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CJD death of Scot raises epidemic fears

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The father of a man believed to be the first person in the world with a particular gene type to have died from variant-CJD has described his son's "heart-breaking" diagnosis and deterioration from the illness.

Grant Goodwin, 30, passed away in January and his death has resurrected fears that some cases of infection might have long incubation periods and patients may yet develop symptoms of the illness, described as the human form of mad cow disease.

Thomas Goodwin said that his son, from Hamilton, but who lived in the Channel Islands, had been a "happy-go-lucky" person before he became ill, but he went on to suffer a "total change in character". He became depressed, lost his short-term memory and found it difficult to support himself.

In an interview with the BBC, Mr Goodwin spoke of the moment his son was diagnosed with variant CJD.

He said: "Grant couldn't take it in – because of his illness, five minutes after he was told, he had forgotten what he had been told. He went to bed every night, expecting to die.

"If we had the choice we wouldn't have told Grant, but Grant didn't have any hope. Once the illness set into Grant, the brain cells were slowly getting killed off and he became someone else.

"He was seeing things, he was paranoid – it was absolutely unbelievable what that illness actually does to people."

Fears of a major epidemic claiming thousands of lives surfaced at the height of the mad cow disease scare in the 1990s. The disaster never materialised, and since 1994 only around 200 cases of vCJD have been confirmed worldwide.

To date, every person confirmed as having vCJD has had a homozygous form of the human prion protein gene known as MM.

But the same gene can also take the form VV or MV. Mr Goodwin had the heterozygous MV form.

Doctors writing in The Lancet said that the MV gene could cause an incubation period spanning decades for those with vCJD.

If this is true, there could be an unknown number of infected people alive today who are unaware they have the condition but may have acquired the disease from eating beef contaminated with the cattle disease bovine spongiform encephalopathy as young children.

Whether or not they develop the symptoms of vCJD and die from the condition would depend on how long it takes to develop, and many infected individuals could die from other causes before reaching the end of the incubation period, experts believe.

Mr Goodwin said his son was diagnosed with depression at first but in May last year he began complaining about pains in his legs and head. Three months later, Mr Goodwin's wife Margaret travelled to Guernsey to visit her son and her husband said by then the deterioration was "absolutely unbelievable".

Mr Goodwin said: "He couldn't support himself. He fell twice when he was walking and he had to be supported. My wife phoned me and told me that I must arrange a flight for Grant and get him home as soon as possible.

"We thought it was a tumour, and his memory had started to go – his short-term memory was bad, he couldn't remember what he had had for breakfast.

"When I saw him coming through arrivals a great knot came into my stomach. It was heart-breaking. He came through like a drunk man and the plan was to bring him home, but when I saw him we took him straight to hospital.

"They eventually diagnosed him with variant CJD."

One month after being diagnosed, the Goodwin family was told that their son had a different gene type from other victims of the disease.

Mr Goodwin said: "I just feel we need to get this out in the open because people need to see the early symptoms."

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