

[guardian.co.uk](http://guardian.co.uk)

# Fear of insurance penalties keeps Huntington's sufferers in the shadows

The neurodegenerative disease is said to affect seven people in 100,000, but experts believe the proportion is higher

**Sarah Boseley**, health editor  
The Guardian, Wednesday 30 June 2010



Gaye Woolford, who suffers from Huntington's Disease, with her husband, John. The disease affects seven in 100,000 but experts believe this is an under-estimate. Photograph: Garry Weaser

There are far more people with Huntington's disease in the UK than has been assumed, but stigma and fear of insurance companies has kept them in the shadows, experts say today.

Huntington's disease is so genetically predictable that insurance companies make an exception to the general principle of not penalising people on the basis of their genetic make-up. The child of an affected parent has a 50% chance of inheriting the disease, which usually shows itself when the person reaches their late 30s or 40s.

Huntington's is a neurodegenerative disorder which affects muscle co-ordination and leads to cognitive decline and dementia. Patients typically suffer involuntary writhing movements known as chorea.

Professor Sir Michael Rawlins, chairman of the National Institute for Health and Clinical Excellence, writes in the Lancet journal in his capacity as an honorary professor at the London School of Hygiene and Tropical Medicine that Huntington's disease needs far more attention.

"As well as having profound implications for the families with a member who has Huntington's disease, the stigma has negatively affected research, particularly studies that have sought to investigate epidemiology and, most especially, prevalence...Huntington's disease is the only genetic condition for which the insurance industry loads those at risk. The stigma – to the insurance industry's eternal shame – is not only societal but also actuarial," he says.

The limited work on its prevalence in 15 locations in the UK produced an estimate of 6.7 cases per 100,000 population. But Rawlins writes that the number of people known to be suffering from the disease is higher than that estimate. The Huntington's Disease Association cares for 6,702 people in England and Wales. "Specialist neurologists have referred all of them, so their diagnoses can hardly be in doubt," writes Rawlins. "From these numbers alone, the minimum prevalence in England and Wales must therefore be at least 12.4 per 100,000."

He believes the true figure is even higher, because the association does not cover all areas of England and Wales. More accurate numbers will help the NHS and encourage researchers and the pharmaceutical industry to focus on the disease.

An all-party parliamentary group is now being formed to draw attention to Huntington's and press for more research, under the chairmanship of Lord Walton of Detchant.

Professor Sarah Tabrizi, from the National Hospital for Neurology and Neurosurgery in London, who leads a large research programme into Huntington's, said only about 20% of those at risk take a test to establish whether they have the genetic mutation. Those who do are often those who know it is in their family and are considering having a child. For the others, there is little incentive. "Once we are in a position to offer some treatment, 100% will go for the test," she said.

It is now possible to screen embryos for the genetic mutation that causes Huntington's disease, but only about 5% of those at risk opt for pre-implantation genetic diagnosis. Those who do have to negotiate NHS funding hurdles because it necessitates IVF (in-vitro fertilisation).

"Funding from primary care trusts is not always easy," she said. "It does get funded but you have to do a business case for it every time."

Others decide instead to get pregnant and then have a test at eight to nine weeks which will reveal whether the foetus is carrying a mutated gene, but that is only useful for couples who can contemplate an abortion.

guardian.co.uk © Guardian News and Media Limited 2010