

Autism



A booklet for adults, partners, friends, family members and carers



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

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

Contents

Who is this booklet for?	1
What is this booklet about?	2
What is autism?	4
Worried you may have autism?	5
How will I find out if I have autism?	11
What can help?	20
What information and support should I receive?	26
Where can I find out more?	28
How are SIGN guidelines produced?	33

Kate's story

"I was being looked after by NHS mental health teams but nobody raised the possibility of autism. There were endless group sessions, group hugs and mental exercises which made me worse.

An occupational therapist at Job Centre Plus recognised the signs and my desperation and arranged for me to see an NHS clinician within a fortnight. I don't know how she did it, given the waiting lists, but I am here today because she succeeded.

I was diagnosed at 47 and it stopped me killing myself. I went from Mad Bad and Dangerous to Know and became an integrated human being. Not overnight of course and I still have autism – all the things that made life so hard before, as well as a couple of the most common comorbidities. It took me five years of thinking and reading before I asked for a place on the post-diagnostic course.

My support now is from the autistic community. I need one-to-one autism-professional interventions every couple of months to stop issues turning into crises. They aren't available, so I end up costing the NHS huge amounts of money in emergency support. The diagnosis has made a huge difference and as I learn more about autism and myself, life keeps getting better!"

Who is this booklet for?

This booklet is for adults who:



may have autism

Or



have already been diagnosed with autism.

Partners, friends, family and carers may also find it helpful.

Employers may find it useful, too. It can help them understand and support people with autism in the workplace.

What is this booklet about?

This booklet explains the recommendations in a clinical guideline, produced by the Scottish Intercollegiate Guidelines Network (SIGN), about:

- how you can get assessed and diagnosed for autism, and
- the approaches that can help after diagnosis.

It gives you information about the care you are likely to get and can expect.

On pages 28 to 32 we give details of support organisations and other places where you can get more information.

The clinical guideline is based on what we know from current medical research. It also gives advice based on the opinion of healthcare professionals who are trained on how best to manage your care.

If you would like to see the clinical guideline, please visit

www.sign.ac.uk

This booklet gives four types of recommendation.



Strong

recommendation

based on good-quality
research evidence



Recommendation

based on
research evidence



Recommendation

based on clinical
experience



Not enough

research evidence

to tell us if something
is of benefit

On page 33 you can find more about us at SIGN and how we produce our guidelines.

What is autism?

Healthcare professionals use the term **autism spectrum disorders** (ASD) to describe a group of similar conditions including **autism** and **Asperger's syndrome**.

Asperger's syndrome – a form of autism where a person has many areas of difficulty, but reaches expected developmental milestones up to the age of three years.

Autism – a lifelong developmental disability affecting social and communication skills and other behaviour.

The system that healthcare professionals use to make a diagnosis has changed. Now the term ASD is used to cover all previous terms for diagnosis including Asperger's syndrome and autism.

We use the term autism in this booklet to cover all of these but you may prefer to use another term.

People with autism usually have some difficulties. These are described on pages 5 to 10.

Worried you may have autism?

You may have noticed things yourself – for example, you may not get on easily with other people or may find it difficult to fit in at work.

Your partner or family members may have noticed you are having difficulties. Some signs of possible autism are listed on pages 6 to 10. The range of signs is broad and any two people with autism may show different signs.

Signs of autism may be different for men and women.

“I am overwhelmed by my senses. Supermarkets are dreadful: the noise, the lights, the smell.” *Kate*

“I would always eat lunch in front of the computer so as to avoid the coffee room and having to make conversation and feeling uncomfortable because I wasn’t joining in the conversation.” *Shelly*

What are the signs of possible autism in adults?

You may have difficulty with social communication and:

- find it hard to understand and use non-verbal communication, for example facial expressions, gestures, eye contact and tone of voice
- may be slow to understand jokes and sarcasm
- find it hard to understand group conversation, for example following multiple conversations. Perhaps you do not know when to speak or you speak over people.



Information

You can get more information on signs of autism from the organisations we have listed on pages 28 to 32 or by talking to healthcare professionals involved in your care.

"I hate using the phone. It is better if I need to phone for a specific purpose such as the need to pay a bill or make an appointment. I never phone simply for a chat." *Kate*

You may have difficulty with social interaction and:

- find socialising exhausting, preferring to do it in small amounts with familiar people and needing time alone afterwards to rest and recover
- have few or no close friends despite a large social network
- prefer online to face-to-face interaction and spend large amounts of time on social media but rarely go out with friends.

"I have friends who I do things with – jog, study, play music, or who share a special interest, but I don't really see them just for a chat." Anne

"Particularly in work I misread social cues or miss them completely. I am not very good at understanding certain types of humour and often feel left out. In the past I was told my facial expressions do not always match what I say I am feeling." Anne

You may have rigid or inflexible behaviour patterns and:

- have a set routine for doing things and become anxious if this changes
- have difficulty imagining situations outside your own routine or experiences. Other people may see this as a lack of initiative or common sense
- have significant difficulty managing life changes, for example moving away to university or college or after a death in your family
- tend to take things literally
- have difficulty in understanding opinions different to your own.

"I prefer routines and like to know what is likely to happen in any given situation. I get increasingly anxious in unknown or unexpected situations." Sarah

You may have sensory difficulties and:

- be under-sensitive or over-sensitive to noise, light, smells, touch or pressure
- seek sensory stimulation.

“I can’t stand foods with really strong smells, like spicy foods. It makes me feel awful.” **David**

“I am a sensory seeker – I sit with my legs beneath me to produce deep pressure and I like hard physical exercise.”
Shelly

“When there is too much noise and I’m not prepared for it I can get increasingly stressed and anxious. It feels overwhelming sometimes.”
Anne

You may also have other difficulties/signs, for example you may:

- have repetitive activities, such as rocking, especially when feeling anxious
- have one particular interest rather than a wider range of interests
- struggle with 'real life' and work after leaving the familiar, structured environment of university, college or school
- have a history of anxiety or depression or have an eating disorder.

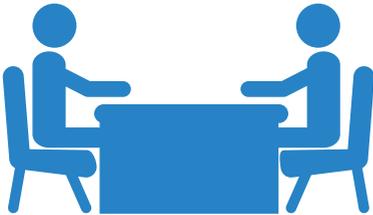
"I was always that kid that was bullied in school. I went to college and people always made fun of me. When I got a job I didn't fit in at all." **John**

"I can talk at length on subjects that interest me and I am knowledgeable about, but struggle with dinner-table conversation." **Shelly**

How will I find out if I have autism?

Assessment and diagnosis

Getting a diagnosis can be positive and can make things better for you. You don't have to tell people about your diagnosis if you don't want to. You can get help for autism by visiting your GP.



“The only real reason for getting a diagnosis is to help make sense of your life experiences; to gain insight; and to signpost you to information and support.”

Sarah

You can take a partner, friend or family member along if you wish. Your GP will ask you questions about the difficulties you have been having.

You may be asked to fill out a form with several questions that can help to find out if you need an autism assessment. Your GP may ask if they can get some more information from a relative or friend (but only with your consent).

How can my GP help?



Recommendation based on clinical experience

If your GP thinks you may have autism, he or she should refer you to a team of specialists for an assessment. This should be discussed with you. Support can be organised for you while you wait to go and see the specialists.



Information

Your GP should do the following things.

- Explain to you that your experiences suggest you may have autism.
- Discuss the advantages and disadvantages of further assessment.
- Check that you understand the reasons for referral and check that you agree.
- Give you a copy of the referral letter to read in your own time if you would like it.

“Anger at injustice will be there for many of us in our prediagnosis lives if we were diagnosed any later than infant-school age. A welcoming approach, positive about the future, of course matters to not making the whole autism scene and services daunting for the person”. *Phil*

Who will be involved in my assessment?



Recommendation based on research evidence

Because symptoms of autism vary, a specialist assessment should be done by various professionals from health and social care (known as a **multidisciplinary team**).



During the assessment, professionals will want to get to know you and hear about your experiences. This can help them work out what approach may help you.

A **multidisciplinary team** can include different kinds of professionals, for example:

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

Speech and language therapists – professionals who work with people who have difficulties with communication.

Occupational therapist – a professional who is trained to help people manage their daily activities.

Physiotherapist – a healthcare professional who helps with physical difficulties.

Psychologists – professionals who specialise in the study of the human mind and behaviour.

What happens at an autism assessment?



Recommendation based on clinical experience

The autism assessment should involve:

- finding out about any difficulties you are having, how they have changed over time, and about your family situation (known as 'history-taking')
- observing your social and communication skills and behaviours
- gathering information about difficulties you may have in other situations, for example at work, at college or when you are with family.



Recommendation based on research evidence

When asking about your history, the specialists may consider using a special approach (for example, using a diagnostic tool such as an Autism Diagnostic Observation Schedule (ADOS)). This is a kind of interview that helps specialists to be consistent when asking about important issues connected with autism. The specialists can tell you about ADOS.



Recommendation based on clinical experience

Some people with autism have difficulties with sensory symptoms. For example, they may be sensitive to particular sounds or find touch uncomfortable. The specialist assessment should take these into account.

"I understood why it was such a big deal getting on the bus or going to the shops."

John

"I finally understood why despite being thought of as highly intelligent, I found seemingly straightforward human interaction difficult and sometimes terrifying." Shelly

It can take some time to decide if you have autism, and the team may have to see you more than once. Waiting for a diagnosis can be stressful, and you may need support. The organisations listed on pages 28 to 32 can offer you support during this time.



Recommendation based on clinical experience

The specialists may also consider assessing your:

- speech, language and communication, and
- mental health needs if appropriate.



Recommendation based on clinical experience

If the healthcare professionals involved in your care think it would help, they may ask an occupational therapist or physiotherapist to assess you. These specialists should discuss the findings of their assessment with you, when appropriate. They should explain these to you and answer any questions you may have.

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

What information should I receive at the assessment?



Recommendation based on clinical experience

To make sure you know what is happening, you should routinely receive written information. This may include copies of the letters sent to the various professionals who have been asked to assess you.



Information

The specialists should do the following things.

- Check you understand the reasons for being assessed, and how far you agree with the views of the professional who referred you.
- Explain the proposed assessments and agree with you how these will be organised and which professionals will be involved.
- Give you information in a way that suits you, for example written or face-to-face.

“You can ask for copies of letters.” David

What will happen after my assessment?



Recommendation based on clinical experience

The specialist team will reach an opinion about whether or not you have autism. This will be based on their observations and the information you give them in the assessment.

They will talk with you about the results of your assessment as soon as they can. You can take a partner, friend or family member with you if you want. The specialist team should also give you a written report of the results and the final diagnosis. If you don't understand or you need things explained, don't be afraid to ask.

You may find that the specialist team's opinion disagrees with your opinion. If so, further time will be spent considering your difficulties. The team will try to reach agreement with you on how your difficulties can be best explained.

"Detailed assessment report may be upsetting at first reading but it's a collection of evidence." David



Recommendation based on clinical experience

You should be encouraged to learn about autism and how it affects you as an individual. Learning about the interventions and support that is available can help you cope with the challenges of living with autism.



Information

Agency and multidisciplinary teams should do the following things.

- Involve relevant colleagues from other organisations (education, social work, voluntary sector, careers advisors, and so on).
- Work with you to tailor the **interventions** to meet your needs.
- Provide more information if necessary (for example, about the difficulties described on pages 6 to 10 or any medical problems).
- Consider putting specific **interventions** in place, including for any medical problems that may have been diagnosed.
- Discuss possible educational approaches with you (as appropriate), including extra support for learning.
- Provide information or point you towards a service that can give information about:
 - any benefits you may be entitled to
 - voluntary or community support
 - opportunities to learn about autism, and
 - other sources of information.
- Organise for you to have a named contact for ongoing help.

Intervention
means an
approach that
will help you

“Take some time to understand the situation after diagnosis.” **John**

What can help?

“Meeting others on the spectrum after diagnosis was helpful.” John

Many things can be done to maintain and improve your quality of life. You, your partner, family and your supporting professionals may want to try a number of ways to help you develop skills and interests, or to adapt things so you can manage better.

When you are diagnosed with autism, the team should discuss with you what is available to help. Autism affects people in different ways. What works for someone else may not work for you. The team will help you find the best solutions. Everybody working with you should help you to reach your goals.

Autism can make life difficult and you may need support with day-to-day activities. You can get advice from the team about how to make changes that will help you live your life.



Strong recommendation based on good-quality research evidence

It is important that everyone working with you has the knowledge and skills to take your autism into account when supporting you. For example, local authorities and NHS boards should make sure staff are trained to work with adults who have autism.

Social skills programmes

These aim to help people with autism make and maintain relationships. They may include topics such as identifying, interpreting and responding to the emotions of others. There is some evidence that these programmes can help. If you have ongoing difficulties with social relationships, your healthcare professional should consider offering you a group-based social-skills intervention (or individual input if you prefer).

Cognitive behavioural therapies (CBT)

These therapies target the underlying thoughts and behaviours that can contribute to difficulties such as anxiety, depression and phobias. There is some evidence that these therapies can help. Your healthcare professional should consider these therapies if you have difficulties that would usually be treated by CBT. Your therapist should think about how they can adapt CBT to make it more helpful for you. One example may be to focus more on behaviour than thoughts and feelings.

Behavioural interventions

Behavioural interventions can help people to learn or develop new social skills. In some cases they replace behaviours that are not very helpful for the person, such as aggression. They often try to help with a wide range of different behaviours. Your healthcare professional should consider them if you would benefit from support to help change parts of your life.



Recommendation based on clinical experience

Your healthcare professional should consider offering you a **psychosocial therapy** if this is usual for a condition you have, such as anxiety or depression.

Psychosocial therapy – used to treat emotional problems and mental health conditions. It involves talking to a trained therapist, perhaps one-to-one, in a group or with your wife, husband or partner.

“CBT really helped me with my emotions.” **David**

Medication (drug treatment)

Medication has not been shown to help with the main problems of autism. But it can help to treat related conditions, such as anxiety, depression or **ADHD**. You should not take medication on its own to help with autism – it should be part of your overall care.

ADHD

– a condition where a person has consistently high and inappropriate levels of activity, acts impulsively and is unable to pay attention for long periods of time.



Recommendation based on clinical experience

You may be offered antidepressant medication for persistent low mood or anxiety (or both). Healthcare professionals will check regularly that this is helping you and will ask you about any side effects you get.



Recommendation based on research evidence

If other interventions have not worked, healthcare professionals should consider offering you **antipsychotic medication** to help with **behaviour that challenges you and the people around you**.

Antipsychotic medication –

these medicines are used to help calm you if you are agitated because of an underlying mental health condition. They can also be used to treat severe anxiety in the short term.

Behaviour that challenges you and the people around you

includes withdrawal, isolation, aggression, self injury, and disruptive and destructive behaviours. These behaviours can be related to agitation and distress, for example because of sensory overload or a change in routine.



Strong recommendation based on good-quality research evidence

Healthcare professionals should check that medication is helping you after three to four weeks and ask you about any side effects. If it isn't helping, they should tell you to stop taking it. If you notice any distressing side effects, you can ask about them sooner by making an appointment with your GP.

Sleep problems



Recommendation based on research evidence

If you have sleep problems that have not been helped by behavioural interventions, your healthcare professional may consider giving you a trial of melatonin.



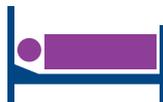
Recommendation based on clinical experience

Before giving you 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 to take this medicine, the sleep diary can show you if the medicine has helped.



Recommendation based on clinical experience

When you start to take melatonin, you should continue to keep a sleep diary. You should also continue with any bedtime and waking-up routine. Your healthcare professional should check regularly that this is working and ask you about any side effects you get.



What information and support should I receive?

Many adults with autism feel better once they know there is a reason for the difficulties they have had in the past. Different sources of support are available if you feel confused and frustrated.

You will become the expert in your own autism. So you should be invited to help guide your healthcare professional in making adjustments that make sense to you and improve your experience of the healthcare service.

When you discuss your autism with professionals, they should encourage you to ask questions at any time.



Recommendation based on clinical experience

Your partner, family or carer may find it helpful to receive information about your autism from your healthcare professional. If you are happy for this to happen, you need to give your permission to your healthcare professional.

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



Information

Information that specialists should give you when you attend any feedback appointments

The specialists should do the following things.

- Ask if you want someone to accompany you.
- Allow enough time for them to explain the findings and discuss them with you.
- Find out what you understand about your diagnosis.
- Offer basic information about:
 - autism and answer any questions you have
 - interventions that may be available
 - how autism could affect you in the future
 - any investigations the specialists will carry out, and
 - the next steps for the multi-agency team to take in giving you suitable support.
- Give information about what written feedback you will get. Check with you (as appropriate) how the feedback will be made available to relevant colleagues.
- If any part of the assessment has been recorded on video, get your written permission (if appropriate) to keep the recording.
- If a definite diagnosis cannot be made, discuss with you how and when to best review or repeat the assessment, or the options for another specialist assessment to take place.

Where can I find out more?

National organisations working with autism

NHS inform

A national health information service for Scotland.

Phone: 0800 22 44 88

Website: www.nhsinform.scot/illnesses-and-conditions/autistic-spectrum-disorder-asd

Autism Initiatives

A parent-led charity offering support to people with autism and their families.

Phone: 0131 551 7260

Website: www.autisminitiatives.org

E-mail: hos@aiscotland.org.uk

Autism Network Scotland

Connects and communicates with those interested in autism. It points autism professionals and practitioners, people with autism, their families and carers toward examples of good practice, resources and useful information.

Phone: 0141 444 8146

Website: www.autismnetworkscotland.org.uk

Email: autism.network@strath.ac.uk

National Autistic Society Scotland

Works across Scotland to provide quality, personalised support and advice services for people with autism and their families and carers. Its website hosts a range of information on autism.

Phone: 0141 221 8090 or the helpline 0808 8004104 (10am-4pm, Mon-Fri)

Website: www.autism.org.uk

Email: nas@nas.org.uk

Research Autism

Provides information on high-quality, independent research into new and existing health, education, social and other interventions.

Website: www.researchautism.net

Email: info@researchautism.net

Scottish Autism

Provides a team of autism advisors trained and experienced in working with people on the autism spectrum and who can offer personalised help and support.

Autism advice line: 01259 222 022

Website: www.scottishautism.org

Email: autism@scottishautism.org

SWAN – Scottish Women’s Autism Network

Works in partnership with Autism Network Scotland. SWAN offers support to women with autism from other women with autism, as well as networking opportunities.

Website: www.autismnetworkscotland.org.uk/swan

Email: swan.scotland@gmail.com

Useful publications

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

Explaining the enigma

U Frith, Blackwell Publishing (2003)

Making sense of the unfeasible

M Fleshier, Jessica Kingsley Publishers (2003)

People with autism behaving badly: helping people with ASD move on from behavioural and emotional challenges

J Clements, Jessica Kingsley Publishers (2005)

Sensory perceptual issues in autism and Asperger's syndrome

O Bogdashina, Jessica Kingsley Publishers (2003)

Understanding and working with the spectrum of autism

W Lawson, Jessica Kingsley Publishers (2001)

The complete guide to Asperger's syndrome

T Atwood, Jessica Kingsley Publishers (2006)

Autism and Asperger syndrome: preparing for adulthood (2nd edition)

Patricia Howlin, Routledge (2004)

Succeeding in college with Asperger syndrome. A student guide

J Harpur, M Lawlor and M Fitzgerald, Jessica Kingsley Publishers (2004)

Personal accounts

Pretending to be normal

L Holliday-Willey, Jessica Kingsley Publishers (1999)

Websites

We do not accept responsibility for the content of the websites listed.

Asperger and ASD UK Online Forums

Website: www.asd-forum.org.uk

A well-supported, well-organised internet support group with e-mail discussions and bulletin boards for sharing information.

Website: www.community.autism.org.uk

Online discussion forum for adults (over 16)

Department for Work and Pensions

Website: www.dwp.gov.uk/lifeevent/discare

Information on benefits and Disability Living Allowance.

My World of Work

Website: 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.skill.org.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

Online resource and community for autism and Asperger 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**.

www.sign.ac.uk



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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.

