



# Warnings over shock dementia revelations from ancestry DNA tests

Companies have been told to accept moral responsibility and provide counselling for people who inadvertently discover health risks

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People who use genetic tests to trace their ancestry only to discover that they are at risk of succumbing to an incurable illness are being left to suffer serious psychological problems. Dementia researchers say the problem is particularly acute for those found to be at risk of Alzheimer's disease, which has no cure or effective treatment. Yet these people are stumbling upon their status inadvertently after trying to find their Viking, Asian or ancient Greek roots.

"These tests have the potential to cause great distress," said Anna Middleton, head of society and ethics research at the Wellcome Genome Campus in Cambridge. "Companies should make counselling available, before and after people take tests." The issue is raised in a paper by Middleton and others in the journal *Future Medicine*.

A similar warning was sounded by Louise Walker, research officer at the Alzheimer's Society. "Everyone has a right to know about their risk if they want to, but these companies have a moral responsibility to make sure people understand the meaning and consequences of this information. Anyone considering getting genetic test results should do so with their eyes open."

Alzheimer's is linked to the build-up in the brain of clumps of a protein called amyloid. This triggers severe memory loss, confusion and disorientation. One gene, known as ApoE, affects this process and exists in three variants: E2, E3 and E4. Those possessing the last of these face an increased chance of getting the disease in late life.

"About 3% of the population has two copies of the E4 variant - one inherited from each parent," Professor John Hardy, of University College London, said. "They have about an 80% chance of getting Alzheimer's by the age of 80. The average person has a 10% risk."

The link with ApoE was made in 1996 and Hardy recalled the reaction in his laboratory. "We went around testing ourselves to see which variant we possessed. I found I have two low-risk E3 versions on my genome. But if I had found two E4 versions? By now, having reached my 60s, I would be facing the prospect that I had a serious chance of getting Alzheimer's disease in 10 years. I would be pretty fed up."

The ability to find a person's ApoE status has become even easier as a result of the development of genetic tests that provide information about a person's ancestry, health risks and general traits. Dozens of companies offer such services and adverts portray happy individuals learning about their roots - 43% African or 51% Middle Eastern - often to the sound of Julie Andrews singing *Getting to Know You* or a similarly happy-sounding track. All you have to do is provide a sample of spittle.

The resulting information about predilections to disease is not stressed - but it is given. Kelly Boughtflower, from London, took a gene test with the company 23andMe because she wanted to prove her mother's family came from Spain. The results provided no evidence of her Iberian roots but revealed she carried one E4 version of the ApoE gene, which increases her chances of getting Alzheimer's, though not as drastically as a double dose.

"I didn't think about it at the time," said Boughtflower. "Then, when I took up work as an Alzheimer's Society support worker, I learned about ApoE4 and the information has come to sit very heavily with me. Did I inherit the ApoE4 from my mother? Is she going to get Alzheimer's very soon? Have I passed it on to my daughter? I have tried to get counselling on the NHS but that is not available for a person in my particular predicament, I was told."

Other examples appear on the ApoE4 Info site, a forum for those whose gene tests show an Alzheimer's susceptibility. "Have stumbled upon my 4/4 ApoE status. I'm still in shock," writes one. Another states: "I got paid a \$50 Amazon gift-card to take part in a genetic study. I was naive and unprepared."

There is no drug or treatment for Alzheimer's and although doctors advise that having a healthy lifestyle will help, the baseline risk for E4 carriers remains high. "That is a real problem," said Middleton. "Genetic test companies say they offer advice about counselling but that usually turns out to be a YouTube video outlining your risks. Affected people needed one-to-one counselling."

For their part, gene test companies say results about Alzheimer's and other such as breast cancer and Parkinson's are often hidden behind electronic locks. A person has to answer several questions to show they "really" want to open these and is informed of potential risks. But Middleton dismissed these precautions. "You know there is medical information about you online and so you will go and find it. It is human nature."

Margaret McCartney, a GP and author of *The Patient Paradox*, agreed. "What worries me is the aggressive way these tests are marketed. People are told all the benefits but there is no mention of the downsides. The NHS is expected to mop these up."

“Meanwhile, the gene test company has made its profit and walks away from the mess they have created. I think that is immoral. They should be made to pay for counselling for their customers.”

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