

## Welcome and what is autism?

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In our opinion self-identified as well as being formally diagnosed are both equally valid.

### [REWIND SOUND EFFECT]

>> **SEAN:** Hi everyone, welcome to the Embrace Autism video series.

This is a series of six short videos that were created as part of a partnership project between Autistic Knowledge Development and National Autistic Society.

My name's Sean and I'm from Autistic Knowledge Development. I was diagnosed autistic later in life in my mid-30s.

The first video here is "What is Autism?"

That's an impossible question to answer, to be honest with you, because there's a saying that goes "if you've met one autistic person, you've met one autistic person".

What it is to be autistic is unique to every person and whilst there'll be some overlap and there might be some things that you can relate to, ultimately, we all have a unique experience of what it is to be autistic.

I'm going to run through some of the more formal officially recognised definitions of what it is to be autistic, but ultimately, we are just keen that

anyone who watches these videos knows that it is up to you to decide what it means to be autistic for you.

There is no one single universally accepted definition of what autism is but anyone who's received a formal diagnosis of autism will have been assessed under the diagnostic criteria which has two main areas.

One is restricted and repetitive behaviours, and the other is social communication and interaction deficits.

This is very much the medical model of autism and deficit based. A lot of autistic people don't like it or don't identify with it.

Different organisations and different groups of people describe autism in different ways.

The Scottish Government's 'Different Minds' campaign described autism as a neurological difference.

National Autistic Society's definition of autism is a lifelong developmental disability which affects how people communicate with and interact with the world.

And the ICD11 definition of autism, which is the main diagnostic manual for autism used in the United Kingdom, describes autism as a neurodevelopmental disorder.

Disorder, difference and disability.

Three different views and approaches to describing autism.

There isn't one universally agreed way of describing what autism is. If you're recently diagnosed or you're recently self-identified as autistic and you watch this video series, you might reflect on what being autistic means

to you. You might even change your mind over the course of these six short videos.

I've been asked quite a few times what it is like to realise that you're autistic later in life.

The best way that I can describe it is it's as if I was born a native French speaker in a world full of people that were native English speakers, except I didn't know I was speaking French.

Then in my mid-30s, all of a sudden, I realised I've been speaking French all my life and everyone else was speaking English.

That helped me make sense and make peace with so much of my life that had gone on previously and also, I realised that I had become reasonably good at speaking 'English' even though it wasn't my first language.

Here's some short clips of some other autistic people sharing what it is to be autistic to them.

» **LEILA:** Autism for me is living a life intensely on the inside but mostly appearing neutral on the outside. It's loyalty, creativity, doing things differently, focusing on the small details amongst a big picture. For me, it's organised, literal, compassionate and ultimately makes me who I am.

» **TOM:** It's like an explanation of your whole life. Diagnosis gave me an explanation for who I am and it made me realize that I'm all right, and actual fact, I need to stick up for myself a little bit more. I'm very at peace with being autistic, I wouldn't say I'm proud of being autistic, because that still feels like the wrong adjective, but I'm very at peace with it and I'm very accepting of it and I get a little bit defensive about it when it's challenged. I love when I speak to another person who is on the Spectrum and I love being able to identify with situations that I thought were unique to my own

particular alien species turns out there's other people in my species it's not just me.

» **KATIE:** Being autistic feels like acting in a play with no script or playing a board game without any instructions and I'm the only one without the script or the instructions but in the right environment being autistic can feel joyful. Sometimes it's like I'm experiencing life in slow motion and my senses go into overdrive taking in every fine detail. I can experience so much joy from the little things in life like I've eaten the same breakfast for five years and I still wake up feeling excited to eat it and when I discover my new favourite song, I have a visceral reaction. I feel so happy I have to feel the music not just hear it. Sitting still is not an option.

» **SEAN:** We would encourage you have a think about what being autistic means to you and to leave some comments below if you're watching on YouTube.

From my own experience, I've learned a lot about myself from listening to other people talk about what it is to be autistic to them.

In our opinion, self-identified as well as being formally diagnosed are both equally valid.

There might be some of you sitting here thinking "oh am I an impostor, am I taking someone else's space here" if you're at the stage of being self-identified.

There's a whole range and variety of reasons why you might not end up with a formal diagnosis. There's a lot of practical barriers to obtaining one, but just to reassure you that in our opinion, both are equally valid.

If you've got a formal diagnosis or if you're self-identifying, you both should be here and you both should be in this space.

The last message in this video is that “you’re not alone”.

This video series may be the first time you've had an opportunity to hear from other autistic people talking about their experience of being autistic.

Welcome to your community.

We hope you've enjoyed this short video and I would encourage you to watch the rest of the series of short videos.

**[END OF VIDEO]**