Mark Newnham chose to discover whether he carries the gene mutation for Huntington's disease.

GENETIC TESTING

Darkness and light

The confirmation that a person will develop Huntington's disease can bring them more uncertainty — but also relief.

BY SIMON ROACH

Mark Newnham has seen the future, and it's etched on his father's face. Despite being in good health, the 31-year-old knows that Huntington's disease is coming — he just doesn't know when.

Like many people living under the shadow of the condition, Newnham, who lives in London, first heard about Huntington's disease when it struck older members of his family. A great-uncle had been diagnosed with it at the end of his life. So when Newnham's father started to develop the involuntary movements associated with the condition, he got tested for the gene mutation responsible. His father's diagnosis meant that Newnham — who was 20 years old at the time — had a 50% chance of carrying the gene. "I didn't know what Huntington's disease was when my Dad told me that he had it," Newnham says.

In the ten years since, his father's symptoms have progressed to include more severe involuntary movements, memory difficulties and mood swings. Later, his driving became worryingly erratic. Thinking about those years, in which his father's mental health began to decline, is painful, Newnham says — he feels as though he has been witnessing someone "at war with himself, every day".

Throughout his early twenties, and despite his father's illness showing him what might await, Newnham did not want to take the genetic test that would reveal whether he had inherited the mutation for Huntington's disease. "I was more of a free spirit," he says. "I thought, 'I don't need to know.' I can get on with it and just see if it happens later on in life."

That attitude reflected his general approach to life. As an actor and musician, he launched from one project to the next with little thought about what would come later. "I wanted to headline the Glastonbury Festival, and I wanted to become the next Johnny Depp," he laughs. "Those were my goals."

He continued on that path, he says, until he met his partner. Finding happiness and stability changed his perspective on Huntington's disease — especially when the couple thought about having children. Could he face rolling the dice when he might pass the condition to his offspring?

Newnham sought genetic counselling through the UK National Health Service, during which he explored the impact that testing could have on his life. This involved considering his motivation for being tested, as well as changes that he might need to make in the event that he did have the mutation. Aside from the emotional strain that such testing can bring, it also raises questions about physical care and finances; the certainty of knowing you have the mutation can make it more difficult to get long-term health or life insurance. Genetic counsellors can help those who might be affected to pick through the entangled pros and cons.

After three sessions, and given his and his partner's desire to have children, Newnham concluded that he needed to know his status with respect to Huntington's disease. "We didn't want to have a child without that certainty," he says. The result was not what he had hoped for. Like his father, he carries the mutated gene.

Newnham is yet to experience symptoms, and it could be decades before he shows signs of the disease. He still works as an actor and musician, but says that his priorities have changed. "The test results made me realize that what really drove me as a person before, and what ambitions I had, they're not as important now," he says. The dream of performing at Glastonbury will never be gone, but spending time with family and friends seems more important. This shift in perspective has given him a quiet contentment, he adds.

More willing to look ahead, Newnham and his partner immediately began to explore how they could have a child who would not carry the Huntington's disease mutation.

"I wanted to make sure that I don't pass this on to the next generation," he says. That meant going through a process called preimplantation genetic diagnosis (PGD).

In PGD, embryos created through *in vitro* fertilization (IVF) are screened for specific genetic disorders; only those without the related mutations are implanted. In England, up to three rounds of PGD are available at no cost to people who meet certain criteria. (In the United States, many health-insurance plans won't cover the process, so people typically pay US$15,000–25,000 for IVF with PGD.)

Not everyone with a family history of Huntington's disease goes to these lengths. Some leave it to chance. And various religious groups have reservations about prenatal genetic-screening methods such as PGD because any embryos found to have genetic abnormalities will be destroyed.

For those who do elect for PGD, the chances of success are low — as Newnham and his partner found out when they received the news that their journey towards parenthood had, for now, come to an end. The IVF part of the process, itself a complicated procedure, had failed and there were no embryos to test.

For now, the couple are weighing up the options. Adoption is a possibility, but people who will go on to develop conditions such as Huntington's disease tend to be at the bottom of the list because of their own care needs later in life, Newnham says.

Despite the prospect of a life without children, Newnham does not regret his decision to get tested. At least, he explains, he is moving forward with his eyes open. And advances in research fill him with "immense hope" that some form of treatment will be available in his lifetime — too late for his father, perhaps, but soon enough that the risk of having a child with Huntington's disease might no longer be one of life or death. ■

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