speech in science?

The campaign to change English libel law often referred to three high profile cases related to medicine. Have new rules reduced the law's global "chilling effect" on scientific discourse, asks **Siobhain Butterworth**

The Defamation Act 2013 came into force a year ago in England, accompanied by a fanfare: "The Act is a major step to reforming our libel laws. Restrictions on trivial and vexatious claims, a new public interest defence, protection for peer reviewed papers and limitations on corporations' ability to sue for libel will help scientists and science publishers everywhere," said Tracey Brown, director of Sense about Science, which campaigned with free speech groups English Pen and Index on Censorship to change libel law.¹

Two brand new defences aimed specifically at scientific discourse should ensure that authors do not get sued over peer reviewed material in scientific or academic journals or reports of academic conferences.

But these defences would have been of little use to the journalist Simon Singh and the doctor and author Ben Goldacre, who found themselves embroiled in time consuming and expensive litigation after publishing their opinions in the *Guardian* newspaper. Nor would they have helped Peter Wilmshurst, a cardiologist sued after making comments to the media alleging flaws in a clinical trial.

Singh was sued in 2008 after writing that the British Chiropractic Association (BCA) "happily promotes bogus treatments." A High Court judge decided his remarks were allegations of fact rather than opinion, and until the Court of Appeal overturned that decision in 2010 Singh faced the problem of having to prove that the BCA "knowingly promoted bogus treatments"—a meaning he had not intended. After the appeal court's judgment the BCA dropped the claim, but that was cold comfort for Singh. Though, ultimately, not out of pocket, "I lost a solid year of work, income, and opportunity," he told *The BMJ*.

Sued over the same article today, Singh might find himself in a similar position. The common law defence of "fair comment" has been codified as "honest opinion" but with no substantial changes. In all likelihood the same arguments



Singh might still have been sued

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would arise about fact versus comment, despite the appeal court's admonishment about using litigation to stifle scientific debate.

The need to prove harm

Under UK law a statement is defamatory if it tends to lower someone in the eyes of "right thinking" people—a low bar for libel claims. What's more, until the recent changes to the law, claimants did not need to show that a defamatory statement caused any harm because damage was presumed to have occurred. The 2013 legislation radically alters that: a statement is now not defamatory unless it has caused or is likely to cause "serious harm" to reputation, and a body that "trades for profit" must show "serious financial loss."

Would any of this have made a difference to Singh's case? It's not certain that the BCA would be required to show "serious financial loss." It might argue that although it is a company, it does not "trade for profit."

In his *Bad Science* columns in the *Guardian* in 2007, Goldacre wrote about Matthias Rath, who promoted vitamins and micronutrients in South Africa and claimed that they were more effective than antiretroviral drugs for HIV/AIDS. After a year Rath dropped the claim and was ordered to pay costs, but not before the newspaper had spent hundreds of thousands of pounds.

What ammunition would the 2013 act have provided against an expensive libel action involving detailed assessment of scientific evidence? Were Rath to sue over the same material today he would have to establish, early on, that he had suffered "serious harm"; but that is something a judge might be prepared to infer. As an individual, he would not be troubled with showing he had suffered "serious financial loss."

Some believe the requirement for claimants to show serious harm is already having an effect. "We know from lawyers that fewer trivial and vexatious claims are being made," Silé Lane, of Sense about Science, told *The BMJ*. "[It] has chilled the ability of the rich and powerful and

those with vested interests to stop critical discussions they don't like by firing off a threat."

Peter Wilmshurst is not convinced: "I do not think the amendments would have made any difference in my case," he says.

"They will make little difference in other cases where wealthy people or organisations want to silence people with little money."

Wilmshurst was involved in libel proceedings brought against him by the US medical device manufacturer NMT for more than three years. The case collapsed when NMT went into liquidation.

Truth continues to provide a complete defence under the new legislation but, despite the efforts of libel reform campaigners, the burden of proving the truth of statements complained about remains with defendants. Claimants do not have to establish falsity.

Shrouds of pseudoscience

Where the defendant is not in a position to prove the truth of statements about a matter of public interest, the act may provide a shield. The new public interest defence is another codification of common law (as set out in the Reynolds case and its progeny; also known as the responsible journalism defence). The court must "take into account . . . all the circumstances of the case," and this is likely to include attempts to verify allegations, tone, whether the claimant was given the opportunity to comment, and anything else relevant to the question of whether it was in the public interest to publish.

Goldacre suggested this might pose problems for his kind of scientific discourse: "I'm generally explaining why someone is wrong on a matter of fact . . . the people I write about are often people who've done well specifically by producing rather elaborate and therefore time consuming shrouds of pseudoscience," he said.

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Competing interests: I was previously legal director and readers' editor for the *Guardian* but was not involved in the cases mentioned.

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