



They can tell us everything from our risk of illness to our ideal diet. But our reporter's shock discovery when she took a High Street genetic test has left her asking...

Do DNA tests do far more harm than good?

L&R / UCL / JOE / AMANDA CLARKE for Joy Goodman

IF YOU could look into a crystal ball and see your future, would you? Would you want to find out – right now – that in years to come you might develop dementia, a condition that could rob you of your memories and independence? Or that you could be struck by breast or bowel cancer? Well today you can, thanks to at-home genetic testing kits, which have soared in

By Sally Wardle

popularity over the past ten years. An increasing number are now available to buy online – a couple of the big names are AncestryDNA and 23andMe – with just a few clicks of a button. They work by analysing genetic fragments from a simple cheek swab, or a drop

of spit, and claim to be able to provide insights on everything from ancestry to personality, hair colour and disease risk. DNA kits have become popular Christmas presents and are even offered in some places as work perks. Prenetics International, a DNA-testing company backed by China's richest man, Jack Ma, is providing genetics tests to

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The A Word

BONNIE ESTRIDGE'S LIFE WITH ALZHEIMER'S

Chugging along...inspired by Pru on her canal trips

YEARS ago, while working for a magazine, I interviewed actors Prunella Scales and her husband Timothy West. They lived just round the corner from me and I popped a note through their letterbox asking if they'd be up for chatting.

The mag was one of those freebies filled with glossy property adverts, and I loved plodding around the area to find articles, semi-stalking celebs who I'd seen out and about (Mark Owen, from Take That, was another of my scalps – he was lovely, if a bit nutty, but that's another story).

Anyway, Tim and Pru were wonderful – it was (I think) around 2011, a few years before they went public about her having The A Word.

But having read subsequent interviews, I realise they knew something was up a good decade before that.

My husband Chris, who's a photographer, came with me when I did the interview to take pictures and Pru kept asking us if we wanted some wine.

I think we said yes to the first one, but Tim told her off after the third or fourth time. It was lunchtime, after all.

I wasn't massively surprised when I read, in 2014, that she'd been diagnosed. But at the time I couldn't have known I'd be getting the exact same diagnosis – mild Alzheimer's – a few years later.

I WAS told in late 2017 but, like Pru, I'd not been myself for years. Isn't it funny – we were probably both sitting together in her living room, with some early stage of dementia, neither of us knowing the other had it. I just thought she was a bit dotty. But then again, I still don't think you'd know, on meeting me, there was anything much the matter. And that's the point about dementia: it's not like you drop off a cliff.

When people find out I have The A Word, they'll often say 'I'm so sorry.' But there's not much to be sorry about, and life goes on.

After 'coming out' about Pru's illness, she and Tim set about making Great Canal Journeys, an award-winning set of travel documentaries, which ran for ten series. I loved them, for the



stunning landscapes and for revealing hidden treasures of the British countryside – and further afield.

More pertinently, the films also show what having this illness is really like. There are moments for both Tim and Pru that show the frustration: she forgets things, causes minor accidents, and repeats herself, which is annoying for both of them.

'Things are a bit harder for me these days...' is the way she sums it up at one point. Tim finishes her sentence: 'But we get by.'

In one episode, Pru says: 'I still have that sense of adventure and possibility and discovery...' I relate to all of this, obviously. Because, yes there are tears and laughter and love and a sense of urgency to make the most of life.

But mostly you just chug along. It was sad news last month that Monty Python star Terry Jones had died – another fellow A Word sufferer. He once quipped: 'My frontal lobe has absconded!'

Again, I know what he means. Mine hasn't totally absconded, it's just half way out of the door.

Obviously, when I read about someone dying of dementia, I think about how much time I have. But I hope I keep on seeing the funny side of it all, like Terry.

Coincidentally, Pru and Tim's last series of Canal Journeys took them to Vietnam – where Chris and I are just about to head off to on holiday.

Weirdly, while planning the trip, I dug out an old DVD of Good Morning, Vietnam, which was one of Robin Williams' most famous films.

He was just 63 when he died a few years back: it turned out he'd been suffering from Lewy body dementia, a rare and really horrible form of the disease that causes hallucinations, among other things. He ended up taking his own life.

Now, I know I go on about the positives of life with this disease.

I suppose I just count my blessings. I'm glad I don't have Lewy body dementia, I'm glad I'm still only slightly dotty and I'm really looking forward to my trip to Vietnam.

And I'm looking forward to telling you all about it.

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thousands of staff at some of Britain's biggest employers including HSBC, Aviva, TalkTalk, BNP Paribas and Heineken, as part of their 'corporate wellness' programmes. Employee data is not shared with bosses. But it's claimed the tests help workers make better decisions about their health and so boost their performance.

'It's about having a healthier, happier workforce,' says Avi Lasarow, chief executive of Prenetics. Few could say there is anything wrong with that.

But DNA tests are not without critics. Experts have warned about their accuracy and about the burden they are placing on the NHS. Patients, they say, are often confused or concerned by their results – and GPs are being left to pick up the pieces.

So do these DIY kits, endorsed by celebrities such as athlete Greg Rutherford and Oprah Winfrey, cause more harm than good? Last month, with a quick swab of my cheek, I set about finding out.

I was not prepared for the can of worms my results would open.

SURPRISE, SURPRISE – I'M A GIFTED MUSICIAN... BUT AN AVERAGE DANCER

MY GENETIC test of choice was CircleDNA, one of the newest on the market. Backed by the broadcaster Kirsty Gallacher, the test – which costs about £500 – was recently launched by Prenetics in the UK. It describes itself as the world's most comprehensive DNA test, using a method called 'whole-exome sequencing' to check for hundreds of conditions.

The results include everything from your risk of cancer, dementia and high blood pressure, to personality type, what type of diet you should follow and the sorts of exercise you are most suited to.

I'll be honest, as I rubbed the cotton-bud like stick across the inside of my cheek, I didn't think too much about how I might feel once I'd unlocked this treasure trove of information. But when my results came back – accessible via the CircleDNA app – I was surprised by just how I eager I was to get at them. One report informed me that I am, genetically, a 'gifted' musician. (Clearly the reason I didn't get that part in the university musical was because the producer could not recognise real talent.) Another stated I was an average dancer, something that would come as no surprise to my friends.

Other results seemed further off the mark. My test told me I'm at a low risk of sunburn – but on a sunny day, I turn red within minutes of stepping outside, despite slapping on SPF at every opportunity. And after more than a decade battling terrible skin, I was surprised to learn that I am also at a low risk of acne.

I opened other results with slightly more trepidation. What if I discovered, at the age of 27, that I was doomed to face a grave illness or destined for an early death?

The more serious conditions were locked until I first completed a guided tutorial to make sure I understood what the report might or might not mean.

To my relief, my results showed I have no cancer-causing mutations in my genes and just an average risk of developing Alzheimer's or other forms of dementia.

But as I flicked through the app, something else caught my eye. Under the family-planning section, a condition called HFE-associated Hereditary haemochromatosis was flagged up. I had never even heard of it – and could barely spell it. I frantically started to Google.

Unlike most of its competitors, CircleDNA includes a 30-minute phone consultation with a genetic counsellor in the cost of its test, as well as time with a 'genetics-trained health coach'. Chief executive Avi Lasarow says: 'We take the technology and the report very seriously, but also the duty of care we have to our clients.'

Concerned by my results, I took up the offer. According to my genetic counsellor, I have two mutations – like spelling mistakes – in my genes, which mean I have a 0.5 to two per cent chance of developing iron overload. She suggested going to my GP, who might refer

me to haematologist to decide how best to keep track of my iron levels.

If they get too high, I'll need to give blood under the supervision of doctors, to bring my levels back down. 'It's something to bear in mind, but I wouldn't lose sleep over

I found I have two mutations that mean I could develop



CELEBRITY SUPPORT:

Genetic test kits are endorsed by TV presenter Kirsty Gallacher, far left, athlete Greg Rutherford and media mogul Oprah Winfrey

our offspring will be at risk of developing haemochromatosis. My brother and sister may also have inherited these faulty genes from our parents – and they too could pass the mutation on to their children.

I'm not prone to worrying unduly about my health, but my counselling session didn't really put my mind at rest. So I called Professor Martin Marshall, chairman of the Royal College of GPs.

He explains that haemochromatosis is 'moderately common' and symptoms occur on a spectrum of severity. 'Only when it's severe does it result in organ damage,' he adds. 'In most cases it wouldn't.'

My genetic variant is a less severe type, apparently.

Dr Frances Elmslie, a consultant clinical geneticist at St George's Hospital in London, agrees.

'What I would suggest is that you go to your GP and ask if they

can check your iron levels,' she says. 'If they are fine, leave it until you are at least 40. But even after the menopause your risk of developing the condition is still very low. At 27 years old, your risk is virtually zero.'

In light of all this, I couldn't help but think that without this test, I would have happily gone my whole life without ever finding out.

THE RESULTS CAN OPEN UP A PANDORA'S BOX

AS A health reporter, I'm lucky enough to have top experts on hand to take my calls.

I didn't have to wait weeks for a GP appointment, or months to speak to a specialist.

But most people would have to.

And, unsurprisingly, the rise of at-home DNA testing has prompted concern within the NHS.

The quality of the tests can vary significantly, causing unnecessary worry or false reassurance.

They can also throw up genetic mutations, such as mine, which in all likelihood will not have a serious impact on my health.

'The main risk is that the genetic test is wrong,' says Prof Marshall. 'But the second risk is that while it may be right, it has no implications for your health.'

Dr Elmslie, who is also President of the Clinical Genetics Society, says the impact of at-home genetic testing is already being felt by the health service.

In more serious cases, patients who have done DNA tests have been told they have genetic mutations likely to cause breast and bowel cancer.

After months of worry – and repeated tests on the NHS – they have discovered they do not have the mutation after all. Dr Elmslie says: 'These are people who have taken these tests for a bit of fun.'

Neil McClements also sees the negative impact these tests can

have. He says: 'People can be very distressed, because often they had only done the test to find out about their ancestry.'

'They are not braced for the results and it can be a bit of a Pandora's Box.'

'It can open up a lot of issues for people that perhaps they hadn't considered when they started.'

OUR GENES ARE JUST PART OF THE STORY

THE fact is, there's only so much our DNA blueprint can tell us. While we may have a genetic predisposition to develop a certain illness or disease, our lifestyle and environment play a big part in whether or not we do.

'Most conditions have multiple causes, with multiple genes interacting in different ways – and interacting with the environment as well,' Prof Marshall explains.

'The simple genetics tests that we are doing simply do not reflect this complexity.'

CircleDNA is clear that its test cannot predict the future.

But it hopes that people will use it as a preventative measure, taking note of their results and making small lifestyle adjustments to lower their risk of certain diseases.

Avi Lasarow says: 'A DNA test isn't a magic solution, telling you what your health is going to be.'

'Roughly, genetics is about 30 per cent and the environment is the rest. So if you understand the genetics, then hopefully you can change your environment accordingly.'

Dr Elmslie adds: 'When you take somebody who is well, and you do whole-exome sequencing, then interpreting their results is very difficult. There might be a genetic variation which says they've got an increased risk of developing bowel cancer, but it may be, actually, they never will.'

'Or, it may be that it's just increasing their risk of bowel cancer a little bit. This is still an immature science.'

In my case, at least, it feels as if my cheek swab threw up more questions than answers.

While CircleDNA offered to talk through my results, many other companies don't.

And I can't help but worry about the thousands of anxious people who will go online for answers, having learned of their risk of developing a previously unheard of disease through what is essentially a random fishing exercise.

When you Google haemochromatosis, you quickly get told you're at raised risk of diabetes, a heart attack, arthritis, liver disease and depression.

Of course, for most, this risk is tiny. But it's scary stuff.

Dr Elmslie is clear in her advice.

'Think about the rest of your family before you do the test,' she says. 'Think about your family history. 'Are you doing this to find out something that's relevant for your family, and trying to interpret the results in that context?'

'If you decide you really want to do it, do it with scepticism. But I haven't done one – and most clinical geneticists tend to steer away from them.'

'If it were me, I would wait five or ten years, the science might be better then.'