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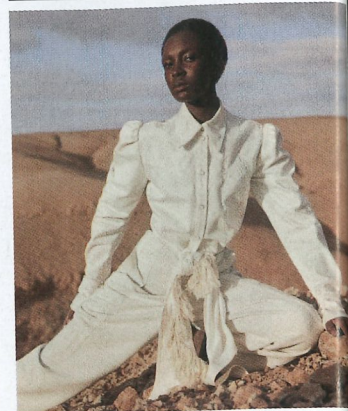


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Photograph by Jean-Baptiste Mondino for Parfums Christian Dior. Styled by Mariel Haenn. Hair by Ben Skervin. Make-up by Peter Philips, creative and image director for Dior Makeup, using Dior Addict Stellar Shine Lipstick and Dior Capture Youth skincare. Nails by Ama Quashie using Dior Manicure Collection and Dior Capture Totale Nurturing Hand Repair Cream. Cara Delevingne wears: jacket, skirt and jewellery, all Dior. Recreate Delevingne’s make-up with: Dior Forever Skin Glow in 2N, £37; Diorskin Forever Undercover Concealer in Light Beige, £22.50; Dior Backstage Glow Face Palette in 002 Glitz, £36; Rouge Blush in 250 Bal, £36; Diorshow Pump ‘N’ Brow in 002 Dark Brown, £25; Diorshow Pump ‘N’ Volume HD in 090 Black, £28; Dior 5 Couleurs Wild Earth Eye Palette in 696 Sienna, £49; Diorshow In & Out Eyeliner in 002 Bronze/Brown, £27.50; Dior Addict Stellar Shine in 976 Be Dior, £30, all Dior



# THE DNA DILEMMA

With millions of us using at-home DNA tests to learn more about our health, *Kate Graham* investigates the hidden risks of spit-and-send

**Ava\* imagined taking a DNA test would simply be a bit of fun.** 'My boyfriend bought the test for my birthday,' says the 34-year-old. 'I wanted to find out about my ancestry as well as my health. I didn't think about it at all once I'd sent my tube of saliva off.' Two weeks later, a blunt email landed in Ava's inbox. 'It said I had two copies of the ApoE4 gene,' she says. 'For women of my genetic profile it means around 80 per cent of us are likely to get Alzheimer's by the age of 75. It was a brutal revelation and I felt panic.'

Ava, who works as a science educator, is one of the 26 million people worldwide to have taken a direct-to-consumer genetic test of some sort. Costs vary, but a typical Health + Ancestry DNA Service from 23andme.com will set you back £149. It's big business with new

research predicting the entire market will be worth £1.9 billion by 2024. According to Branded Research, around 15 per cent of British women aged 18 to 45 have taken a test in the last two years alone. One third said they wanted to get health information, the same number were interested in their ancestors, while 21 per cent did it 'for fun'.

And it can be fun. Who wouldn't want to know what percentage Neanderthal you are or how fast you metabolise caffeine? For £129, DNAfit gives diet and fitness insights into how to pick the best meals and workout for your genetic profile. Orig3n has DNA tests for beauty (to reveal 'how your skin and hair may look, feel and react to various conditions'), and you can also discover more about your metabolism, such as how your body stores and processes fat, and plan your habits accordingly. On 23andme.com, one happy customer explains how she struggled for years with low energy and stomach pain until her DNA test revealed she could have lactose intolerance. Her doctor confirmed the diagnosis, and eliminating dairy has improved her health and quality of life.

These tests can literally be life changing. When it comes to family trees, we can find out where we really come from, arming ourselves with knowledge about our genetics in a way we've never been able to before. Ancestry.com includes information from 500 different regions and ethnicities. Relatives have been reunited, and twins separated at birth have discovered each other for the very first time. Diane Meek knew that she'd been adopted and had searched for years for her birth mum, without success. When a friend suggested she took an Ancestry DNA test she was reluctant to get her hopes up, but not only did she discover a cousin living just down the road, that cousin led her to her mother.

As these cases illustrate, DNA testing offers many positives, except for cases like Ava's, when unexpected conditions come to light. 'I spent a lot of time crying and frantically googling after I got the results about my increased risk of Alzheimer's,' she recalls. 'The site warns, "you may receive upsetting information", but I wasn't aware of a strong genetic link to Alzheimer's, and so never considered it to be a problem.'

Ava's experience is far from uncommon. Receiving the results of her husband's BRCA1 carrier status was a similarly shocking revelation for Fiona\*, 40, a teacher who describes the news as devastating. Having a variant BRCA1 gene sharply increases a man's chance of developing male breast and prostate cancer. 'It's a life-changing moment, but

‘There are companies whose business model isn’t the cost of the test. What they want is your valuable DNA raw data, which they will sell. If they do sell your personal profile, your 3 billion bits of DNA will be in the hands of a commercial company,’ explains Dr Middleton. Dr Anelka Phillips, author of *Buying Your Self On The Internet: Wrap Contracts And Personal Genomics*, shares these concerns. ‘Once your genetic data is sequenced, it has the potential to be stored indefinitely. It can serve as a unique identifier and be used to trace your family members,’ says Dr Phillips.

‘Our genetic data can be used for many other purposes, such as investigations by law enforcement or intelligence agencies. People considering testing should discuss this with their family. Everyone should read the privacy policies to understand how data can be used. If they have concerns, ask the company questions.’ For instance, many potential testers wonder how results may influence health insurance premiums. Dr Phillips says it’s possible that we

could soon have to declare this information. ‘It’s already happening in some countries,’ she says. ‘In Australia, insurers can require individuals applying for life insurance to disclose genetic test results.’

Despite privacy concerns, 74 per cent of British women believe these tests should be available. Ava agrees, adding, ‘People have the right to use technology to understand and improve their health. I battle with anxiety about my brain health now, but I don’t think it was a mistake to find out the information. I’m now armed to deal with it.’

Yes, DNA testing can present problems, but we can’t turn back the clock. The science is here – we just need to be ready for it. ■

**‘TESTS ARE  
INCONCLUSIVE.  
THEY MAY SAY  
YOU’RE NOT  
AT RISK WHEN  
YOU ARE’**

### **‘I DISCOVERED MY DAD WAS A SPERM DONOR’**

**Charlotte\*, 39, a professional coach, shares her experience**

‘Taking a test at 33 seemed a simple, sensible step. My parents were elderly and my mum had dementia, so I wanted to know my own genetic health risks. I spat into the vial and asked my parents to do the same. The results seemed fine at first, and then I looked at the page that connects you to others who share your DNA. There was my mum, but where was my dad? I knew Mum was incapable of cheating and that only left sperm donation. I’d taken the test looking for health information and instead I’d found this.

‘At first, I felt a strange sense of relief. It explained why I’d felt different growing up. But the next few months were agonising. My mum was too ill

to answer sensitive questions and I wanted to protect my dad. The emotional anguish of holding it in became too much. I needed answers.

‘I began to search for my biological father by uploading my DNA data to websites that endeavour to find people who are related to you. One day, I logged on and the site said it had found him. I cried with joy. Four months of messaging later and we were finally face-to-face. It was strange but wonderful to meet my biological father, and I felt an instant connection. I met his wife and learned that I had four half-siblings.

‘Taking that test changed my life. You need to be aware of what you might find though, because there’s no going back.’

you receive the email like you’d get a reminder that your Ocado shop is about to be delivered,’ she adds. The couple have a son and a daughter, and were torn over whether to test their children too. After a lot of soul searching, they decided it was better to know if they were carriers. It transpired that their seven-year-old daughter is, which means she has an increased chance of developing breast cancer (up to 85 per cent), and up to 60 per cent chance of developing ovarian cancer. They know at some point they will have to break this news to her and worry about how and when that moment will arise.

Dr Anna Middleton, vice-chair of the Association of Genetic Nurses and Counsellors, frequently encounters worried patients. ‘While it’s fantastic to make testing more accessible, companies don’t often offer a pathway to discuss results,’ she says. This leaves the NHS to pick up the pieces. ‘One patient’s home DNA test said she was carrying the BRCA1 gene and other test companies confirmed it,’ says Dr Middleton. ‘Distraught, she insisted on NHS genetic services, believing she’d need a mastectomy and her ovaries removed. But when tested again, they found the companies had made a mistake.’ There’s also the danger of a false negative. Marie-Claire Platt, head of campaigns at Ovarian Cancer Action, says home kits only test for a handful of BRCA mutations, when in fact there are many. ‘The tests are inconclusive and may tell carriers they’re not at risk when they are,’ she warns.

Olivia Montuschi, co-founder of Donor Conception Network, has also seen an upturn in enquiries from testers who find out they were donor-conceived. ‘Consider whether you’re prepared to discover information about yourself that may undermine everything you believed about your genetic background *before* you start this journey,’ warns Montuschi.

Even when the dust settles on family secrets or future health risks, there’s another worry: what happens to your data? Six in ten British women who have taken a test say they’re concerned about how their genetic material is being used and stored.