



How do autistic people experience maternity care?



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This month's guest expert is [Dr Aimee Grant](#), a Senior Lecturer in Public Health at [Swansea University](#) and a Wellcome Trust Career Development Fellow.

After I was diagnosed as Autistic in 2019, I had an ectopic pregnancy which is when a fertilised egg implants itself outside of the womb. I had to have an emergency surgery. My partner wasn't allowed into the hospital because of Covid-19 lockdown rules, even though I said I was Autistic and that it impacted my communication. In the end, I discharged myself against medical advice.

This experience led me to think: what do we know about the experiences of Autistic people during maternity?

My research on this topic led me to apply for a [Wellcome Career Development Award](#). Our eight-year study looks at the reproductive health needs of Autistic people with wombs. That includes people who were born as women, trans men and some non-binary people.

At the moment, we don't know much at all. Historically, [Autism research funding has focused on Autistic children](#) and research on [Autistic adults has been about white men](#). Today, a lot of Autistic women are told 'you don't look Autistic'. We are – we're just able to pretend to be neurotypical. This is known as 'masking' and is incredibly energy intensive and associated with burnout.

Through this study, we want to find out as much as we can about Autistic people's health experiences. We're looking at different life stages, from teenagers starting their periods to later in life when people go through the menopause. If we can understand the healthcare available to them, we can make recommendations about what to improve to better meet the needs of Autistic people.

What do we know about Autistic people and pregnancy?

We know that Autistic people tend to either be hypo or hyper aware of their sensory environment – so things like bright lights, loud noises or touch. This increases for Autistic people during pregnancy. It can make aspects of maternity care, like having gel put on their tummy during an ultrasound scan, very unpleasant. At the worst, it can lead to Autistic people being in severe pain from the sensory environment during birth, which can be traumatic longer-term.

Autistic people report struggles in their interactions with health professionals. [Sometimes that's attributed entirely to the Autistic person, but we also have good evidence that health professionals feel awkward dealing with Autistic patients](#). They can have negative preconceptions and believe an Autistic patient isn't having a difficult time because they don't present outwardly with their emotions, and our pain responses can be much more muted.

We know that pain in Autistic people is inadequately treated by healthcare professionals. Several people in my research have said that even when their baby was almost delivered, they were not believed to be in established labor. That meant they didn't get adequate pain relief.

In my research, Autistic people also noted that their questions about the maternity period were not being answered, leading to anxiety and confusion. This resulted in me working with Autistic parents and Autistic health professionals to create [a series of short videos answering common questions](#).

This research could transform healthcare for Autistic people

When I was looking for funding for this project, I was particularly drawn to [Wellcome's Discovery Research programme](#). This programme recognises the potential in researchers and research teams. Even if the exact research project doesn't go as planned, they believe that something interesting will still come out of it. I've applied to do similar research with other funders previously and not been accepted because they thought it was too ambitious. But Wellcome read my application and saw its potential for transforming the way Autistic people are treated in healthcare.

What we're doing with this project is really important. For gold standard Autism research, we need the Autism community to be guiding it. We've seen excellent participatory projects before where a community council of Autistic people will co-govern a project with a non-Autistic lead researcher, but we haven't seen something like our study.

We have an Autistic principal investigator and an entirely Autistic team of four researchers. We also have a community council of 12 Autistic people who are not researchers who will help guide and govern us. Autistic people are the best placed people to put forward recommendations for how to improve our lives.

It's really positive that Wellcome has funded something like this because I think it's a model for the future. Moving forward, I think we will see more neurodivergent people lead research about themselves.

Hopefully by the end of this project, we will have improved knowledge of how to do Autism research ethically, what Autistic adults' lives are like – and how we can make healthcare more accessible.

Note: The article author has requested to capitalise Autistic and Autism as a marker of community, culture and identity.