

# Sally Phillips: Do we really want a world without Down's syndrome?

A new prenatal test could eradicate Down's syndrome. Actress Sally Phillips, who has a child with the condition, explains why that would make the world a poorer place

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Sally Phillips and her husband, Andrew, didn't find out that their first child, Olly, 12, had Down's syndrome until he was 10 days old. Nobody noticed on the day he was born. "I had a caesarean because he was breech," says Phillips. "I reacted badly to the anaesthetic so everyone was focused on me. Olly scored highly on all the tests and no one noticed there was anything different about him. I noticed. And I asked them to look at him. There was something about his eyes that was troubling me. It was as if his cheeks were really big and not allowing his eyes to open. I said, 'Does he look like that because I ate a lot of cake when I was pregnant?' They said, 'Yes, probably.'"

Best-known for her roles in the Bridget Jones films (as Bridget's best friend, Shazza) and Miranda (where she plays Miranda's old school friend, Tilly), she has a knack of making comedy out of life, including her own. And she is not afraid of making fun of herself or her family. Indeed, showing that you can have a normal family life (because what is that anyway?) with a child with Down's syndrome is one of the main points of a documentary Phillips has made for BBC2, *A World Without Down's Syndrome?*

Her first documentary, it examines whether the new, non-invasive screening tests that are available will eventually eradicate Down's syndrome. Phillips finds the prospect chilling.

She didn't know that Olly would have Down's syndrome. "Babies with Down's syndrome quite often have poor muscle tone and find it hard to feed. We would stay up all night trying to feed him and by 10 days after his birth, he had gone down from 8lb to 3lb. Everyone was still saying, 'You're a first-time mum and you're worrying. Babies always lose weight.'"

She had all the usual prenatal tests but they all came out as indicating an average risk. She admits she felt strange during the pregnancy but put it down to being a first-time mother. "I'm not one of these people who thinks they are psychic. But I just didn't feel good during the pregnancy. I was all swollen up. It was like I'd been stung by a giant hornet. But everyone kept saying, 'You're a first-time mum, it's all fine.' Now, being politically correct, I wouldn't say that I felt that something was 'wrong' but I knew that it was different."

Phillips' instinct was right. But she is evidently resilient and resolved to be open-minded about parenting a child with Down's syndrome.

She has been pleasantly surprised. "There were lots of moments during Olly's babyhood where I would think to myself, 'Wait a minute, I am not experiencing this as a disaster.' But you are so bought into the narrative. All the pregnancy books refer to Down's syndrome as a 'defect'. All you get is this information that says 'High incidence of leukaemia, high incidence of deafness' ... It's totally overwhelming and unhelpful."

Her family life, as seen on the documentary, is the counter-narrative: water fights, paint fights, an obsession with Barcelona football club and a lot of dancing. Olly, it turned out, was completely different to the “tragedy” she was reading about. “Olly smiled his first smile at four weeks, like any baby, and it was this massive great big smile. I remember I had this one moment when I was going into town on the bus and there were these two mums with their ‘perfect’ babies and they were complaining and whingeing about everything. I thought, oh. I’m supposed to be having a dreadful time? I’m really not.

“At that point I was swinging Olly around the house in a towel, trying to teach him to crawl. That is something you would not have to teach a ‘normal’ child. But we were learning to crawl together and our bond was incredibly strong. We would laugh like lunatics for large portions of the day.”

We are talking in a large room overlooking the garden at her house in south-west London. Every two seconds we are interrupted by her two younger sons, Tom, four, and Luke, nine, showing off and being random. Their father, Andrew, a shipping industry executive, hovers nearby. She chases the boys out but they keep coming back. Eventually Olly wanders in with his iPad, looking for peace and quiet.

“Turn the sound off if you’re coming in here, Olly,” says Phillips.

“It is off,” he looks at us, witheringly, suddenly deciding against sharing space with two boring old people, “But bye bye.” It’s standard 12-year-old behaviour.

Olly attends a mainstream school and has disproved a lot of theories Phillips was told about when he was born. “I was told he would never ride a bike. He goes for a bike ride every day. I was told he would never be able to climb anything. Then we started having this problem where he would scale the back fence of the garden because he wanted to make friends with the neighbour’s children. None of the rest of us could scale that fence. The thing is, nobody knows what Down’s syndrome children can achieve.”

It took years for her to decide that she was willing to front a documentary about Down’s syndrome. For a long time she had been hoping that someone else would make one and show the truth about how living with a child with Down’s syndrome is not depressing and life-ruining - in fact, the opposite. Eventually she realised that this wouldn’t happen and she would have to make it herself.

The tipping point? The new prenatal testing that should soon be available on the NHS - NIPT (non-invasive prenatal testing). This is a blood test that is done from week 10 of pregnancy and detects Down’s syndrome with 99% accuracy. In countries such as Iceland (which Phillips visits in the film), the introduction of the test has meant that 100% of Down’s syndrome pregnancies are terminated.

Phillips wants to pose the question: Do we really want to eliminate this community of people - 40,000 strong - in the UK?

“We have the most expensive state-of-the-art Down’s syndrome detection test and the ability to terminate right up until birth. But no allowance is made for the point of view of the other side. The families of people with Down’s syndrome are not consulted. People with Down’s syndrome are not consulted. There has never been an ethical debate about it.”

Phillips didn’t particularly want to be the one to start this debate, but that’s how it has worked out. Her status as an apologetic and reluctant activist is what makes the film appealing, funny and easy to watch. Although she has made no secret of the fact that she is a Christian and a lot

of her fascination with ethics is clearly informed by her faith, she is keen to emphasise that she is pro-choice. Plus, she has a fierce curiosity about the views of those she disagrees with.

The film shows her struggling with her emotions as she interviews a woman who decided to abort a Down's syndrome child. Phillips shows the woman a video of a Down's syndrome woman competing at a gymnastics competition. The woman is unmoved and unimpressed. As the mother of a Down's syndrome child, Phillips is clearly angry. But you can also see that she is empathetic, trying to understand. She's a good person to put across two sides of the story.

There are, of course, two sides to her own story in this context: life before and after Down's syndrome. "I didn't know anything about Down's syndrome at all," she says. "I didn't even know anyone with a disabled child. In fact, I don't think I knew anyone who was disabled."

Her point is that we are sleepwalking into a world where we could eliminate Down's syndrome. Is that what we really want? There is a question she has faced all her life as a parent that has always bothered her. "I get asked, 'Did you know?' But what I hate is that I also get asked, 'Didn't you know?'" The implication being that if she had known, surely she would have terminated the pregnancy.

"And that's what worries me."

She would not have terminated the pregnancy. And with what she knows now, she wants to make more people aware of the fact that a Down's syndrome child does not need to be in the "defect" category. Quite the opposite, she would argue.

She adds: "In a system where everybody screens and where you know at 10 or 12 weeks with 99% certainty whether your unborn baby has Down's syndrome, it becomes 'your fault' if you choose to have the baby. We have imperceptibly flipped into a situation where the woman is under societal pressure to have that termination. Where does it lead? If you choose to have that child, should the government help you? After all, it was your choice. Why should anyone else help you?"

"We are really close to that attitude already. There is already a new kind of pernicious discrimination towards disabled people, the idea that they are scroungers. 'Why should you steal my taxes?' Who, then, would want to have that child?"

*. A World Without Down's Syndrome? will be shown on BBC2 on 5 October*

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