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## 'It's time for us to live our lives to the full': Line of Duty's Tommy Jessop on changing the world for people with Down's syndrome

**Emine Saner**

**His parents hoped he might get a job in a library. Instead he became an actor, a campaigner - and a role model**



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ost of Tommy Jessop's acting plans are, he says with a smile, "top secret". His

**M** biggest ambition is to play James Bond, and there's an opening now. Jessop laughs, and says he has been told he looks like Bond. "It's when you're wearing black tie," says Jessop's mother, Jane, who is sitting next to him. Jessop has had cause to wear black tie a fair amount - last year, [Line of Duty](#), in which he starred as murder suspect Terry Boyle, picked up a National Television Award. Jessop's first big role saw him star alongside Nicholas Hoult in the 2007 BBC drama [Coming Down the Mountain](#), which was nominated for a Bafta.

Last year was a particularly successful one for Jessop. As well as appearing in 2021's biggest TV show, he has been filming a Steven Spielberg-produced second world war drama, *Masters of the Air*, for Apple TV+ (those are the rumours, at least, after he was photographed on set). He was awarded an honorary doctorate at the University of Winchester and, most significant of all, added his voice to the campaign for the [Down Syndrome](#) bill, which passed its second reading in the Commons in November.

"We can be proud and honoured that it has been passed," says Jessop. "It can also be history-making, changing the world for the better. We really have waited long enough to be treated equally and it really is time now for people living with Down's syndrome to have the same chances in life that anyone else has, to live their lives to the full, and not get hidden away."

Likely to become law this year, if passed at further stages, it was introduced as a private member's bill by the Conservative MP Liam Fox, and will place an obligation on local authorities to assess and meet the needs of people with Down's syndrome across aspects of life including healthcare, education and housing. People with Down's syndrome are born with an extra chromosome, which causes a degree of learning disability, and are more likely to have a range of physical conditions. There are about 47,000 people with the syndrome in the UK. Previously, people with Down's syndrome were not expected to live rich lives and had short life expectancies but this is improving all the time; now many live into their 50s and 60s, with some into their 70s. Fox said it would be "a stain on our country and a scandal" not to make provision to ensure they live full, independent and happy lives.

**// People think we are all the same but that is wrong**

Although there is existing legislation, says Peter Brackett, chair of the National Down Syndrome Policy Group (NDSPG), "it will clarify what the position is, what support people with Down's syndrome should be getting". It will help, he says, professionals providing services, as well as people with the condition, and their parents and carers, to

navigate the system. Brackett's 15-year-old son has Down's syndrome and he says "at every stage in his life, whether healthcare or education, we've had to go through the process of explaining what his requirements are, and almost educate the professionals. Unfortunately, we hear that from everybody else. There has to be a more efficient way of doing this, and it has to be something that is not dependent on where you live, the postcode lottery. It's all about clarification of existing duties, and ensuring people understand what they should be doing." By treating people with Down's syndrome as a specific group - though this, too, has been criticised as divisive, leaving out those with other learning disabilities or chromosomal disorders - it will identify and meet their appropriate needs, as the 2009 Autism Act was designed to do for people with autism spectrum disorder.

How will life change for people with Down's syndrome if the bill passes? "Hopefully for the better," says Jessop. "To get proper care from people who believe in them - teachers, doctors, nurses and employers too, just like other people, so we can all be healthy, happy and living our lives to the full." For himself, he says, he has always "lived my life to the full. I have also been campaigning for better chances in life for people with Down's syndrome all my acting life."



📷 Jessop as Terry Boyle in Line of Duty. Photograph: Steffan Hill/BBC/World Productions

Jessop is one of a number of people with Down's syndrome who have worked with the NDSPG, and other organisations, giving talks to universities and conferences, and being interviewed on podcasts and in the media. "It involves speaking up, and recording video messages to MPs, speeches, press interviews," he says. "What

[people with Down's syndrome] need is to have a voice, so they can say what they really want in life.”

Why does he think it has taken this long for people with Down's syndrome to be given a voice? “I think [other people, including politicians] tend to label us, saying that we cannot do things. Except we can do things. People think we are all the same but that is wrong. We all are different with different skills and personalities.”

When we speak over Zoom, Jessop is at home near Winchester and it's clear he has a keen sense of humour – he joins the call, ensuring his novelty T-shirt with a picture of a pizza on it, is on full show. Jane sits nearby, helping him when he needs it, which he rarely does. Instead, he teases her. At the start, Jessop's parents didn't take his professional acting ambitions seriously. Did they realise they'd got it wrong when he was cast in *Coming Down the Mountain*? “Er, no,” he says, deadpan. “We did!” protests Jane, smiling. “Walking on set, the very first day, there were 100 people, and huge contraptions for cameras and lights and things. I thought: ‘Wow, I hope Tommy can pull this off.’ And then they got Bafta-nominated so ...” Jessop laughs.

He is one of the UK's most high-profile people with Down's syndrome, although the field is not exactly crowded. How does it feel to be a role model? He smiles broadly. “I am really proud and honoured to be noticed that way. Hopefully I can inspire other people as well.” Would it have helped to have seen someone like him on primetime TV when he was growing up? “Yeah,” he says. He would love to see more people with Down's syndrome being cast in high-profile shows “because it will make a difference. You can see what we truly are capable of.”

Jessop is the middle of three children; Jane was a publishing and marketing executive, and his father is a retired doctor. As a child, says Jessop, he liked performing. “I do like making people laugh and cry, in real life and in character.” He attended a mix of mainstream school and schools for those with special educational needs. He remembers in his first school play, he played a snowman. “That was quite intriguing,” he says with a smile.

After leaving college, he auditioned for a play, *Adam*, which would go on to be performed in schools around Hampshire, and at Chichester Festival theatre. It was political, about giving people with learning disabilities the right to make choices about their lives, and the start of Jessop acting as a voice for people with Down's syndrome. He played the title character, who wants to be a chef, although nobody takes him seriously. It was the same for Jessop with acting, says Jane. “We'd asked him what he'd like to do with his life and he said he wanted to be an actor. We thought: ‘No, we'll get him a job in the library,’” she remembers.

The producer of the play suggested Jessop apply for an initiative run by the BBC and Channel 4 to discover and nurture talented disabled people. From about 2,000 applicants, just over 20 were chosen; Jessop was one of only two with a learning disability. That led to the role on *Coming Down the Mountain*, written by Mark Haddon. That experience, says Jessop, was “wicked”. “My favourite scene was talking about what sex was like, with Nicholas [Hoult].” They kept getting the giggles during filming.

Working on film sets, he says, “makes me feel quite alive and free”. Filming *Line of Duty*, with its budget, secrecy and slick professionalism “was like being on a James Bond set”. People have recognised him in the street. “I do not mind being the centre of attention,” he says. He would love to see more people with Down’s syndrome being cast in high-profile shows “because it will make a difference. You can see what we truly are capable of.”

Jessop had searched for an inclusive theatre company to join but found most were based in London. In 2005, his mother set up an arts organisation, Blue Apple theatre, in Winchester, to give people with learning disabilities opportunities to perform in dance and drama. They put on ambitious productions, including a lot of Shakespeare. “My favourite play has to be *Hamlet*,” says Jessop, in which he has played “the main man himself”. He breaks into the “to be or not to be” soliloquy, lines still remembered.



📷 With his Special Recognition award for *Line of Duty* at the National Television Awards in September 2021. Photograph: Ian West/PA



Jessop also played Prospero in *The Tempest*, but there have been contemporary dramas too, such as *Living Without Fear*, in which he played a victim of disability hate crime. He also appeared in a short film, *Freddie's Story*, which was inspired by a Mencap report, *Death by Indifference*, that exposed healthcare inequalities for those with learning disabilities, and detailed the NHS failings that it believes led to the deaths of six people ([a further report blamed institutional discrimination for the deaths of 74 people with learning disabilities](#) within a decade, though Mencap believes this is “a tiny proportion” of the real figure).

Jessop says he doesn't spend too much time thinking “about living with Down's syndrome. If I do think about it, it's a label, which is really quite depressing.” Most people, he says, “are nice to me” and when I ask if he experienced any bullying growing up he replies: “Not really.” Did he feel different from other people? “Possibly,” he says, but not because he has Down's syndrome. “I'm the exact opposite of other people, really. Other people tend to be serious and I see the fun side of life and have a laugh.”

Since the summer, non-invasive prenatal testing has been available to pregnant women in England on the NHS (Wales brought it in in 2018, and Scotland introduced it in 2020). The blood test can detect Down's syndrome fairly early in the pregnancy and previous research has found that [about 90% of women choose to terminate a pregnancy when Down's syndrome is diagnosed](#). Campaigns led by those with Down's syndrome, such as [Don't Screen Us Out](#), want to end the remaining stigma and improve life for those with the condition, rather than eliminate it. Jessop finds it too painful to talk about. The idea of antenatal testing “really does scar me for life”, he says. Jane picks it up instead, explaining that people with Down's syndrome “were still segregated a lot, right up until this century. So they never had a chance to explore their skills or find out about life, or do anything interesting, so they had nothing to talk about.” Many people with Down's syndrome weren't encouraged to eat healthily or exercise, which led to health problems, she says, “because we hid them away”.

Jessop, on the other hand, says he has always been a confident and positive person. Aside from acting, he follows football news avidly, loves music, likes travel and cooking. The pandemic has given him a quieter life, as it has for many of us, but he says, “I'd like to get back to the theatre.” He would also love to have a girlfriend, “hopefully, at some point”.

He will continue to speak out, especially as his profile grows. Last month, it was announced that he had become an [ambassador for Mencap](#). By living fully, he wants to show what people with Down's syndrome can do. This includes working, he says,

and “falling in love and living really healthy good lives”. It’s also the reason why he believes it’s “about time” the bill becomes law.

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