

WHAT IS AUTISM AND WHY DOES MY GRANDCHILD HAVE IT?

Autism spectrum disorders (ASDs) are estimated to touch the lives of over 500,000 families throughout the UK. We use the term 'autism' here to refer to all people on the autism spectrum, including those with Asperger syndrome.

People with autism are not physically disabled; they do not need wheelchairs and they 'look' just like anybody without the disability. It can be much harder to create awareness and understanding of the condition, because of its invisible nature.

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. Children and adults with autism have difficulties with everyday social interaction. Their ability to develop friendships is generally limited as is their capacity to understand other people's emotional expression.

People with autism can often have accompanying learning disabilities but everyone with the condition shares a difficulty in making sense of the world.

There is also a condition called Asperger syndrome, which is a form of autism used to describe people who are usually at the higher functioning end of the autism spectrum. People with Asperger syndrome would usually be of average or above average intelligence.

People with autism have difficulties in three areas, often referred to by professionals as the 'triad of impairments'. These areas are social interaction, social communication and social imagination.

Social interaction

A child with autism may:

- take someone's hand and throw it towards something they want which is out of reach
- seem to be unaware of social rules, such as saying please and thank you
- not want to be hugged when they are upset.

Social communication

A child with autism may:

- develop speech in a way that is slow, disordered or have no speech. They may echo speech they hear (this is called echolalia)
- if they have Asperger syndrome may use words beyond their years and sound like a little professor
- not use eye contact or have very intense eye contact.

Social imagination

A child with autism may:

- line up toys or sort them, for example into colour groups rather than playing with them in any other way
- like routine and can become distressed if this changes without warning
- not choose to take part in make believe play or may copy make believe play they have observed
- not be able to use an object for any other purpose than it is intended. For example when feeding teddy a banana, the banana will not in pretend play then become a hair brush, then a telephone then a microphone. As well as the difficulties with the triad of impairments some people with autism may have sensory difficulties, such as not liking noise or certain lights; have a limited diet; or not want to keep clothes on because they are uncomfortable or restrictive.

Autism is a lifelong disability and as yet there is no 'cure', although with appropriate support and intervention a child can go on to develop to their full potential.

The cause of autism is still unknown, although genetic factors are thought to be important. However, we do know that autism is **not** caused by poor parenting skills.

"Most of the family didn't really know what autism was and those who had heard of it had the usual stereotypical idea of autistic savants. We explained autism, as we understood it then, but felt annoyed that everyone was trying to be positive and saying he will get better and that he's probably choosing not to talk, or just being naughty, as he was so young."

Mother of a child with autism

Did you know?

There are an estimated 14 million grandparents in the UK, and lots of those are more and more involved in caring for their grandchildren. One in five children under 16 is looked after by their grandparents in the day time and more than a third of grandparents spend three days a week caring for their grandchildren.

But what if your grandchild has an autism spectrum disorder (ASD)? What is an ASD? Will you need to raise them differently to your own children or other grandchildren? How can you help them? How will you support your own children and what if you are first to notice the difference in your grandchild's development? What about support for yourself?

Supporting your son or daughter

Looking after your grandchild may not be an option for all grandparents, so how else can you support your family?

Parents often say they feel devastated when they realise their child has autism and that they grieve for the child they thought they had. Parents can often feel depressed and do not know which way to turn.

It may be that you can support them by becoming their advocate. As well as learning about autism and how best to manage their child, there are other considerations parents need to take into account. They may be entitled to benefits, social services may be able to offer respite or a support worker for the family and their child may be able to have extra support at school. There are also a number of courses and support networks available for parents.

Claiming extra support often means spending hours filling in forms, which is often very difficult and draining if you have a child with autism. It may be that you offer to research and help them to apply for benefits and services.

Every child with autism is different and has different needs. There is a range of services that families may be able to access, including respite care, after-school or holiday schemes, and grants for housing adaptations or equipment.

If your son or daughter's family is not entitled to support from social services or do not wish to take this route, there are charity respite services that may be able to help.

Again, the amount of support your son/daughter may need or want from you may vary. Some parents do not want to involve social services at all, so their wishes need to be respected.

Schooling

Some children with autism will go to mainstream schools, perhaps with extra support; others will go to a specialist provision. Depending on their needs, your grandchild may access different 'stages' of support at school.

In the UK, these include Early Years/School Action; Early Years/School Action Plus; or the support that come from having a statement of special educational needs. Your grandchild may or may not need a diagnosis to access some extra support in school. Perhaps you could help your son or daughter to find out what is available?

There is SO much you can do to help – but always make sure it is what your son or daughter needs!