

Autism



A booklet for young people



We would like to thank all the young people with autism who contributed to this booklet.

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This booklet can be photocopied for use by organisations and individuals in Scotland.

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Who is this booklet for?

This booklet is for young people of high-school age who:



may have autism

Or



have already been diagnosed
with autism

You may like to read it with a parent or another adult who can help if there are parts you don't understand.

What is this booklet about?

This booklet explains advice for healthcare professionals on how to help people with autism.

The advice is published in a book called SIGN 145.

It looks at:

- assessment and diagnosis of autism, and
- what can help people with autism.

We think you may want to know about the main points of this advice. If so, we hope you find this booklet useful.

There are details of where you can get more information on autism at the end of the booklet on pages 21 to 24.

Thoughts from young people

When we decided to produce this booklet, we asked some young people who have autism about their experiences. We wanted to hear:

- what it was like for them before and after they knew they had autism
- how they were told they had autism
- what they had found helpful, and
- what information they needed about autism.

We asked young people how they felt before they knew they had autism. These are just examples and your experience may be different.

"I was angry and upset before I was diagnosed"

"Bad tempered"

"I felt confused and angry"

"I was excluded from school."

"I was picked on"

"I was just like everybody else"

After some young people found they had autism, they felt like this.

"I was confused, I didn't know what it meant"

"It's better socially"

"I wasn't bothered"

"I was very angry"

"I understand more"

"I thought they had got it wrong"

"Things have been ok for me"

"This boy didn't speak to me"

"I felt better once I knew what was wrong"

"I think people put in more effort to understand me now"

"I've got plenty of friends actually"

"People are more understanding"

"I felt relieved because I knew what was wrong, that I wasn't a freak"

Young people felt it was important for you to:

- be told you have autism
- be told you are not a 'freak', and
- tell a teacher if you are being bullied.

The young people we spoke to also felt it was important that the people who work with you and your family understand that you may:

- need some space
- get confused
- lose your patience
- find it hard to concentrate, and
- need a quiet place to go.

The young people we talked to had read different books to help them understand autism. In case you want to read them too, we have listed them on pages 22 and 23. You may also want to talk to someone who has autism. If so, tell the people who work with you or your parents or carers that you would like to do this. They can help to arrange it.



What is autism?

Healthcare professionals use the term **autism spectrum disorders (ASD)** to describe and diagnose a group of similar conditions. Over the years, different words have been used to describe ASD, including **autism, atypical autism and Asperger's syndrome.**

Autism – a lifelong condition causing difficulties with social and communication skills and behaviour.

Atypical autism – a form of autism where a person has many areas of difficulty. This condition may not be noticed until the person is at least three years old.

STUDIES SHOW ABOUT
**ONE
IN 100**
YOUNG PEOPLE HAVE ASD

Asperger's syndrome – a form of autism where a person has many areas of difficulty, but not learning difficulties or delayed speech.

We use the word autism in this booklet to cover all these because young people told us this is the word they prefer.

If a young person has autism, they usually have some difficulties during their development. These are:

- social difficulties
- difficulties with their behaviour and using their imagination
- difficulties with language and communication, and
- sensory sensitivities.

Sometimes children show early signs of autism and are diagnosed in childhood. Other children may be diagnosed later, as teenagers.

Autism is recognised more often in boys than girls.

Girls may be better at hiding their difficulties. To fit in with friends, they may copy the behaviour of girls in their class.

We know that autism can be linked to some medical conditions. But, for many young people, the cause of autism is not known.

What are the signs of possible autism in school-age children?

You may have difficulty communicating with people

You may:

- have had unusual language development when you were younger – in other words, you used language that was different from children of your age
- sound unusual when you speak – for example, your voice may be too loud or soft, or too fast or slow, or not go up and down like voices usually do, or
- have unusual speech – for example, you may say things over and over again.

You may have difficulty with social situations

You may:

- have difficulty doing things with people your own age
- do things that others find difficult to understand – for example, you may criticise teachers or not do as you are told
- not like people coming into your personal space, or
- not like being hurried.

You may think and act differently to other people

You may:

- struggle to join in with games that need you to understand what other young people might be thinking (for example, a game of football), or find it difficult to share imaginary stories or ideas with people your own age
- have difficulty with large open areas – for example, you may prefer to stay round the edge of the playground, or
- have difficulty coping with changes or new situations – for example, school trips or teachers being away.

You may also find that you:

- have unusual skills – for example, you may have a very good memory or be gifted at maths or music, or
- don't like the sound, taste, smell or touch of certain things.

What are the signs of possible autism in teenagers?

You may find that you:

- have difficulties in social situations such as school breaks or work breaks, but not with the lessons or work, or
- are not as independent as other people your age.

You may think and act differently to other people

You may:

- prefer very particular interests or hobbies, or may enjoy collecting, numbering or listing things
- have a strong liking for familiar routines and may repeat things you have done before
- have difficulty using your imagination – for example, in writing stories or planning ahead, or
- have unusual sensory or anxiety issues (for example about some types of food, clothing, busy places), so you try to avoid these.

This information may seem complicated but it is important you are aware of these signs. You may only show some of the signs. You can ask any of the people working with you to help you understand this information.

How do people find out if I have autism?

Assessment and diagnosis

"I knew I was different, always jumble my words, other people don't get it. It's hard speaking to people." **Jamie**

You may have noticed things yourself, for example, you may not get on easily with other people of the same age as you. You may also find it difficult to fit in at school.

Your parents, carers, friends or family members may have concerns about you. Sometimes you may be aware of other problems – things like speech or language difficulties or feeling depressed.

Professionals may also have concerns about you.

These people could include:

- doctors
- nurses
- therapists
- teachers and other school staff
- **social workers**, and
- outreach workers (youth or community workers).

Social workers
– help children, young people and families with their day-to-day living

If professionals think you need help and may have autism, they should talk to you and your parents or carers about the advantages and disadvantages of assessing you further.

Who will do the assessment?

The assessment will be done by a specialist. Having an assessment for autism is not a test.

Specialist teams can include different kinds of professional, for example:

Psychiatrists
– doctors who specialise in diagnosing and treating difficulties people have with thinking, emotion and behaviour

Speech and language therapists
– work with children and young people who have difficulties with communication



Paediatricians
– doctors who specialise in treating children and young people

Occupational therapists – are trained to help people manage their day-to-day life

Psychologists
– specialise in the study of the human mind and behaviour

What will happen at the assessment?

An assessment should involve:

- asking you and your family about any difficulties and strengths you have
- seeing how you are in the clinic, and
- collecting information about how you get on day to day, for example at school.

An assessment can give a better overall picture of what you are good at or find difficult.

You may not like certain sounds, sights and smells. The specialist assessment should take these into account so you get help from a suitable therapist.

It can take some time to decide if you have autism. So the team may have to see you and your family more than once.

What will happen after my assessment?

The team will talk with you about the results of your assessment as soon as they can. They will want to meet you and your family, and also write a report to share with you. They will usually want to try to agree the report with you. They will give you a copy of it.

“I was fascinated at first, I wanted to look into it and I did myself. My mum and I didn’t get any information, we had to look it up ourselves.” Mark

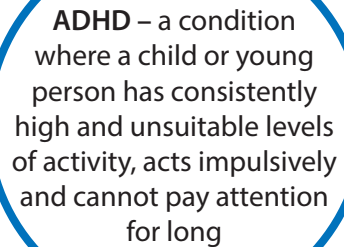
Many young people feel a sense of relief when they are told they have autism. It helps to explain the difficulties they have had. It also takes the pressure off them because they can begin to understand why they are different.

However, not all young people find the diagnosis helpful. If it doesn’t help you, please tell the team why.

Can my assessment find out anything else about me?

Children and young people with autism may have other medical problems that need to be assessed and treated separately. You may have noticed some difficulties yourself, for example, you may feel very anxious or unhappy. Other difficulties you may have include:

- anxiety
- depression
- attention deficit hyperactivity disorder (ADHD)
- epilepsy
- eating problems, and
- difficulty sleeping.



ADHD – a condition where a child or young person has consistently high and unsuitable levels of activity, acts impulsively and cannot pay attention for long

You should receive help with these difficulties too, but this will not be part of your assessment for autism.

Will my condition change?

All young people with autism change as they grow up. It is not possible to predict exactly how your condition will change.

What can help?

"People have to help us to understand it." Callum

"You overcome the bad things." James

Many things can be done to help you. You, your family and the team looking after you may try to help you develop skills and interests, or to adapt things so that you can manage better.

The team will talk with you and your family about the different things you could try.

Autism affects young people in different ways. What works for someone else may not work for you.

Your team will talk with you and your family to find the best way for you. Everybody working with you should try to help you lead a life that satisfies you.

"Parents are the most important people to help, but they have to know what's wrong and what can help." Fraser

Having autism can make life difficult for you and you may need extra help with day-to-day activities.

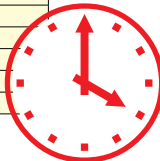
Your parents or the people looking after you should get advice from your team about how to make changes to help you live from day to day. If you need help with communicating or 'fitting in' at school, many different activities can help you.

The professionals working with you can help to find an activity that is best for your learning and development.

Your school could help. For example, if you are sensitive to sunlight, the teacher could allow you to find a well-shaded place in the classroom.

Your teacher could use a timetable each day so you know exactly what is happening at certain times. Using lists or calendars may also help you.

| TIMETABLE | | | | | | |
|-----------|------|-------|-------|-----|-----|-----|
| | 9-10 | 10-11 | 11-12 | 1-2 | 2-3 | 3-4 |
| Mon | | | | | | |
| Tue | | | | | | |
| Wed | | | | | | |
| Thu | | | | | | |
| Fri | | | | | | |
| Sat | | | | | | |
| Sun | | | | | | |



You may feel frightened and worried from time to time. Healthcare professionals can work with you and other people your age who are just like you. They can help you to talk about how you feel and how you can overcome your fears.

Can a special diet help?



All young people benefit from a healthy balanced diet. There is no need to eat a special diet or take food supplements such as vitamins. If you have difficulty eating a healthy diet, your doctor may ask a dietician for advice.

Are there any medicines that can help?



Medication (drug treatment) has not been shown to help the main difficulties of autism. You should not take medication on its own to help with your autism – it should be part of your overall care. Medication can be useful for some of the other symptoms or difficulties you may have, such as ADHD.

Before considering medication, healthcare staff should find out about your surroundings (at school and home) and your daily routines (for example, your sleep, meals and activities). Changing some of these may help.

The healthcare staff will also talk with you and your parents or the people looking after you about the risks and benefits of taking medication.

Medication can be used alongside other kinds of treatment. Sometimes, using them together makes them more effective.

What if I also have ADHD?

Not all young people with autism have ADHD. If you have autism and ADHD, you may benefit from taking a drug called methylphenidate. This can improve your attention and ability to concentrate, and reduce how overactive you are. You will be able to take a test dose of methylphenidate to check if you get any side effects.

Any side effects of methylphenidate should be carefully monitored. They can include:

- reduced appetite
- feeling irritable
- having difficulty sleeping, and
- emotional outbursts.

You can use this space to write down any side effects you may have.

What can help with sleep problems?



If you have difficulty sleeping, healthcare staff may consider giving you a drug called melatonin.

Before you start taking melatonin, you should be asked to keep a diary of your sleep pattern – in other words, what time you go to sleep and what time you wake up. Once you start the medicine, you should keep going with your sleep diary and continue with any bedtime and waking-up routine you have. The sleep diary can help to show if the medicine is useful for you.



What if I have other medical problems?



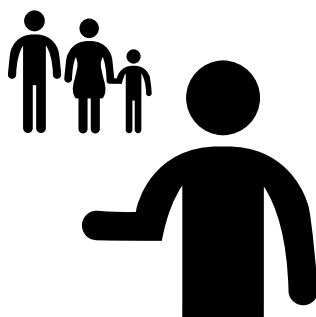
If you have other medical problems, these should be treated the same way as they would for someone who doesn't have autism.



Will people working with me understand me?

It is important that everyone who is working with you understands you as much as possible. They should have the knowledge and skills to be able to support people with autism. For example, teachers should be able to include you in their classroom (see page 16). Everyone who works with you should know about autism, including:

- teachers
- doctors
- social workers
- careers advisors
- youth workers.



What should happen as I get older?

The things you need to help you cope with your autism will change as you get older, so the services you get should also change. This may bring new challenges and opportunities. To make it easier, there should be a plan about what will happen.

You will want this plan to be as clear as possible. You, your family and the people who work with you should be involved in making the plan. Social work departments should also help you with this.



What information will I get?



Information

It is important you get different types of information in clear language to help you understand your condition. This information may include:

- explanations from your team
- a booklet explaining what autism is
- copies of letters sent to your team about you, and
- copies of any reports about you.

You can read the information in your own time to help you understand it.

You should be able to ask as many questions as you want. If you are not sure about something, the team should explain it to you in a way you understand. Your team should offer as much support as you need.

You can use this space to write down any questions you want to ask.

Where can I find out more?

We have listed some useful sources of information that may help you learn and understand about autism.

You can buy any of the following books from bookshops. You may also be able to borrow them from your local library.

Personal accounts written by children and young people who have autism

Asperger Syndrome, the universe and everything

Kenneth Hall, Jessica Kingsley Publishers (2001)

Martian in the playground

Claire Sainsbury, Lucky Duck Publishing (2000)

Freaks, geeks & Asperger syndrome. A user guide to adolescence

Luke Jackson, Jessica Kingsley Publishers (2002)

Standing down falling up: Asperger's syndrome from the inside out

Nita Jackson, Lucky Duck Publishing (2002)

Survival strategies for people on the autism spectrum

Marc Fleisher, Jessica Kingsley Publishers (2005)

Fiction and adventure stories where the main character of the story has autism

Blue bottle mystery: an Asperger adventure

Kathy Hoopman, Jessica Kingsley Publishers (2001)

Haze

Kathy Hoopman, Jessica Kingsley Publishers (2003)

The curious incident of the dog in the night-time

Mark Haddon, David Fickling Books (2003)

Born on a blue day

Daniel Tammet, Hodder and Stoughton (2007)

Other helpful books

Different like me: my book of autism heroes

Jennifer Elder, Jessica Kingsley Publishers (2006)

How to be yourself in a world that's different

Yuko Yoshida, Jessica Kingsley Publishers (2007)

Succeeding in college with Asperger syndrome. A student guide

John Harpur, Maria Lawlor and Michael Fitzgerald, Jessica Kingsley Publishers (2004)

Websites

We are not responsible for the content of the websites listed.

Den – Autism Education Trust

Website: www.autismeducationtrust.org.uk/the-den

Provides excellent information, practical advice and games for young people.

My World of Work

www.myworldofwork.co.uk

Provides services, information and support for people of all ages.

The National Autistic Society

Website: www.autism.org.uk

Offers a range of information on autism and the support available for parents and carers.

Scottish Strategy for Autism

Website: www.autismstrategyscotland.org.uk

The Scottish Government's Strategy for Autism website aims to help improve access to services and keep people informed of current developments and progress on the strategy.

Skill Scotland

Website: www.skillsdevelopmentscotland.co.uk

An information and advice service for young people and adults with any kind of disability in post-16 education, training and employment.

Wrong Planet

Website: www.wrongplanet.net

An online resource and community for people with Asperger's syndrome.

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



1

Identify questions



2

Search for evidence



3

Look at the evidence



4

Make judgements
and recommendations



5

Publish



6

Let everybody know
about our guidelines

You can read more about us by visiting www.sign.ac.uk or you can phone **0131 623 4720** and ask for a copy of our booklet *SIGN guidelines: information for patients, carers and the public*.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available.

We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

If you would like a copy of this booklet in another language or format such as in large print, please phone **0131 623 4720**.

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The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group, the Scottish Intercollegiate Guidelines Network (SIGN) and the Scottish Medicines Consortium are key components of our organisation.

